

**Predictors of Success in Fistula Surgery among Vesico Vaginal Fistula Patients in East Africa: a
Mixed Method Study**

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ABBREVIATIONS

AMREF	African Medical Research Foundation
CASP	Critical Skills Appraisal Programme
CCC	Comprehensive Care Clinics
CINAHL	Cumulative Index to Nursing and Allied Health Literature
FGM	Female Genital Mutilation
OF	Obstetric Fistula
QUAL	Qualitative
QUAN	Quantitative
RVF	Recto Vaginal Fistula
UGF	Urogenital Fistula
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Fund for Population Activities
UNPF	United Nations Population Fund
USI	Urinary Stress Incontinence
VCT	Voluntary Testing and Counselling
VVF	Vesicovaginal Fistula
WHO	World Health Organization

ABSTRACT

Background: A vesico vaginal fistula (VVF) is an abnormal communication between two epithelial surfaces. In VVF, an abnormal communication may develop between the urinary system and the reproductive system of a woman. Prolonged labour is a major cause of fistula in women: however, fistulas may be caused by rape, malignancies and as a traumatic outcome in abdominal surgeries. The cardinal sign of VVF is continuous urine leakage with offensive smell. Often, these patients are stigmatised and depressed. **Objective:** The main objectives of the study were to establish predictors of fistula healing and to gain understanding of the first-hand experience of women before and after repair of a vaginal fistula.

Design: A mixed method study which employed quantitative and qualitative data collection approaches. Consecutive sampling was used to recruit participants for the quantitative component. A standard tool was developed, pilot tested and used to collect demographic and fistula characteristics. Quantitative data was managed using IBM SPSS and analysed using descriptive and inferential statistics. Purposeful sampling was used to select participants' for in-depth interviews. In-depth guide used to guide interviews. All interviews were recorded and transcribed per verbatim. Analysis was done in thematic themes.

Results: A total of 1224 women with a confirmed diagnosis of fistula were recruited over a three year period, in East Africa. In all of the countries, literacy levels were low. Overall, most women had only been educated to primary school level 62.9%, 17.0% had no education. Only 4.8% women had been educated to college level or higher and all were from Kenya. Most women were unemployed varying from 92.1% for DR Congo and 76.1% for Southern Sudan 76.1%, to 13.5% for Rwanda and 13.2% for Uganda. The mean fistula size was 2.15 cm in diameter, with most fistulas measuring 1-2 cm from the external urethral orifice (EUO) or urethral meatus. At the time of joining the study, 22.4% of women had undergone a previous surgery to repair the fistula and lived with urine leakage for up to twelve months. Vaginal stenosis/scarring were very common (72.4%). There were few combined fistulas (VVF/RVF) (3.0%). The mean success rate of surgery was 94.1%. Sixteen women were interviewed for the qualitative component of study. Two main themes representing the women's journeys emerged: from social isolation to social reintegration. Women felt euphoric following fistula repair, believing that a 'miracle' had occurred. However, the 'post-miracle component' demonstrated that the social and psychological impact of fistula leaves scars that are not easily healed, even when fistula repair is successful.

Conclusion: Fistula surgery alone is not adequate in restoring women's health. The impact of fistula in women's lives is felt far beyond the surgical period. These findings point to the urgent need for researchers to conduct psychological assessment in the management of women with fistula and design community based programs aimed at social integration and women empowerment.

Key words: *Fistula, surgery outcomes, lived experiences, East Africa*

DECLARATION

There is no portion of the work referred to in the thesis that has been submitted in support of an application for another degree or qualification of this or any other University or other institute of learning.

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PUBLICATIONS AND CONFERENCES ARTICLES SUBMITTED

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1. **Weston Khisa**, Sabina Wakasiaka, Linda McGowan, Malcom Campbell and Tina Lavender. Understanding the lived experience of women before and after fistula repair: a qualitative study in Kenya. *British Journal of Obstetrics and Gynaecology*. Published online 19 February 2016. DOI: 10.1111/1471-0528.13902. www.bjog.org
2. **Weston Khisa**, Sabina Wakasiaka, Lavender, T, Linda McGowan, Malcom Campbell. The Correlates of Bladder Stones and Vesico-Vaginal Fistula. *African Journal of Midwifery and Women's Health*. Volume 8, October, 2014.
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Poster Presentations

Weston Khisa, Tina Lavender, Malcom Campbell, Linda McGowan. Lived Experiences in Women Living With Fistula: The Monster at Work, Manchester, 2014.

Chapter 1: BACKGROUND INFORMATION

1.1: Introduction

The thesis presents a mixed-methods study design which investigates predictors of successful surgery and exploration of lived experiences of women with fistula in East Africa. Chapter one, comprises of a discussion on background information pertinent to the study. The chapter draws the reader to the context of the investigation into predictors of fistula surgery and aims of the study. Chapter Two focuses on a structured literature review where relevant and contemporary issues on fistula surgery have been discussed. This includes predictors of surgical outcomes and lived experiences of women with fistula. Furthermore, fistula classification tools have also been discussed in the chapter.

In Chapter Three, the author discusses the philosophical stance underpinning the mixed-method study design and overall methodological issues. The rationale for choosing Phenomenology over Grounded Theory or Ethnography has been discussed. Ethical issues that guided the research have been described in the chapter. Chapter Four is a detailed description of materials and methods applicable in the study. Chapters 5 present quantitative findings relating to predictors of successfulness of surgery and duration of leakage in this group of fistula patients. In chapter 6, the author presents qualitative findings which relate to lived experiences of women with fistula before and after surgery. Chapter seven captures the synthesis of both quantitative and qualitative components, which brings to light the complementarity of the study findings: how and when the mixing happened. In Chapter eight, sections 8.0 to 8.6, the author presents quantitative and qualitative discussions. Sections 8.7 -8.9 of the chapter describes the originality of the research and strengths and limitations of the design. Recommendations for future research and policy, as well as transferability of the data are highlighted in section 8.7- 8.10. Finally, the author narrates his personal reflections in this doctoral study.

1.2: Definition and Scope

A fistula is defined as an abnormal communication between two epithelial surfaces. In vesico-vaginal fistula (VVF), the abnormal communication occurs between the urinary system and the reproductive system of a woman. The most common cause of VVF is prolonged labour and trauma that may occur during childbirth, abdominal/pelvic surgeries, malignancies, and rape. The cardinal sign of VVF is continuous urine leakage with offensive odor, left unattended the fistula may complicate from a minute tissue injury with minimal tissue loss to a cloaca, i.e. an empty pelvis with extensive intravaginal, neurologic and systemic lesions. When the abnormal communication

is between the vagina and the rectum, the fistula is referred to as a recto-vaginal fistula (RVF). Rectovaginal fistulas appear to be significantly less common than VVF. Patients with the problem of RVF leak stool because the normal controlling mechanism is altered/destroyed. At times, the patient may present with both VVF and RVF, in which case the patient leaks both stool and urine. Left unattended, fistula patients are neglected, depressed or ostracised from their community. Such situations rob the fistula patient of their livelihood and human dignity.

1.3: The History of Vesico Vaginal Fistula

VVF is as old as womankind. The oldest evidence of VVF was reported around 2050 BC in the remains of Queen Henhenit, the wife of Egypt's ruler (Zacharin, 2000). The Queen's mummy was originally sent to the Metropolitan Museum of Art in 1909, only to be returned to Cairo in 1923 where an extensive anatomical review found a defect in the bladder communicating directly with the vagina. During the 11th century, a Persian physician, Avicenna, observed that VVF is common where women are married too young, and in patients who have weak bladders. He suggested that a physician attending a fistula patient should instruct the patient on methods of pregnancy prevention. However, he reported that VVF is an incurable condition and that the patient will live with until death (Zacharin, 2000). In 1663, a Dutch physician, Hendrik Van Roonhuysse, gave a clear description of the vesico-vaginal fistula and proposed a method of repair. Later on, in 1838, Dr. John Peter Mettauer of Virginia reported that he had successfully closed a vesico-vaginal fistula with wire sutures. In 1845, Dr. Sims completely closed the enormous fistula of a 17 year old slave who had been in labour for three days and had been operated on 30 times. Sims reported the detailed surgical principles used to close vesico-vaginal fistulas, principles that continue to guide fistula surgeons around the world today.

1.4: Epidemiology of Vesico Vaginal Fistula and Recto Vaginal Fistula

In 2004, the World Health Organization reported that VVF is rare in developed countries, but when they occur it is usually associated with abdominal surgery, radiation or pelvic malignancies. Fortunately, because of the advanced skills, diagnosis is often made and repair done as soon as the fistula develops. Generally, global distribution of VVF follows the global maternal mortality mapping. It is considered that regions with high maternal mortality also have a high VVF occurrence. A phenomenon commonly observed in Sub-Saharan Africa and Asia. For instance, in Jordan, Amr (1998) explains that poor referral systems in that country contribute to fistula development; this may be a reflection of poor standards of obstetric and gynaecological care. Amr

(1998) continued to report that most fistulae are due to obstetric causes such as prolonged and obstructed labour and difficult instrumental delivery.

The low incidence of VVF in developed countries has been attributed to accessible emergency obstetric care and other maternal health services. Surveillance reports also show that each year about 210 million women get pregnant, of these 500,000 die from pregnancy related complications and childbirth. In those who have childbirth complications, about two million suffer from VVF (Browning, 2004). The larger burden of these complications and deaths occur in developing countries (Ahmad *et al.*, 2017).

At present, available published papers have two major shortcomings in VVF. First, there is an overall paucity of reliable data on VVF especially in East Africa. Secondly, almost all reported studies have been done in hospitals where fistula repair is carried out. Such trends are subject to considerable selection bias and cannot provide reliable estimates of the true incidence of preference. Perhaps, this is the most useful comparative health statistic particularly in Africa.

1.4.1: The Burden of Vesico Vaginal Fistula in East Africa

Although, the prevalence of VVF in Kenya is not known, estimates show that 1000 new cases occur yearly, out of which only 7.5% get treated (UNFPA, 2003). VVF still afflicts the young, the poorly educated and unemployed, primigravidas in the country (Khisa *et al.*, 2011). This observation is replicated across East Africa (Browning, 2008). In these countries, fistula repairs have been scaled up, which is a great undertaking. However, the ultimate goal should be to eliminate fistulas in the region. Researchers in neighbouring countries, such as Malawi, have presented a view which implies that VVF prevalence is lowest in that country (Rijken and Chilopora 2007). This observation is made amidst National level commitment in developing a fistula centre, a government commitment which tends to contradict reports by Rijken and Chilopora (2007).

1.5: Predisposing Factors

Studies from Africa (Khisa *et al.*, 2011) indicate that VVFs affect young rural and poor women. In this study, the mean age of patients with VVF was 22.4 years (range 9-45 years); 42% were less than 20 years, and 65% were less than 25 years of age. The same study also reports that fistula formation is more likely to follow a first labour and often these patients may have been victims of forced marriages. Similar findings have been documented in Ghana where 53% of the VVF

patients were under the age of 25 and nearly 43% of patients were primigravidas, (Danso *et al.*, 2007).

Access to antenatal and emergency obstetric care is a major contributing factor to VVF occurrence. In their study, Wall *et al.* (2006) showed that fistula patients had little or no access to prenatal care, and that even patients who had attended antenatal screening still delivered at home attended by family members or traditional midwives. The few, who sought skilled birth attendance from trained midwives or medical doctors, came to health facility late in labour, long after serious complications had already occurred (Wall *et al.*, 2006). In such instances, the health care provider is helpless; he or she cannot reverse serious complications such as intrauterine fetal death or ruptured uterus or VVF. In this regard, health care providers can only take necessary steps in saving the lives of the mother where possible and help prevent further disability.

Thaddeus and Maine (1994) described three classical stages of delay that may lead to fistula formation. All three stages interact to produce maternal death and serious maternal morbidity. The first stage involves individual factors whereby the woman delays to take decision to seek care. The second delay is associated with transportation which hinders faster arrival at a health care facility. Lastly, even when the woman arrives at the facility, there may be delay in receiving adequate care at that facility (Thaddeus and Maine, 1994).

1.6: Mechanism of Fistula Formation

The commonest cause of VVF in Africa is prolonged obstructed labour (Orach, 2000). During prolonged labour due to foeto-maternal disproportion during the course of birth, the presenting part of the foetal head or any other presenting part constantly puts pressure on the soft tissues around the vagina and the bladder or rectum. As a result, the foetal head becomes trapped in the pelvis such that it cannot pass through, trapping the woman's soft tissues between two bony plates. Unrelieved, this causes ischaemic necrosis of the affected tissues which eventually slough off leaving a hole through which urine leaks within 3-5 days. The extent of injury has been linked to the duration of labour. The foeto-maternal disproportion that causes obstructed labour may be due to a small pelvis particularly in young, teenage primigravidas who have become pregnant before they have reached their full adult pelvic growth. Other causes may be due to reduced pelvic proportions due to disease or injury or an abnormal foetal presentation such as transverse lie, shoulder or breech presentation. Studies show that this kind of foeto-pelvic disproportion occurs in 0.5% to 6.5% of deliveries (Arrowsmith *et al.*, 1996).

Vesico vaginal fistula can occur following hysterectomy or caesarean section or during inappropriate use of vacuum extraction and forceps delivery. In 2004, UNFPA's Campaign to End Fistula conducted a needs assessment in 20 countries. They found that caesarean section as a life saving measure range from 0.1% to 3% (Velez *et al.*, 2007); this is well below the absolute minimum rate of 5% recommended by World Health Organization (WHO) to meet maternal health needs. Reports from Nigeria have shown that there is a substantial difference in caesarean rates between urban and rural areas (Gunn *et al.*, 2017) The majority of women in Africa live in rural areas and therefore have less access to caesarean delivery than women who live in urban areas (Buekens *et al.*, 2003). This is because specialised health care providers are more concentrated in urban areas and that many rural health facilities do not have the infrastructure necessary for performing caesarean sections.

Fistulas can also be caused by accidents, sexual abuse and rape. Evidence from the Democratic Republic of Congo, Sierra Leone, Sudan, and Somalia indicate that violence against women is a cause of fistulas in these countries (Goh *et al.*, 2005). Though the actual prevalence is not known, sexual abuse has been associated with fistulas in war torn countries. For instance, studies show that 17 of the 100 female victims of sexual violence developed a fistula as a result of their injuries (Kalume 2004; ACQUIRE Project and EngenderHealth, 2005). Still in Ethiopia, Muleta *et al.* (2007) reported 91 cases of fistulas that occurred following sexual violence. This problem knows no age limits as demonstrated by Nduati and Muita (1992) who report two cases of fistula among 21 sexual abused children in Kenya. Observations such as this demonstrate the discrepancies in prevalence and the need for detailed studies in these settings.

Fistula formation has also been associated with traditional cutting, practices based on erroneous assumptions of disease aetiology or other cultural values. For instance, in northern Nigeria a harmful practice called *gishiri*-cutting accounts for between 2-13% of Vesicovaginal fistulas. *Gishiri* is the Hausa word for "salt." It also refers to a disease state in the Hausa ethno-medical system. There is a belief that if a mother takes too much salt, sugar or similar substances, especially during pregnancy, it will result in the narrowing and an encrusted vagina or that the vagina may be covered with a flimsy membrane that will prevent the child from being born. Hence, during obstructed labour a traditional healer (barber, midwife) makes a series of *gishiri* cuts in the vagina to "relieve" this obstruction; often causing direct trauma to the urethra or bladder, leading to fistula formation (Wall *et al.*, 2004). In this study, Wall *et al.* (2004) identified 21 (2.3%) out of 932

(100%) cases of fistula that might be caused by this practice. Higher rates have been reported among children with fistulas where *gishiri*-cutting was carried out in 12 (15%) of the 80 (100%) children with fistulas (Tahzib, 1983).

The most appropriate explanation as to how FGM predisposes to fistula, would be direct injury to the genitourinary system at the time of the procedure, as already noted, or scarring at the vaginal outlet that leads to prolonged labour. Since most cases of obstructed labour occur higher up in the pelvis than at the outlet, it seems unlikely that female genital cutting by itself is the sole cause of the obstruction that leads to a fistula. Regardless of the cause of the fistula, the condition is debilitating and no woman in the world should suffer for bringing forth new life.

1.7: Presenting Symptoms

The cardinal sign of VVF is continuous urine and/or faecal leakage with offensive odour. In a few cases, especially where the fistula is small or involving the ureters, leakage of urine may be intermittent. Specifically in ureteric fistula, leakage of urine will also be accompanied by normal micturition. Other common symptoms include: foot drop (as a result of sciatic nerve injury), urine dermatitis of the genital area (excoriations), pressure sores and secondary amenorrhea due to severe blood loss. In earlier reports Khisa *et al.* (2011) described how women with this condition are faced with multiple challenges, which include: living with social stigma, loss of income and various psychological distress related illnesses.

1.8: Classification of Vesico Vaginal Fistula

Around the world, there is no single acceptable method of fistula classification. For this reason, various classifications of VVF have emerged. A study looking at development and comparison of prognostic scoring systems for surgical closure of genitourinary fistula was described by Frajzyngier *et al.* (2013), with a purpose to test the diagnostic performances of five existing classification systems developed by Lawson, Tafesse, Goh and Waaldijk. Results from their study showed that Goh and Tafesse's classifications to have the highest predictive accuracy, at 0.63. The study concluded that further evaluation of the validity and reliability of existing classification systems to predict closure is warranted. However, the WHO recommends only two: the Waaldijk (1995) and Goh (2004) classification systems.

1.8.1: Goh's classification system

Goh's approach aims at standardising the classification system, to reduce subjective variations and assess possible long-term complication. The fixed reference points are utilised to facilitate standardisation of fistula description and make comparisons by different caregivers. The external urinary meatus is used for the fixed reference for genitourinary fistula and the hymen for genito-anorectal fistula. The length of vagina allows assessment of the relative size and position of the fistula and is also a risk factor for subsequent sexual dysfunction. This system assumes that the length of the sphincter mechanism is a risk factor for pelvic organ dysfunction and incontinence. The sphincter mechanisms for both genitor-urinary and genito-anorectal fistulae are situated more than 3.5 cm from the fixed reference points. Size of fistula is measured in centimetres in the maximum antero-posterior and transverse dimensions. It also has implications on anatomical closure, tissue deficit and use of graft tissue to augment the fistula repair.

The new classification divides genitourinary fistulae into four main types, depending on the distance of the distal edge of the fistula from the external urethral meatus. These four types are further sub-classified by the size of the fistula, extent of associated scarring, vaginal length or special considerations. Type 1: Distal edge of fistula > 3.5 cm from external urinary meatus Type 2: Distal edge of fistula 2.5–3.5 cm from external urinary meatus Type 3: Distal edge of fistula 1.5 – < 2.5 cm from external urinary meatus Type 4: Distal edge of fistula < 1.5 cm from external urinary meatus (a) Size < 1.5 cm, in the largest diameter (b) Size 1.5–3 cm, in the largest diameter (c) Size > 3 cm, in the largest diameter:

- i. None or only mild fibrosis (around fistula and/or vagina) and/or vaginal length > 6 cm, normal capacity.
- ii. Moderate or severe fibrosis (around fistula and/or vagina) and/or reduced vaginal length and/or capacity.
- iii. Special considerations e.g. post radiation, ureteric involvement, circumferential fistula, previous repair. For instance, with this proposed classification in a Type 2bi fistula the ureteric orifice can be close to the fistula edge and it is recommended that ureteric orifices be identified prior to or during surgery, whilst the woman with a Type 3aii fistula is probably at a higher risk of postoperative urinary incontinence and requires follow-up (Goh, 2004).

1.8.2: **Waldijk classification System:**

In his classification, Waldijk (1995) based his work on the quantitative and qualitative amount of tissue loss of the continence-closing mechanism of the bladder/urethra. These were measured according to anatomic/physiologic location of the fistula as shown in Table 1.1. The classification also describes the severity of tissue damage, the likely complexity of the repair and the prognosis after repair. It also measures the size of the fistula as to whether it is small (< 2cm in diameter), medium (2-3 cm), large (4-5 cm) or extensive (> or equal to 6 cm).

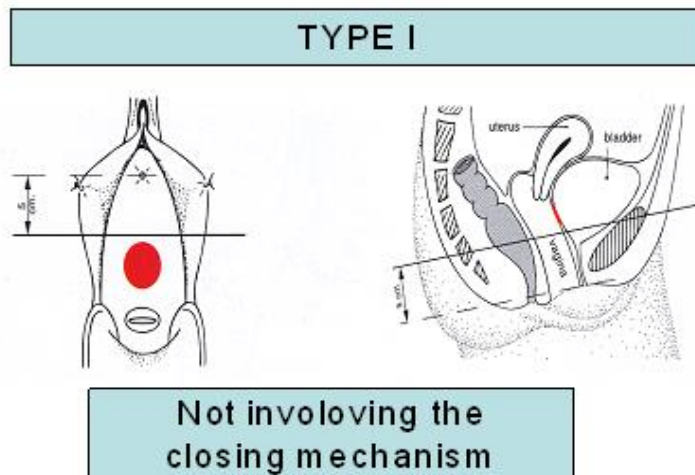
The severity of the lesion and prognosis worsens from small to extensive. This means that the more extensive the fistula is, the more likely it is to fail to close after repair. As such, this becomes the most suitable classification method for this kind of study whose aim is to establish factors that predict fistula healing post repair. In clinical practice, most surgeons in Eastern Africa use this classification because of its precision in assessing the fistula and when choosing the repair technique. In Table 1.1, the researcher presents a narrative description of fistula classification according to Waldijk. Corresponding diagrammatic illustrations are also presented in Figure 1.1.

Table 1.1: Fistula Classification Guidelines by Waldijk

Fistula Type	Description
Type I:	This is where the fistula does not involve the closing/continence mechanism (Intact continence-closing mechanism i.e. the fistula is > 5 cm from the external urethral orifice).
Type II:	Here the fistula involves the closing/continence mechanism. (Closing mechanism is compromised i.e. the fistula is < 5 cm from the external urethral orifice).
Type II A:	The fistula is without (sub) total urethra involvement (minor involvement of continence-closing mechanism). a) Without circumferential defect (minor involvement of continence mechanism). b) With circumferential defect (moderate –major involvement of the continence mechanism).
Type II B:	This fistula is with (sub) total urethra involvement, moderate to major involvement of the continence-closing mechanism). a) Without circumferential defect (major involvement of the continence mechanism). b) With circumferential defect (extensive involvement of the mechanism).
Type III	Miscellaneous, e.g. ureteric fistula.

Below are illustrations of fistula classification according to Waaldijk. The severity of tissue damage, complexity of repair and prognosis worsens from type I through to IIBb, IIBb being the most difficult with poorest prognosis (Waaldijk, 1995). The diagrams below help illustrate the classification.

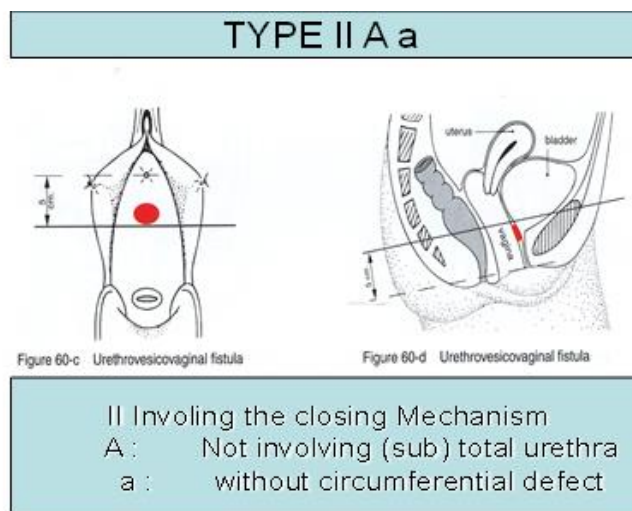
Figure 1.1: Diagrammatic illustration of Fistula classification



Illustrations provided by courtesy of Dr. Waaldijk

Type II: In this type the fistula involves the closing/continence Mechanism. Type II is further subdivided into A and B

Type II Aa: The fistula does not involve (sub) total urethra, it is without circumferential defect



Type IIAb: The fistula has a circumferential defect

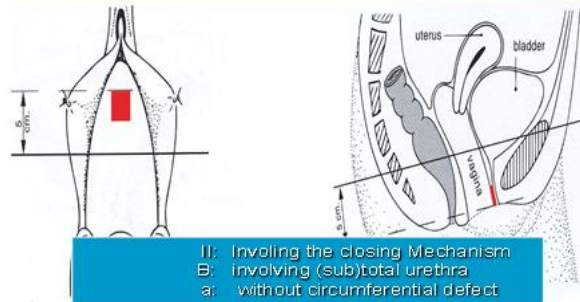
TYPE II A b



II: Involving the closing Mechanism
 A: Not involving (sub) total urethra
 b: with circumferential defect

Type II B: This type Involves (sub) total urethra. This type is also subdivided into two parts a, and b. **Type II Ba:** The fistula presents without circumferential defect

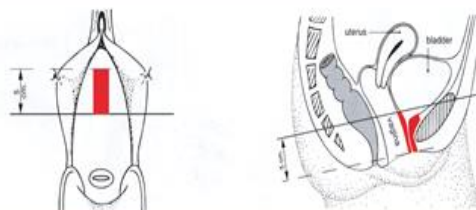
TYPE II B a



II: Involving the closing Mechanism
 B: involving (sub)total urethra
 a: without circumferential defect

Type II Bb: The fistula presents with circumferential defect

TYPE II B b



II: Involving the closing Mechanism
 B: involving (sub)total urethra
 b: with circumferential defect

Type III: Miscellaneous Fistulas

Miscellaneous fistulas include ureteric and other exceptional fistula.

Circumferential defect refers to fistulas which involve a destruction of the bladder neck, not only on the vaginal side, but in many instances, on the pubic side as well. The result is a circumferential sloughing with subsequent discontinuity of the urethra and bladder: the intervening tissue is merely the epithelium that has grown over, and becomes adherent to the periosteum of the back of the pubic bone. Usually these fistulas are more difficult to operate on and require a surgeon with good skills and experience. It is important to note that closing the fistula and restoration of continence, the main objectives of surgery, becomes increasingly more difficult with the severity of tissue damage. Complexity of the repair and prognosis worsens from type 1a through to 11Bb, 11Bb being the most difficult with poorest prognosis (Waldijk, 1995).

Indeed, the damage may involve many organs, including the gynaecologic, urologic, gastrointestinal, musculoskeletal, and the neurologic systems. This syndrome has been described as 'obstructed labour injury complex' (Arrowsmith *et al.*, 1996). The injury can be quite extensive and when associated with amenorrhoea, cervical damage, and severe stigma, can lead to infertility.

1.9: Management of Vesico Vaginal Fistula

Management of VVF is dependent on fistula classification, its location, tissue quality and the timing of surgery. When the patient arrived at the fistula centre for the very first time, medical and social history were documented to help establish the cause of fistula. A history of constant, painless urine leakage following difficult child birth or pelvic surgery is a key indicator. On physical examination, pooling of urine in the vagina may be noted: speculum examination may reveal the fistula and quality of surrounding tissues. A dye test may be done to confirm diagnosis and rule out concurrent pathology.

1.9.1: Conservative Management

Conservative management refers to non-invasive fistula treatment where the woman is not operated on. The primary objective of conservative management is to prevent stigma and other complications associated with fistula formation. This mode of treatment is used mainly where fistulas are fresh and small in size. Fresh fistulas are those that present within three months of formation. This period is also referred to as the physiologic healing period. Women who get

obstructed labour may leak urine and or stool due to a fistula or stress or overflow incontinence (Waaldijk, 1995). Overflow incontinence can result from an atonic bladder following overstretching of the bladder muscle common when labouring happens with a full bladder.

The patients should have an indwelling Foley catheter for 4-6 weeks and advised plenty of fluids orally. In these settings, in his guideline, Waaldijk (1995) recommends that any woman leaking urine after childbirth should be managed by continuous catheterisation with Foley catheter size 16–18 and plenty of fluids which allows free drainage of urine and allows the bladder to rest. This promotes spontaneous healing of the bladder.

It is important to note that routine antibiotics are not administered during the 4-6 week period because fistula is caused by pressure necrosis and not systemic infection. Studies show that 30% of small and fresh VVFs heal spontaneously by catheterisation and plenty of fluid intake (Waaldijk, 1995). These patients should be advised to have haematinics to boost the haemoglobin and promote healing. In addition, they should be mobilized immediately to prevent permanent foot drop, a common complication of neglected obstructed labour which can injure the sciatic nerve. Regular vaginal hygiene and debridement of the sloughing tissues promotes just like in treatment of burns (Waaldijk, 1995). It is advisable that as soon as the fistula edges are clean, fistula closure should be attempted. This has been reported as highly successful and prevents the woman from becoming stigmatised and ostracised as it is continuous with the delivery event (Waaldijk, 1995).

1.9.2: Surgical Repairs

James Marion Sims reported the first documented procedure for fistula repair in 1849, as quoted by Elkins (1997). During this period in time, very rudimentary procedures were used. Since then, surgical procedures have evolved tremendously. In the past, surgical repair of any obstetric fistula before 3 months was discouraged for fear of recurrence and inadequate healing. However, the principle of delayed repair is no longer tenable. The timing of fistula repair is now dictated by the nature of the local tissues around the fistula site. Surgical repair may commence if no vaginal infection is present and if the inflammatory process at the fistula site has resolved as described above.

There are some instances when surgery is contraindicated. For instance, the presence of an active vaginal infection or persistent inflammatory process at the fistula site is a contraindication to

surgical repair. The objective of surgery is principally dual: close the fistula and make the woman continent of urine/stool (Waaldijk, 1995).

Historically, the transvaginal approach to surgery has been contraindicated for supratrigonal fistulas. However, this is no longer an absolute contraindication: to use a trans-abdominal or transvaginal approach is now dictated by the surgeon's experience and preference. The practice today requires that prior to surgery: comprehensive pre-operative and nursing care is carried out to ensure the patient is ready for intraoperative as well as post-operative care. Section 1.7.3 describes the pre-operative care.

1.9.3: Pre-operative Care

During the pre-operative period, the patient receives basic information regarding fistula. This focuses on informed consent discussions, and the need for perineal hygiene and a high protein diet. Most importantly, patients are encouraged to maintain high fluid intake of 5 litres per day. This helps improve visualisation of the ureters during surgery and facilitates emptying of the bladder after surgery. Constant flushing of the bladder is useful in prevention of infection and catheter blockage post-operatively. Minimum laboratory tests are done, including urinalysis and a full haemogram, because these tests are cheap yet useful in patient evaluation. Broad-spectrum intravenous antibiotics are not administered routinely since the fistula is caused by pressure necrosis and not infection. Once the patient has had her questions answered, consent is obtained and the patient is ready for surgery.

1.9.4: Intra-Operative Care

The surgeon may choose the vaginal or trans-abdominal route after examination of the fistula under anaesthesia. The choice of surgical technique and site is dependent on the surgeon's experience and fistula characteristics.

1.9.5: Post-Operative Care

Post-operative recovery varies with the extent of the repair and individual characteristics. Most surgeons agree that the bladder should be continuously and completely drained for at least 10 days postoperatively, and up to 2 to 3 weeks in extensive fistula (Waaldijk, 2004). A suprapubic bladder drain is preferred, which, if appropriately positioned, reduces bladder spasms and patient discomfort, subsequently preventing premature catheter removal. However, locally, a trans-

urethral catheter is utilised. This is easier to insert and manage post-operatively than suprapubic catheter. The patients are also advised not to resume sexual activity for 3 to 4 months, as abstinence allows tissues sufficient time to heal (Kelly and Kwast, 1993a).

1.9.6: Postoperative Complications

The commonest complication associated with fistula repair is catheter blockage. When this occurs, the catheter is flushed and the patient is encouraged to drink plenty of oral fluids. Also, fistula may recur/does not close: this is the most feared complication. If the fistula does not close, a three month waiting period is advised. This period allows for tissue healing before the second repair can be attempted. Persistent urinary leak can also occur after repair due to stress or urge incontinence. A secondary repair may help treat or improve continence especially in stress incontinence.

1.10: Predictors of Fistula Healing

Current practice lacks a standardised definition of success following VVF repair; the reporting of surgical outcomes varies from study to study. Most researchers, however, report as success, the surgical closure of the fistula at the time of hospital discharge, without further evaluation of the effect of the procedure on continence or patient's subsequent quality of life. Reports from the Kenya Ministry of Health (Kenya MoH, 2004), show that there is paucity of data on predictors of success in fistula repair. However, several factors are known to affect success of fistula repairs, they include: general health status of the patient, fistula type, fistula location, haemogram results, intraoperative complications, post-operative care and history of previous fistula repairs (Kayondo *et al.*, 2011).

In addition, major classifications have poorer healing rate. In part, this explains why failures are attributed to extensive and multiple fistulas including a combination of VVF and RVF. In Malawi, a study by Rijken and Chilapora (2007) reported that patients with OF only had a higher chance of healing on first attempt (94.1%) compared to those with a combination of VVF and RVF (78.8 %). Such observation indicates that patients with dual fistulas are less likely to heal at first attempt. Most importantly, these women face the greatest burden of living with both VVF and RVF because they leak both urine and stool in a continent where the condition is highly stigmatised. Other studies have shown 86.7% success rate was achieved where the fistula was single and had not previously been operated on (Gupta *et al.*, 2012).

The occurrence of scarring tissue is a key factor in predicting fistula healing (Kayondo, *et al.*, 2011, Barone *et al.*, 2012). Scarring can occur as a result of infection especially where there is a combination of VVF and RVF. It is therefore recommended that successful fistula closures require an accurate and timely repair using procedures that exploit basic surgical principles.

1.11: HIV Infection and Fistula Occurrence

The burden of HIV in Africa has been well documented. Although HIV prevalence has declined over the last eight years by 17%, the fact remains that women, especially in Africa, continue to acquire the infection at a higher rate than men (UNAIDS, 2009). Also, women get infected at an earlier age; more often they acquire HIV infection from older men. For instance, In 2016 alone, new infections among young women (aged 15–24 years) were 44% higher than they were among men in the same age group (UNAIDS, 2016). This may imply that some of these women get HIV during their first pregnancy, the very pregnancy that gives them a fistula. Once the fistula develops and the woman tests positive she bears all the blame. Such women live a very traumatised life; rarely does the family care for them. Data regarding HIV seropositivity and VVF is limited; it is for this reason that this study was designed to establish the effects it may have on fistula prognosis/healing.

1.12: Prevention of Vesico Vaginal Fistula

The primary strategy in fistula prevention is the empowerment of the girl child and the abandonment of cultural practices that violate the rights of women. Although research has not demonstrated the direct link between FGM and fistula formation, this cultural practice is detrimental to the health of the girl child because as soon as the young girl gets the cut, she is seen as an adult ready to be married off to an older man who can afford to pay the pride price. This is because FGM is a rite of passage in communities where it is practiced. Some of these girls are as young as ten years old and have no idea of or access to family planning (Khisa, *et al.*, 2012). Sooner or later the girl gets pregnant before the pelvis is fully developed to accommodate the passage of the foetus during labour. This group of girls is reported to be at highest risk for VVF formation (Maheu-Giroux *et al.*, 2016).

Education has been linked to economic power, which inversely boosts decision-making power for the woman at the household level. Studies in Africa by Thaddeus and Maine (1994) and Wall *et al.* (2006) indicate that the more educated the woman is the more likely she is to improve her health seeking behaviours. This means that when a woman is empowered, she can access information

and use the information in deciding when to seek medical assistance. For instance, a woman with good education will be well informed about the state of her pregnancy and whether or not she is at risk. For such a woman, when labour starts she will be ready to travel to hospital because she can afford the fare and the minimal fee charged, as opposed to the other woman who has no income and has to rely on the spouse to avail transport and pay hospital costs. In most cases, funds are unavailable due to endemic poverty coupled by large families common in rural communities.

The poor health infrastructure in Africa is an impediment in fistula prevention. For instance, the distance from the villages to the health facility is on average 50-100 km (Thaddeus and Maine, 1994). The geographical terrain and poor road network makes it impossible for the woman to reach the facilities in times of emergencies. A woman can labour for days without relief and the presenting part of the foetal head causes pressure necrosis; subsequently, the infant dies and she develops a fistula. In addition, labour management in these settings lack rigorous use of supportive technologies such as the partograph. Although the partograph is known to be very useful in identification of problems arising during labour, it is rarely used for various reasons, including staff shortages (Lavender *et al.*, 2007).

Evidence from literature advises that, in the case of obstructed labour, the skilled birth attendant should ensure continuous urinary drainage for 7-10 days, irrespective of mode of delivery. Where caesarean section or hysterectomy is indicated, proper surgical technique must be used to prevent surgical related fistulas that seem to be prevalent in these settings. Unfortunately, many African countries, including those in East Africa, are in political turmoil and civil strife. This impact negatively on women's health because of the trauma associated with sexual assault. The women living in war torn countries are not only raped, they acquire sexually transmitted infections as well as fistula. In these settings abortion is criminalised and the family planning services are out of reach for most women, making them carry unwanted pregnancies with virtually none or little psychosocial and/or economic support.

Africa needs a shift in policy formulation and increased health budgets to facilitate access to health care across the lifespan. This way, childhood diseases and malnutrition can be addressed early enough before the girl child gets stunted with a contracted pelvis, which is likely to lead to obstructed labour. This situation will predispose the woman to fistula formation and subsequent psychosocial disorders.

1.13: Study Rationale

Vesico Vaginal Fistula is a poor woman's condition affecting mainly young women in rural settings. Moreover, the lived experiences of women who attend a fistula service are not well documented. This study was designed to single out factors that predict fistula healing or failure, duration of urine leaking as a health seeking indicator and to explore how women experience life, before and after surgery. The study aims to establish social-scientific and physical factors that would predict surgical closure of the fistula. The outcomes will help improve clinical care and outcomes for fistula patients, including prevention eventually culminating into restoration of the dignity of many afflicted women.

1.14: Research Questions

1. What are the predictors of obstetric fistula closure following surgical repairs?
2. What are the predictors of duration of urine leakage among obstetric fistula women?
3. What are the lived experiences of women with vesico-vaginal fistula before and after fistula surgery?

1.15: Study Aims and Objectives

To establish factors that predict successful fistula closure, duration of urine leakage and document lived experience of women with fistula before and after fistula surgery.

1.15.1: Specific Objectives

1. To describe demographic characteristics of obstetric fistula patients in East Africa
2. To describe the pre- and intra-operative fistula characteristics of obstetric women in East Africa.
3. To describe predictors of successful fistula closure among obstetric fistula women.
4. To describe predictors of duration of urine leakage among fistula patients undergoing surgery at selected fistula centres in East Africa.
5. To understand the lived experience of women living with obstetric fistula women before and after fistula surgery.

1.16: Study Benefits

A fistula robs a woman of her dignity. In many instances, a woman with a fistula is stigmatised, ostracised and maybe divorced. VVF is commonplace in countries with poor access to maternal health services particularly in Africa.

In recent times, country programs targeting fistula care have been launched but the number of patients awaiting surgery is remains very large. It is the 21st century yet new fistulas continue to occur with no signs of a decline, a development that is undesired in any community. Furthermore, it is unclear as to how many patients have received care and how many have healed. Without evidence-based guidelines fistula teams continue to operate on patients using non-standardised approaches because there is a limited data to suggest the most appropriate approach when handling different fistula types.

Now, there is an opportunity to develop training curriculums and guidelines that encompass new study findings which offer predictors in fistula healing in a cohort of patients. This data answers clinically important questions that, there are other factors to consider in relation to fistula classifications and healing. Predictors of fistula healing have not been accurately reported in East Africa and there has been no attempt to consider how HIV sero- positivity affects fistula healing.

In responding to these issues, this prospective cohort study conducted a primary analysis to identify relationships between demographics, HIV sero status, fistula size, fistula location and duration of leakage. Study findings address knowledge gaps and will help revise the training curriculum for both on the job trainees; post graduates and undergraduates in all medical/other health care courses. Exploring the experiences of women pre and post-surgery will enable greater understanding of psycho-social issues which may help to inform strategies to improve the support and care given to women.

1.17: Conclusion

The burden of fistula is common in most communities in East Africa. Most fistulas in the region are obstetric in origin and mostly affect young women. The author intends to utilise a mixed method design in addressing predictors of successful fistula surgery in the region and gaining understanding of the lived experiences of women.

Chapter 2: LITERATURE REVIEW

2.1: Introduction

The chapter presents findings from a review of studies that evaluated predictors of obstetric fistula closure, duration of urine leakage and lived experiences of women with the condition. It is presented in three parts. Section 2.2 provides a discussion of the two main types of literature reviews, followed by a description of the search strategy and appraisal processes. Sections 2.3 and 2.4 present a structured search and review of quantitative literature, which address the first research question: predictors of obstetric fistula closure. Sections 2.5 and 2.6 present a search and narrative review which address the second research question; the lived experiences of women with the condition. Section 2.7 is a summary of the chapter.

The background, purpose of the review, characteristics of the articles, appraisal of the quality and conclusions of the reviews are all included. The chapter situates the study within the context of this specialised field of fistula surgery, providing a clear justification for the doctoral study.

2.2: Types of Literature Reviews

This section provides a discussion of the types of literature reviews which have been considered in this study. There are two types of literature reviews used in this chapter; structured and narrative reviews. Each review is preceded by an explanation of the search strategy and critical appraisal process used.

A literature review is defined as a “systematic, explicit, and reproducible method for identifying, evaluating, and synthesising the existing body of completed and recorded work produced by researchers, scholars, and practitioners” (Fink, 2005: p3). Robson (2015) agrees with Fink's definition; he reports that systematic literature reviews focus on a research topic, following a process of identifying and analysing documents of what is already known and written down. This seems to differ with the common notion and use of the word ‘systematic’ in the term ‘systematic review’. Therefore, in this chapter systematic literature review is described in such a way that it reflects the structured and practical approach to the literature search process.

2.2.1: **Narrative Reviews**

A narrative review summarises primary evidence which is commonly provided by leading experts in the subject matter (Greenhalgh, 2005). The expert tends to discuss a topic or clinical condition based on his/her views or experiences. In many cases, the narrative reviews are less structured than systematic reviews; this subjectivity contributes to their susceptibility to bias. However, narrative reviews can be advantageous, for example when broadly discussing a topic and getting the history and development of a disease (Cook, 1997). Narrative reviews help form a basis for future research and their flexibility makes them attractive to many researchers.

2.2.2: **Systematic Reviews**

Evidence indicates that systematic reviews are ranked highest in the hierarchy of evidence (Clarke and Stewart 1994; National Institute for Health and Care Excellence, 2005). The rigorous methods used in appraising the literature contribute to the high-ranking of systematic reviews; this is because systematic review methods can be applied to other study designs and remain explicit and reproducible (Tricco *et al.*, 2011). In this type of review, the reviewer develops pre-defined eligibility criteria and a specific research question to answer. The review is well structured and planned to respond to the specific research question; it uses a systematic and explicit methodology to identify, select, and critically evaluate results of the studies to be included in the literature review. This structured process helps minimise biases, thereby producing valid and reliable search outcomes (Higgins and Green, 2011).

2.2.3: **Structured Reviews**

A structured literature review is a process that critically analyses and evaluates available information on the subject matter. The outcomes are presented in an organised way, clearly addressing a well-articulated research question or series of questions. Unlike the traditional narrative reviews, structured reviews avoid extremes of subjective versus objective views. It uses explicit methods in literature searching with a clear, structured, replicable strategy. Because of this, structured reviews are considered more credible since they are less biased than expert opinions. Structured reviews are more flexible and more pragmatic than systematic reviews but still follow a systematic approach.

2.2.4: **Literature Research Questions**

There are two main literature review questions in this study:

a) Quantitative review question (Question 1)

This review addressed the research question: *“What are the predictors of successful fistula closure in obstetric fistula women attending services in East Africa?”* Studies in this review section included quantitative, empirical, randomised/non-randomised experimental and observational study designs.

b) Qualitative review question (Question 2)

The second part of the review explored responses to the research question titled: *“What are the lived experiences of women living with fistula in East Africa?”* Qualitative empirical studies such as those informed by grounded theory, phenomenology and ethnography were included for review.

2.2.5: Literature Review Choice

A structured system of reviewing literature was used to answer research question one. This approach was thought to be more pragmatic and more in keeping with the mixed study methods. The main aim of the structured review was to explore knowledge sources to either discover gaps, or guide the decision-making process of obstetric fistula care in clinical practice. Hence, critical appraisal of the available evidence was of paramount importance. The systematic approach enables the reader to follow the whole process.

The narrative synthesis was utilised in the qualitative literature review to allow flexibility in the approach to answer the specific question. Importantly, the qualitative research focused on gaining an understanding of lived experiences of women living with obstetric fistula. This approach enabled the researcher to be selective, including only those articles that were most relevant to the area of investigation. As such, the narrative approach enabled the search to evolve according to research interests and initial articles read.

2.3: Literature Search for Predictors of Successful Fistula Closure

This section presents a synthesis of quantitative literature on predictors of successful closure of obstetric fistula.

2.3.1: Search Strategy

This structured review utilised a systematic approach to searching the literature and a narrative presentation of the results. This type of review permits replication of the same question with the potential for transparency. This ensures a comprehensive search for existing primary articles of the review question and reduces the susceptibility of reviewers to subjectively select the primary studies as indicated by Liberati *et al.* (2009) and Higgins and Green (2011).

The credibility of the literature search is founded on a sound process of article retrieval at a given point in time (Cooper, 1998). As such, the articles retrieved must rely on effective search terms for the title and abstract as well as the clarity of context/subject matter. However, it is important to recognise that the assignment of database indexing terms is dependent upon the indexer's interpretation of the paper; at times this may affect the outcomes of a literature search (Evans, 2002). To minimise retrieval challenges, it is advisable for researchers to develop a focused research question with appropriate and identifiable resources to search. With this in mind, the search strategy for this first review was guided by the need to identify existing evidence relating to fistula surgery outcomes.

2.3.2: Search Elements

To identify relevant studies for review, a choice of appropriate search terms is critical. Search terms are usually derived from the main concepts in a review question. The PICO framework, originally designed to allow physicians to access evidence-based knowledge to guide their practice, has been extended to formulating review questions for accessing evidence in other fields (Huang *et al.*, 2006). However, PICO has increasingly been recognised as limited in retrieving studies from databases for review questions that are based on sociocultural phenomena or have a wide perspective (Cooke *et al.*, 2012). For example, in some research, especially based on the social sciences where the subject is contextualised, the definition of terms is subjective and based on context. This was evident when searching the literature for lived experiences of women with obstetric fistula.

Before searching the databases, additional words/synonyms from the review question were obtained through scoping and mapping out of the key concepts using the Mesh tool in Medline, and suggested terms in both Embase and CINAHL.

2.3.3: Data Sources for the Review

The databases were searched using the following keywords: Vesicovaginal Fistula (VVF), Vaginal Fistula (VF), urogenital fistula (UGF), Obstetric fistula (OF), Female Genital fistula (FGF) and Treatment outcome. Use of the keyword "surgical outcomes" did not reveal any results suggesting instead the use of "treatment outcomes". The Boolean operators 'OR' and 'AND' were applied as shown in Table 2.1. Each keyword was utilised to search for the literature in all four databases, i.e. Medline, Embase, Cinahl and PsycINFO.

Also, the reference lists and bibliographies of included articles were manually searched. All likely conforming studies were saved and then exported into EndNote after thoroughly scanning the databases. In EndNote the duplicates were screened out leaving only single studies. These were thoroughly screened, sorted, and those that did not meet the inclusion criteria by titles were removed.

Table 2.1: Keywords used in the literature

#1 Vesicovaginal Fistula/ #2 Vesicovaginal Fistula/ #3 Urinary Bladder Fistula/ #4 Urinary Fistula/ #5 Vaginal Fistula/ #6 Rectovaginal Fistula/ #7 Obstetric fistula. #8 Obstetric fistula/ #9 Female genital fistula.mp #10 Female genital fistula/ #11 Urogenital fistula. #12 Urogenital fistula/ #13 Vaginal fistula/ #14 Experimental Treatment Outcomes/ #15 Treatment outcomes #16 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or10 or 11 or 12 or 13 #17 14 or 15 #18 16 and 17

2.3.4: Inclusion and Exclusion Criteria

The criterion applied for exclusion and inclusion of the articles in the review were: the population under the study, the phenomenon under study and the type of research design in favour of identification of appropriate data to adequately explain the phenomenon (Denzin and Lincoln, 2005; Silverman, 2010).

Other criteria were: geographical location, year of publication and language of publication as explained by Bettany-Saltikov (2012). Women with obstetric fistula are a specific group and studies had to be restricted by gender (only women); men with fistula were excluded. It was necessary to include women of all ages as some acquired fistula when they were too young for the review to be meaningful, and findings were understood in the context of this group. The studies explored were also restricted by the aetiology of the fistula (obstetric in origin) and settings, hence the higher concentration of African studies.

The study criteria allowed all research designs so that relevant data were not missed. It also covered the years from 1970 to July 2017, the period where much publication on the topic has happened. Table 2.2 presents a summary of the exclusion /inclusion criteria.

Table 2.2: Inclusion/exclusion criteria

<p>Inclusion criteria</p> <ul style="list-style-type: none"><input type="checkbox"/> Predictors of fistula surgery related studies<input type="checkbox"/> Articles relating to any healthcare setting<input type="checkbox"/> Studies published in English<input type="checkbox"/> Primary or secondary research articles <p>Exclusion criteria:</p> <ul style="list-style-type: none"><input type="checkbox"/> Articles not written in English<input type="checkbox"/> Poor quality of the articles<input type="checkbox"/> Case studies<input type="checkbox"/> Case series<input type="checkbox"/> Opinion pieces and Articles not related to female genital fistula<input type="checkbox"/> Cancer and radiation-related fistula<input type="checkbox"/> Fistulas in males<input type="checkbox"/> Fistulas in Crohn's disease or ulcerative colitis<input type="checkbox"/> Infant fistulas
--

The selected articles were saved and then exported into an Endnote library. Selected articles were manually assessed for relevance to the key research question, i.e. predictors of fistula closure. To be eligible for full review, the paper needed to address fistula outcomes or predictors,

either as a primary or secondary paper. Articles identified included search terms in the title or abstract. It was intended that this would highlight any articles where the aim or findings were significantly related to the research question. A difficulty in using vaginal wound healing as a search term is that it highlights a significant number of articles where the term is used in wound healing not specific to obstetric fistula healing. Hence, full paper searches were not carried out in connection with the terms 'fistula healing' and 'predictors'. The inclusion and exclusion criteria for studies were developed from the keywords in the review question.

The review excluded Mesh headings unrelated to female genital fistula such as infant fistula, fistula due to radiotherapy, renal diseases, and cancer-related fistula studies. All articles identified were reviewed for relevance. Relevant articles were then selected, downloaded and scrutinised to ensure that they were answering the research question of the study.

2.3.5: Assessment of Quality

The quality of the articles was evaluated using the Hawker tool (Hawker *et al.*, 2002). The tool assesses factors in a study, as shown in Table 2.3, and scores each factor as shown in Appendix 2.2. The minimum score of 9 means inferior quality and a maximum of 36 a good study. The tool was selected because it is comprehensive but easy to understand and can be applied to different study designs. It allows the reviewer to assign a value to various methodological elements like abstract, methods, sampling and analysis, to show the rigour of the study.

Table 2.3: Hawker’s Tool for Quality Appraisal

Researcher and title: _____ **Date:** _____

Areas Appraised	Good	Fair	Poor	Very Poor	Comment
1. Abstract and title					
2. Introduction and Aims					
3. Method and data					
4. Sampling					
5. Data analysis					
6. Ethics and bias					
7. Findings/results					
8. Transferability/generalizability					
9. Implications and usefulness					
Total					

2.3.6: Search Findings

The initial literature search was conducted in the year 2013 and revealed eight relevant articles. The search was updated in July 2017 which revealed additional literature. The search of literature in July 2017 produced 446 articles after removing 98 duplicates. Further screening of the 446 articles was done using titles and abstracts, which led to the exclusion of 414 articles which did not meet the inclusion criteria. A thorough repeat screening of the abstracts was performed, this time with an independent assessor, which yielded 32 articles. Out of these, nine were eliminated at this stage either because the fistula occurred following radiotherapy or a malignancy complication, it occurred in different settings or it was associated with Crohn's disease. The total number that met the inclusion criteria came down to 23 articles.

The full text of the 23 articles meeting the inclusion criteria was requested. The articles were mainly African studies with a concentration in West and East Africa. Articles not written in English were excluded.

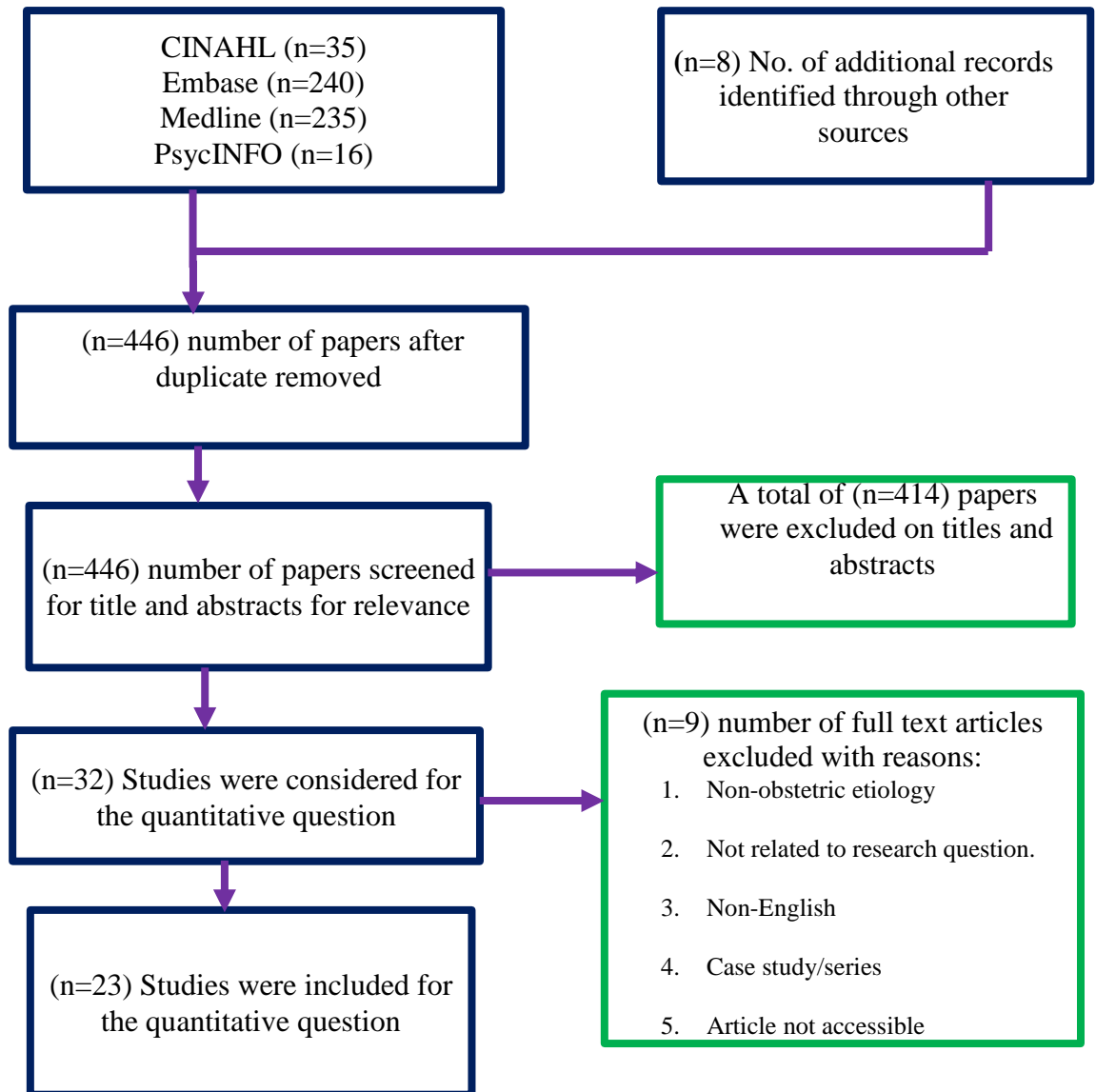


Figure 2.1: Flow Diagram of Quantitative Review Process

Appendix 2.1 Presents a summary of steps followed in identification, review and scoring of existing quantitative literature about predictors of successful fistula surgery. Each score of an element on the tool represents the quality of articles reviewed regarding the particular element. The total scores represent the quality of the studies. The 23 included articles were synthesised and appraised for quality using Hawker’s tool (Table 2.3.). The highest score was 35 and lowest were 18. However, there was little variation between articles, demonstrating a degree of consistency in the quality of the studies selected.

The narrative synthesis of the extracted results utilised the thematic synthesis approach, which has been effectively used to combine and discuss evidence generated from diverse research designs (Thomas and Harden, 2008). Each paper had the characteristics of the paper and key

findings relevant to the review question extracted and entered into a table. Appendix 2.2 illustrates the characteristics of the articles included and data extracted. All of the key ideas from the articles were pooled, labelled and refined into similar ideas iteratively until the final themes emerged. These themes form the topics of the discussion answering the review question. The synthesised findings are presented in part two of this chapter.

2.4: Literature Review for Predictors of Successful Fistula Closure

2.4.1: Introduction

This section presents a review of the relevant quantitative literature. The first part (Sections 2.3.2-2.3.5) focuses on the synthesis of primary articles relating to predictors of fistula healing/closure and related clinical information, while the second part (Section 2.3.6) presents published systematic reviews on the subject. Section 2.3.7 summarises the findings and Section 2.3.8 describes the gaps identified, while Section 2.3.9 presents conclusions.

2.4.2: Predictors of Successful Fistula Surgery

In the literature, various factors affecting fistula healing after surgery have been discussed, as summarised in Appendix 2.1. In Uganda, Kayondo *et al.* (2011) conducted a prospective study looking at some factors that influence surgical outcomes of VVF. The aims of this study were to determine the outcome of surgical repair of VVF and establish the factors that predict results of surgical repair of VVF in Mbarara, a regional referral hospital. For unknown reasons, patients presenting with fistulas of less than two months were excluded from the study, even though most patients indicated that they had given birth through caesarean section; 46 (59.7%) with a 90% perinatal mortality. This may mean that patients had been discharged from the hospital after the fistula developed following the caesarean section. Out of 77 patients who had fistula repaired, the majority (n=55, 79.7%) gained continence. However, among patients presenting with both Vesicovaginal fistula and recto-vaginal fistula, 3 (60%) had unsuccessful fistulae closure.

Reports from Uganda also indicate that major classifications have poorer healing rates (Kayondo *et al.*, 2011). In part, this explains why failures are attributed to extensive and multiple fistulas including a combination of VVF and RVF. The reports indicate that the presence of scarring tissue and circumferential defect are key factors in predicting fistula healing. Scarring can occur as a result of infection, especially where there is a combination of VVF and RVF. The same study shows

that patients who had large fistulas were more likely to have unsuccessful repair than those with small fistulae, with an odds ratio of 6.0, 95% CI 1.46 to 24.63 (Kayondo *et al.*, 2011).

The major limitations cited in the study were: a small number of cases (77 participants), limited supplies and equipment, as well as challenges in individual surgeon competencies. A conclusion that circumferential fistulae, marked vaginal scarring and patients with previous unsuccessful fistula repair are more likely to yield negative surgical outcomes has been made (Kayondo *et al.*, 2011).

Others define predictors of fistula outcomes in terms of fistula size and pathology (Hategekimana, 2005). A questionnaire was used for data collection in this prospective hospital-based study. A total of 112 patients were recruited over a five-year period (1997 to 2001) in Kigali, Rwanda. Postoperatively, patients were reviewed at months 1 and 6, a time when surgical outcomes were assessed. Symptomatic infection associated with Foley's catheter was observed in this cohort. During the immediate postoperative period, 13 (11.6%) fistulas recurred. Further, the study indicates that fistula diameter, bladder neck involvement and vaginal fibrosis are predictors of fistula failure. This observation is in agreement with their description of patient profiles where it is said that 64% of the patients presented with more complex fistulas, this may be associated with a breakdown in health systems following the 1994 genocide. The researchers have presented a background to the subject matter and described materials and methods. However, data management processes failed to pinpoint the factors that predict fistula success. Hence, the paper does not provide a conclusive statement on factors that affect fistula outcomes in this setting.

In a similar study, Goh *et al.* (2008) conducted a prospective study among 987 women with the aim of assessing predictors of failure of fistula closure and post-fistula urinary incontinence. The assessment for fistula closure and residual urinary incontinence was performed before the patients were discharged. The majority (n=960) had successful closure and 229 reported urinary incontinence after surgery. The highest number of urinary incontinence was reported among women whose fistulas were located closest to the external urinary meatus. Similarly, patients with significant vaginal scarring were more likely to report fistula closure and incontinence; an observation shared by Kayondo *et al.* (2011).

At the same time, researchers looked at predictors of fistula outcomes three months after surgery was conducted (Barone *et al.* 2013). Countries included in the study were: Bangladesh, Niger, Nigeria, Guinea and Uganda. The study focused on fistula closure and residual incontinence in women with a closed fistula. Patient and fistula characteristics and context of repair were said to be potential predictors in the study. A total of 1,274 women were recruited for study over a three-year period. The results indicated that severe vaginal scarring (adjusted RR 1.56, 95% CI 1.20-2.04), partial urethral involvement (adjusted RR 1.36, 95% CI 1.11-1.66) and complete urethral destruction or circumferential defect (adjusted RR 1.72, 95% CI 1.33-2.23) predicted failed fistula closure. Furthermore, severe vaginal scarring, partial urethral involvement, and complete urethral destruction or circumferential defect (adjusted RR 2.06, 95% CI 1.51-2.81) and previous repairs were significantly associated with residual incontinence. The researchers concluded that fistula closure is related to preoperative bladder size, previous repair, vaginal scarring and urethral involvement.

At the Jimma University in Ethiopia, 168 women were recruited in a cross-sectional study (Sori *et al.*, 2016). The survey recorded a success rate of 93.4%, but it failed to evaluate the risk factors associated with failure to close the fistula. The study had minimal details in the data analysis, and the results are unadjusted. There was no new knowledge presented in this paper.

In a cohort study, Delamou *et al.* (2016) looked at factors associated with failure of obstetric fistula repair in 754 women in Guinea retrospectively and found that presence of urethral damage and a history of vaginal birth in the previous pregnancy predicted failure. However, the study cautioned surgeons to exercise diligence in repair whenever they are faced with patients with both factors. Also, the study proposed a mixed method design to assess further insights into these factors. Although the study gave elaborate details in the background, it had minimal details on data analysis. The sample size was adequate to measure effect size and to validate their results. In the similar settings, a retrospective study conducted by Lopoosso *et al.* (2016) failed to identify urethral damage and previous vaginal deliveries as risk factors for failed fistula closure. This study concluded that a history of previous repair, the presence of multiple repairs, the severity of the fistula, surgeon's experience and duration of the fistula were reasons for failed repair.

In a retrospective cohort study of 640 women, Javed studied the factors to determine recurrence of fistula after VVF repair (Javed *et al.*, 2015). The study described factors for VVF recurrence as the presence of multiple fistulas: pre-operative bladder size, secondary repairs and duration of

fistula. The study reported no ethical clearance and appeared much like an audit of the hospital procedures. The researchers made proposals for a prospective study and standardisation of terminologies in fistula for purposes of comparison of results and to determine the prognostic factors. Also noted were non-prognostic factors like age, parity, and aetiology, route of repair and location of the fistula, which partially contradicts Gedik's (2015) observations on the choice of technique for VVF repair.

Studies by Loposso *et al.* (2016) were determined to evaluate factors to predict recurrence and successful treatment following surgical repair of VVF. This retrospective cohort study in DR Congo, with a sample of 166 women, went on to show that fibrosis and fistula location was a significant predictor of success and that the use of Martius flap and fistula size cannot significantly predict success nor recurrence of fistula after repair. The method utilised in the classification of fistula is not entirely true, because unlike Waaldijk, classification of VVF looks at anatomic/physiologic factors and fistula sizes to assess prognosis. These views are different from those described by Loposso *et al.* (2015), which essentially compromises comparability.

A recent cohort study in Malawi comprehensively investigated factors to identify patients at risk of urinary incontinence after surgery (Bengtson *et al.*, 2016). The study had a sample size of 401 women and prospectively looked at sociodemographic data, fistula factors, body mass index, and fistula classification. Bengtson *et al.* (2016) further described a risk scoring technique that would identify women at risk of urinary incontinence following repair. The study, conducted between 2011 and 2014, used logistic regression to develop a risk score to identify women with the likelihood of residual urinary incontinence defined as grade 2-5 within 120 days of VVF first fistula repair. The study based the score on preoperative clinical and demographic characteristics such as age, the number of years with fistula, human immunodeficiency virus status, body mass index, previous surgery at an outside facility, revised Goh classification, VVF size, circumferential fistula, vaginal scarring bladder size, and urethral length (Bengtson *et al.*, 2016). At each cut-off point, the study assessed the sensitivity, specificity, and positive and negative predictive values of the risk score. A risk score of 20 or higher had an associated increased the likelihood of residual incontinence with satisfactory sensitivity and specificity. The score had an excellent sensitivity of 82% and specificity of 63%. The negative predictive value was 91%. It recommended validation in the future with different populations and data sets to promote its application. This risk score is a new outcome. However, the centre, run by expert surgeons only, would compromise its

generalisability. If validated, it could be applied by surgeons to know which clients with VVF to refer to expert surgeons.

2.4.3: The Circumferential Fistula

The circumferential fistula is a more difficult fistula to close as it requires anastomosis of the bladder to the urethra. In Ethiopia, researchers in a prospective study set out to use a classification system in predicting surgical fistula closure and residual incontinence. Their findings indicate that circumferential fistulae had a risk for surgical failure and residual incontinence was reported even after fistula closed (Goh *et al.*, 2008). One retrospective cohort study in Sub-Saharan Africa by Wright (2015) set out to quantify circumferential urethral fistula and their prognosis. In a sample of 106 women, the study reported a 25% success rate of continence after repair. This paper also notes that use of buccal mucosa flap to augment repair of circumferential fistula was advantageous in improving urine continence and should be used.

On the same issue of flaps, Wahab *et al.* (2016) looked at the omental flap interposition in the repair of VVF. Although the study noted an improvement in the application of the flap, the result was limited by the small sample size (n=28), hence would not serve to affect practice.

2.4.4: Models of Treatment

On models of care, Taylor-Smith *et al.* (2013) described a comprehensive model involving psychological support, conservative and surgical management, postoperative care and follow-up of 458 women in Burundi. Although it served as a benchmarking exercise for the country and proposed use of telephone technology to aid recruitment of patients, the study noted challenges in early case finding and recruitment, capacity building of VVF surgical repair and assessing the psychological impact of the model. The results of this paper encourage fistula units to offer comprehensive care to fistula patients.

2.4.5: Mode of Repair Techniques

The choice of appropriate surgical technique for benign primary VVF remained a question for many surgeons. The idea prompted Gedik *et al.* (2015) to study 53 women retrospectively to evaluate and advise surgeons on appropriateness. The study was not appropriately designed to answer effectiveness of one method over another, and the sample was limited to give a good

effect size. A randomised clinical trial or an adequately designed observational study would help answer the question.

Other studies that looked at new technologies in the management of VVF concentrated on minimally invasive laparoscopic and robotic techniques on iatrogenic VVF (Tenggardjaja *et al.*, 2013; Wang *et al.*, 2012; Moses *et al.*, 2017). Unfortunately, the studies were in different settings where obstetric fistula is rare. Obstetric fistula occurs in poor settings in rural Africa and South East Asia where these techniques applicability is limited owing to poor hospital infrastructure. Furthermore, the time taken for training and the expenses involved would deplete resources for many ordinary surgeons and institutions in the low-resource settings. Needless to say, that the most appropriate technologies would be those that are safe, easy to learn, easily applicable with excellent results and at minimum cost.

2.4.6: **Systematic Reviews**

The first time the literature was searched was in 2013. The literature search found a paucity of systematic review articles. The narrative review by Creanga *et al.* (2007) broadly looked at VVF and its management in general. The paper did not present a focused review question. However, a broad objective was designed to review the existing clinical and epidemiological knowledge on VVFs. Also, the paper sought to identify issues that require immediate attention from both clinicians and policy makers including factors that determine surgical outcomes. This objective is quite elaborate and does not consider key items that make a focused review. A targeted review helps the researcher to capture all studies of interest, thereby maximising benefits to the clinician and patient. For example, a good review must indicate the participants, the intervention(s), specific outcomes, comparators and study design, items obviously lacking in this review paper.

During the initial search, the second systematic review identified was by Frajzyngier *et al.* (2012) who describes a systematic overview of primary studies with a clear, focused review question on a specific problem, i.e. the review is well structured with explicit eligibility criteria. A total of 20 articles were reviewed; the results show that scarring and urethral involvement was associated with poor prognosis. The report concluded that a unified, standardised evidence-base for informing clinical practice is lacking. Out of the 20 articles reviewed, none qualified for inclusion in the current review; either only abstracts were available or researchers did not analyse surgical outcomes or the articles discussed incontinence as post-operative complications.

Although the reviewed articles by Frajzyngier *et al.* (2012) were mainly observational studies and not randomised controlled trials (RCTs), they did help answer the review question and formed a basis for future research. The question has addressed the populations, interventions, outcomes and study design, which are important indicators for a good review.

In recent years, more evidence has emerged. Literature searched by July 2017 yielded four secondary records: two systematic reviews (Bodner-Adler *et al.*, 2017; Cowgill *et al.*, 2015) and two narrative reviews (Mellano *et al.*, 2014; Moses *et al.*, 2017). In Mellano's narrative review, the study described the literature on the epidemiology of VVF, presentation and diagnosis of VVF patient, fistula classification systems available, fistula management and postoperative care. Though the narrative style review limited the applicability of the results, nevertheless it brings out current issues in VVF. Unfortunately, the review did not discuss any factors to predict surgical closure of VVF. The other narrative reviews (Moses *et al.*, 2017) were on state-of-the-art treatment of VVF. The review examined the literature on management of VVF, specifically the mode and technique of VVF repair. Also, the study attempted to make a comparison of trans-abdominal laparoscopic and robotic techniques. There was no evaluation of predictors of success with the researcher keen to promote laparoscopic/robotic techniques. Conversely, the systematic review by Bodner-Adler *et al.* (2017) looked at the same techniques of repair and effectiveness of operative techniques or conservative management. This review considered randomised clinical trials and additionally conducted a meta-analysis. The study concluded that there was no clear favourite regarding disease management and surgical approach and that the vaginal route of repair remained the path of choice in the repair of VVF. The study was, however, limited to gynaecological iatrogenic VVF. In 2015, Cowgill *et al.* (2015) set out to search for literature on population-based obstetric fistula incidence, prevalence and rate of stillbirths among OF patients. This systematic review searched widely and found that the incidence varied considerably between Africa and Asia with ranges of 0-4.09% per 1000 deliveries while the prevalence ranged between 0-81.0 per 1000 deliveries. However, the study noted that the prevalence was prone to bias. The stillbirth rate associated with OF in the study was 32.3%.

2.4.7: Summary of Literature Review

Articles reviewed identified the following negative predictive values: a history of previous repairs, presence of scarring tissues and size of the fistula. Larger fistulas with bladder neck involvement were mentioned more commonly as having a negative healing predictive indicator. Some fistulas occur during caesarean section, particularly when the surgeon is less experienced. Articles

presented by Frajzyngier *et al.* (2013) and Barone *et al.* (2012) also reported predictors of fistula healing to be scarring tissue, circumferential defects and previous repairs. These are good reports but most studies were mainly quantitative in nature and did not address sociocultural factors that may predict success of fistula closure. The context in which researchers designed short-term follow up periods in most reviewed studies may have been feasible/practical at the time in the these settings. However, longer assessment periods may yield unexpected critical outcomes.

Some studies describe the context in developing countries where other factors predispose women to fistula, they include: poverty, long distances to health facilities, poor referral systems and poor road networks. These make patient follow-up a daunting task. Such scenario is compounded by the scarcity of specialised fistula centres in East Africa. Studies utilising the abdominal route of fistula repair were associated with longer hospital stay; these were said to be more likely to fail than those optimising on the vaginal route. Most researchers have not described a detailed view of factors that are associated with their conclusions.

2.4.8: Gaps Identified

There is lack of robust designs in understanding the fistula burden in developing countries. Most articles were descriptive designs, single site and small sample size to measure predictive values. In addition, there are no original articles looking at fistula surgery and predictors of closure or healing, especially in East Africa.

In all of the reviews, there was no evidence of mixed method studies relating to fistula characteristics, duration of leakage and women's lived experiences in multiple settings. Although articles by Kayondo *et al.* (2011) and Frajzyngier *et al.* (2013), described assessment of fistula surgery and outcomes in some African countries, cultural labour practices and demographic characteristics peculiar to Kenya were not captured. Also, in documenting predictors of fistula healing, researchers did not highlight the contribution of inexperienced surgeons in fistula care and their contribution to fistula outcomes.

Nevertheless, there were assumptions drawn regarding the presence of infection and antibiotic use, but none of these studies attempted to measure HIV seropositivity and its association to successful surgery. These reviews clearly point to multiple grey areas that link existing individual or fistula characteristics and surgical success.

In addressing these gaps, the current multi-site and mixed method study in East African settings was designed to explore clinical and social factors that may predict fistula healing in these settings. The first question aimed at establishing predictors of successful surgical fistula closure by

a single surgeon. The social context, duration of leakage and labour practices has also been studied to unearth untold predictors of surgical success in the cohort. In chapter five, the findings are described with due diligence and statistical precision unique to this study.

2.4.9: Conclusion

There is a paucity of evidence related to fistula surgery and outcomes, especially in Kenya. There is a glaring lack of research relating to predictors of fistula surgery and lived experiences of women living with fistula. Given the lack of evidence in this area of women's health, this study explored the predictors of successful surgery and determinants of duration of leakage. Surgeon's choice of classification style, route of repair and duration of leakage was also considered in detail. The study also explored the effects of pre and postoperative care on fistula outcomes.

2.5: Literature Search for Lived Experiences of Women Living with Fistula

2.5.1: Introduction

This section presents a synthesis of qualitative literature on women living with fistula before and after surgery. Although women living with fistula may have lived with the condition for many years, literature search outcomes were much less compared to the epidemiology of the condition, especially in Africa (Pope and Bangser, 2011). In part, low evidence in qualitative work may be a reflection of surgeons' training, whereby more emphasis is laid on fistula closing techniques than documenting the social and psychological aspects of the condition.

In recent times, evidence relating to women's experiences with fistula has emerged. This qualitative synthesis presents research findings emanating from either purely qualitative or mixed methods designs. The desired information has been presented in a narrative form starting with a description of the search process, scoring of articles and a summary of articles, as provided in Appendix 2.3. Sections 3.2 to 3.5 provide the synthesis of the reviewed articles. Section 2.5 presents the synthesis of the articles and the table in Appendix 2.4 presents scores of articles reviewed using Hawker's tool.

2.5.2: Data Sources for the Review

The literature search aimed to include all qualitative work published to date. Although the qualitative research aimed to explore the lived experience of women living with fistula, the search term 'lived experiences' did not reveal meaningful studies. Therefore, qualitative search terms

were searched and utilised in Medline and Embase databases. Similarly, the Boolean operators 'AND' and 'OR' were applied, combining these search words: Vaginal Fistula, Rectovaginal Fistula, Obstetric fistula, "in-depth" or "face-to-face" or interview or discussion. A summary of the process is shown in Table 2.4. Also, the reference lists and bibliographies of includes were manually searched. All likely conforming studies were saved and then exported into Endnote after thoroughly scanning the databases. Duplicates were screened out leaving only single studies. These were thoroughly screened, sorted, and those that did not meet the inclusion criteria by title were removed.

Table 2.4: Keywords used in the qualitative literature search

<i>Qualitative Literature Search Strategy</i>
<p>1 Vesicovaginal fistula/ #2 Vesicovaginal Fistula/ #3 Urinary Bladder Fistula/ #4 Urinary Fistula/ #5 Vaginal Fistula/ #6 Rectovaginal Fistula/ #7 Obstetric fistula.mp. #8 Obstetric fistula/ #9 Female genital fistula. #10 Female genital fistula/ #11 Urogenital fistula. #12 Urogenital fistula/ # 13. Vagina fistula #14 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or10 or 11 or 12 or 13 #15 ("semi-structured" or semi structured or unstructured or informal or "in-depth" or in-depth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*) #16 (focus group* or qualitative or ethnography* or fieldwork or "field work" or "key informant"). #17 interviews as topic/ #18 focus groups/ #19 narration/ #20 qualitative research/ #21 15 OR 16 OR 17 OR 18 OR 19 OR 20 #22 14 AND 21</p>

2.5.3: Inclusion and Exclusion Criteria

To be eligible for review, articles needed to be either qualitative or mixed methods. The population was women living with fistula before or after surgical repair. Articles that were associated with experiences of women living with fistula were included for review since they focused on the same phenomena (Bernard, 1994: Denzin and Lincoln, 2005: Silverman, 2010).

2.5.4: Assessment of Quality

As for the quantitative review in Section 2.3.5, the quality of the qualitative articles extracted in this review was evaluated using the Hawker tool (Hawker *et al.*, 2002).

2.5.5: Search Findings

The search found 530 articles after removing duplicates; 330 duplicates were removed. The remaining 200 articles were screened based on titles and abstracts; this yielded 50 articles. The remaining 50 were further scrutinised and 29 rejected. A total of 21 articles met the review criteria as presented in Section 2.3.3 (Figure 2.2).

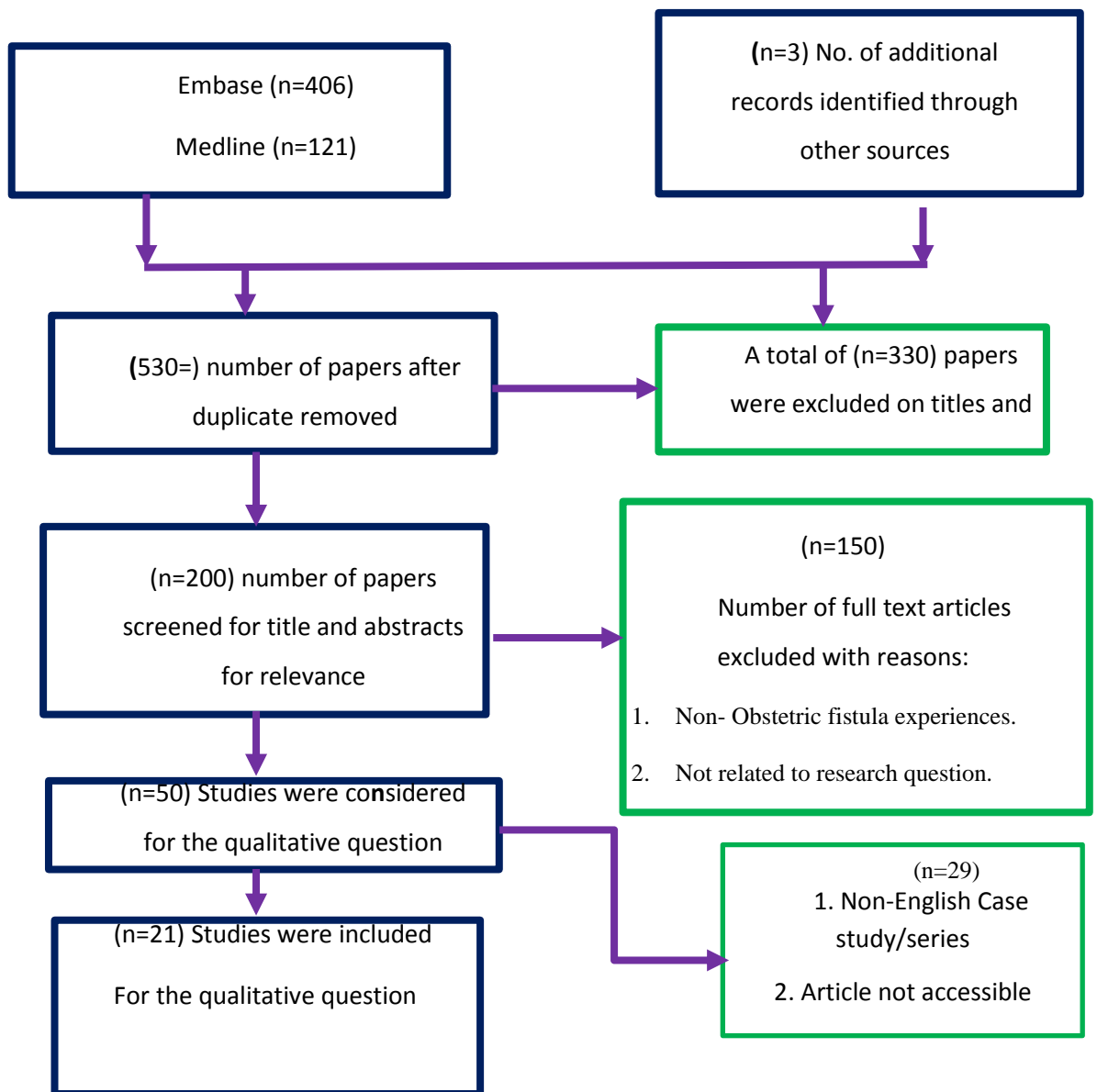


Figure 2.2: Flow Diagram of Qualitative Review Process

2.6: Literature Review for Lived Experiences of Women Living with Fistula

2.6.1: Introduction

In keeping with the research question, a narrative synthesis of identified qualitative articles was preferred as it allowed in-depth understanding of woman's lived experience. Although articles reviewed were from diverse settings, their findings generated similar themes and subthemes relating to women's experiences. For these reasons, they were reviewed under broad themes, each of which consists of subthemes which are discussed in context. Section 2.5.2 discusses negative social effects, Section 2.5.3 untoward culture, Section 2.5.4 physical trauma and issues with sequela, Section 2.5.5 social economic implications, Section 2.5.6 fear and rejection, Section 2.5.7 divorce following fistula and Section 2.5.8 the psychosocial effects of the fistula. Following successful fistula surgery, Section 2.5.9 discusses the improvement in quality of life while Section 2.5.10 looks at social reintegration and the regaining of self-esteem. Section 2.5.11 describes the gaps identified.

The paradigm of understanding women's experiences with and perceptions of their recovery must account for aspects of well-being beyond just surgery (Donnelly *et al.*, 2015). At the onset of this study, the few available studies strengthened the fact that rehabilitation and reintegration for these women with fistula were necessary to help women regain their pre-fistula status (Pope and Bangser, 2011). In Ethiopia, Muleta *et al.* (2004) had described depression and persistent health issues affecting the women after repair. The need for understanding isolation and reintegration was building up, forming the rationale for the synthesis.

2.6.2: Negative Social Effects

As soon as fistula developed, the narratives followed almost the same description; most women either self-isolated themselves or society rejected them (Mohammad *et al.*, 2007; Browning, 2008; Muleta *et al.*, 2008; Pope and Bangser, 2011). In essence, the drivers of social isolation emanated from the onset of uncontrollable urine and/or faecal incontinence, which occurred as soon as fistula developed. Coupled with the characteristic foul urine smell that follows, women became vulnerable and isolated (Muleta *et al.*, 2008; Browning *et al.*, 2008; Pope and Bangser, 2011). Because of the vulnerability and isolation, women's economic power was severely depleted.

2.6.3: **Untoward Culture**

Most communities in Africa believe in the natural labour process, such that when obstructed labour occurs, people quickly blame the women for adultery, invoking the help from spirits/soothsayers before labouring women get transferred to hospital (Mwini-Nyaledzigbor, 2013). The Ghanaian cultural beliefs, reported by Mwini-Nyaledzigbor, (2013), are shared with most countries in Africa, such that as soon as fistula develops, women are devalued and often divorced. Soon after the divorce, men remarry quickly, denying women their family inheritance, such as subsistence farming and family land (Browning, 2008: Mohammad *et al.*, 2007: Pope and Bangser, 2011). These reports highlight the culture and gender disparities that seem to justify the pain that women have to endure in country specific cultural contexts. However, Mohammad *et al.* (2007) does not underscore country specific contexts, hence, findings are not generalised. Although Pope and Bangser (2011), recruited women only in Tanzania, they provide good lessons for reintegrating the women back to society.

2.6.4: **Physical Trauma and Sequela Issues**

The physical trauma that follows fistula development are devastating, they include: uncontrolled urine leakage, genital sores/rashes from irritating urine, abdominal pains due to recurrent UTIs, irregular menstrual cycle and foot drop. The symptoms alone cannot allow women to interact with society because the awful smell and lack of sanitary pads alter their physical well-being, negating their very human existence (Muleta *et al.*, 2008: Khisa *et al.*, 2011). These studies were designed to provide a descriptive perspective of women's lived experiences but they failed to link each symptom with the degree of trauma. Such information would have been useful in developing holistic strategies aimed at restoring women's health (Mohammad *et al.*, 2007).

2.6.5: **Social Economic Implication**

The implications of living with fistula are that woman may not have a source of income, since they can no longer work even in their husband's farms. The patriarchal nature of most African families does not encourage married women to have investments. In part, this explains the financial challenges that follow women's vulnerability. In the studies reviewed, economic and employment challenges were noted: financial hardship was present before fistula developed, but exaggerated by the condition (Pope and Bangser, 2011: Muleta *et al.*, 2008: Browning *et al.*, 2008: Khisa *et al.*, 2011). These observations tend to explain why suicidal tendencies and depression will remain a

common feature in this group of patients for a long time, unless their physical and socioeconomic issues are attended in a holistic way (Mohammad *et al.*, 2007).

2.6.6: **Fear and Rejection**

The self-isolation brought about by physical trauma and sequelae leads to fear of social interactions (Baragaine *et al.*, 2015). Subsequently women were stigmatised by the same community where they were born and bred. This Ugandan study highlights the fact that women use both problem and emotion-focused coping mechanisms to minimise their sense of fear, rejection and isolation. In this hospital based study, Baragaine *et al.* (2015) missed an opportunity to conduct a mixed method study, where community perspectives would have been explored. These situations make women to be abandoned by family, relatives and friends (Yeakey *et al.*, 2011). This social isolation predisposed women to depressive illnesses including suicidal tendencies because they were scorned by members of their nuclear families where they should have felt safe and secure (Browning *et al.*, 2008). The rejection and fear denied women access to employment. Without money or reliable family support, decision making power gets eroded. This partly explains why women lived with the condition for many years, even though fistula services are freely available in their countries, as reported by Velez *et al.* (2007). The advantage is that this study was conducted in a multi-site setting bringing on board diverse issues affecting women and multiple options for interventions (Velez *et al.*, 2007). However, the study tools were not standardised for all sites hence, analysing large amounts of data together presents a challenge in the reliability and transferability of findings.

The fear and rejection necessitated a community based programme in Nigeria by Mohammad *et al.* (2007). This project focused on improving the social, economic, and health status of women. This project provided more than surgical repair and rehabilitation: they incorporated skills for helping fistula women improve their physical and economic well-being. In the process of implementing this project, Mohammad *et al.* (2007) helped raise awareness on general health, reproductive health and rights, and the necessity of integrating women into mainstream community development programmes. The prospective nature of this study helped identify factors that improve the quality of women's lives but failed to link health systems with the community.

2.6.7: Divorce Associated with Fistula

Regardless of the country of origin, women experience marital disruptions following fistula development. In earlier studies, Browning (2004) reported that 50% of fistula women in Nigeria were divorced as a direct result of having developed the fistula. Countries in Africa continue to document similar findings with minimal signs of arbitration. For instance, in Ethiopia, Muleta *et al.* (2007) reported multiple health and social problems of women with fistula. In this study, 69.2% of fistula victims were divorced, 44.2% were separated from other family members and only 19.2% were members of a local community association. These women had been forced out of their homes, ostracised by family and friends and even stigmatised by health workers. With such experiences, it is not surprising that surgery tends to reduce the prevalence of psychosocial pathologies (Pope *et al.*, 2011). This applied mainly to situations where the woman had to wait for a longer period before fistula surgery, e.g. in Kenya as reported by Khisa *et al.* (2011).

For these reasons, the care and support fistula patients require to rebuild their lives goes far beyond the initial medical interventions; similar suggestions were made by other researchers in the region (Mohammad, 2007; Yeakey *et al.*, 2009; Khisa *et al.*, 2016).

2.6.8: Psychosocial Effects of Fistula

Women with obstetric fistula are faced with many challenges of having to deal with smelly, continuous urine leakage, stigma, loss of income and stress related illnesses (Gupta, 2012). A cross sectional study titled 'Depression among women with obstetric fistula in Kenya' had shown that stress and depression, were common in women with fistula (Khisa *et al.*, 2011). These findings shed some light onto the psychological effects of fistula in the country. This study was undertaken at one time point, i.e. during a fistula camp where patients are treated and discharged without long-term follow up plans. The study also failed to assess other clinical factors such as duration of leakage and its effects on women's psychosocial well-being.

Other regional study findings indicate that in the majority of these women, the precedent pregnancy ended up in a stillbirth, which endangers their social value and marital harmony putting them at risk of stress, depression low self-esteem, low quality of life and hopelessness (Browning *et al.*, 2007; Pope *et al.*, 2011) although these studies agree that women with fistula also experience stillbirths, none of these studies clearly demonstrated the link between having a fistula, a stillbirth and its effects on women's psychosocial well-being. Pope *et al.* (2011) explored these issues using only qualitative methods, which may have failed to capture depression

precipitating factors such as a combination of vesico vaginal fistula and recto vaginal fistula. By failing to capture precipitating factors, researchers tend to augment the secrecy that inhibits women's well-being, as reported by Lavender *et al.* (2016).

West African studies also report the psychological effects of living with fistula. In Niger, Alio *et al.* (2011) explored the psycho-social impact of vesico-vaginal fistula (VVF) on women in Niamey between 2008 and 2009. In this period, 21 women were studied during their post-operative period. These women had two entry criteria: they had a previous history of repair (1-3) and all had given birth to stillborn infants. The outcomes indicate that many women in the study reported psychological consequences which included depression, feelings of shame and loneliness. Almost half of the 21 women lost their social networks due to the fistula problem. Women also narrated experiences of rejection by spouse, family and society. Others were isolation or divorced by their partners Alio *et al.* (2011). These experiences made women feel devalued as a woman, leading to suicidal tendencies. Interestingly, in this paper it was reported that society blamed the women saying that the fistula condition was a women's own fault, but the researcher did not seek the views of the community. Another major issue in this study is found in their contradictory conclusions; they attribute fistula development to lack of access to maternal health services, which in their view is not related to endemic poverty in that country, contrary to other regional reports (Mohammad, 2009; Khisa *et al.*, 2011).

Experiences from 40 women in Malawi follow the same scenario as women in the Kenya and Niger studies. In their research, Yeakey *et al.* (2009) interviewed 45 women with fistula in Malawi. The interviews were conducted in home settings similar to work done in West Pokot by Khisa and Nyamongo (2012). These reports document challenges faced by women following corrective surgery and discusses their needs within the broader context of women's health. The two studies report long-term emotional, psychological, social and economic challenges: unfortunately, these issues have received less attention, particularly in Africa (Yeakey *et al.* 2009; Khisa and Nyamongo 2012). The study recommendations targeted community outreach programmes to include a broader range of outcomes of women living with fistula and not merely fistula closure. They chose to work in an arid region where other extraneous variables such as nomadic lifestyle, water scarcity and illiteracy among the endogenous people are a big problem, but the study went silent on these pertinent issues (Khisa and Nyamongo, 2012).

In neighbouring Ethiopia, similar findings have been reported by Browning *et al.* (2007). In this study, 51 women with fistulas in the north of Ethiopia were screened for mental health issues before and after surgery. Browning noted that before surgery all women had signs of mental dysfunction, but two weeks after fistula surgery only 36% still had signs of mental distress. Although some women continued to exhibit signs and symptoms of mental illness despite having gained continence, the study did not seem to follow up the women for more than two weeks. Long-term follow up would have reported other community/family issues that negate/facilitate the psychosocial well-being of these women. In addition, it would be expected that the study would further explore the experiences of women for a longer period, especially those whose symptoms persisted: instead the researchers missed the opportunity because the study design had no provisions to do so.

Other observations, by Turan *et al.* (2014), describe the impact of group psychological therapy (GPT) on the mental health of obstetric fistula patients. The findings were encouraging, whereby the severity of mental illness significantly reduced after surgery. The proportion of women with a depression score of 4 and above reduced by half i.e. from 71.7% to 43.4%, and women with score of less than 4 increased from 28.3 to 56.6 percent (Turan *et al.*, 2014). Also, after surgery, suicidal ideation reduced as follows: severe (from 15.0 to 0%), moderate (from 16.7 to 5.0%) and mild (from 25.0 to 21.7%). In the same group of women, there was an increase of suicidal ideation (from 43.3 to 73.3%). Women who reported low self-esteem before group psychotherapy reported an improvement from 65.0% to 18.3% after therapy: the women also reported a reduction in suicidal ideation. In part, this may be an indication of positive psychosocial changes that follow successful fistula surgery where group therapy is implemented as part of fistula care. Such reports are upheld even though the inclusion criterion was not uniform because women were interviewed before surgery while other was interviewed after surgery, bringing to light the limitations in the reliability of findings. It is important to note that not all women in this study regained their pre-fistula period, which may imply that there are other pending/unresolved issues beside psychotherapy yet they did not form an objective for study. The unresolved/unexplored issues have a significant contribution in the quality of life for women even after fistula heals (Mohammad, 2007).

The psychosocial effects of women living with fistula transcend culture and geographical barriers. In most cases, women share similar experiences, as targeted interventions seem to be slow or elusive; this raises the need for legislation and community engagement in in Africa. Despite the

methodological challenges in reviewed narratives, observations in this section highlight the importance of mainstreaming mental health care within fistula programs, as suggested by others (Browning *et al.*, 2007; Turan *et al.*, 2014).

2.6.9: Quality of Life Following Successful Fistula Surgery

The quality of life in a cohort of Nigerian women shows remarkable outcomes after surgery. Quality of life was assessed using the WHO Quality of Life tool (WHOQOL), (World Health Forum, 1996). Before surgery, only 20% of women felt satisfied with the quality of their life; this increased to 90% after surgery (Umoiyoho *et al.*, 2011). However, the study does not present the characteristics of the 20% of women who felt satisfied with their pre-fistula life even before surgery was done.

Similar findings were reported in Ethiopia where surgery improved quality of life among women with fistula. Others observed that successful surgeries improve the quality of life and facilitate social reintegration to levels comparable to the pre-fistula period (Nielsen *et al.*, 2009). These may imply that successful surgery is directly associated with significant reduction on stress related illnesses, inversely improving the quality of women's lives. Although this was commendable work, the study fails to describe the variables and methods used in the assessment of the pre-fistula period, making it difficult for the reader to visualise the pre and post-operative characteristics. In an attempt to better understand lived experiences before fistula occurred, the current study was designed in such a way that women had an opportunity to describe their pre-fistula and post-operative experiences.

2.6.10: Social Reintegration and Regaining Self-esteem

After successful surgery, it is conceivable that women would be reintegrated into society without any problems. Surprisingly, their full reintegration was not guaranteed instead, it was dependent on their physical and economic status exhibited in the pre-fistula period (Mehmood *et al.*, 2009; Donnelly *et al.*, 2015). In a Tanzanian study, the ability for women to return to work and have family support was of paramount importance in their recovery process (Pope and Bangser, 2011). These three studies (Mehmood *et al.*, 2009; Pope and Bangser, 2011; Donnelly *et al.*, 2015) demonstrate a growing need for understanding the needs of this group of women.

In their mixed method study, Mselle *et al.* (2012) explored women's expectations, worries, and hopes related to returning to their family and community after fistula repair. A total of 151

women were recruited for a quantitative component of the study; out of these, only eight (5%) participated in the qualitative component which was done after surgery and at one time point. The findings indicate that women were concerned about where they could live, being un-accepted by their husbands and in-laws. Although many women in the quantitative study expected to go home and stay with their husband, more than half 51.3% (78/151) felt that their husband would not accept them regardless of their being fully recovered. Reasons for the fear were not fully explored, presenting an opportunity for further research. More than half 9/16 of the women wished to live with their parents because they felt that they would be accepted by their families, but reasons for this preference were not extensively explored. All women hoped to have children in the future, although some expressed fear of inability to have children later on in life. Despite these fears, women expressed hope in regaining their full pre-fistula economic and social status.

In 2003, UNFPA and Engender health described the minimum components for rehabilitation and reintegration programmes. They include: counselling, education, life skills training and support services (both financially and socially) for restoration of dignity in these women. It is in this regard that studies in Ethiopia were initiated to help health care providers and communities understand challenges women endure even after fistula is successfully closed. The country reports show that social reintegration in Ethiopia is slow; it is taken for granted, yet women urgently need assistance in participating in simple social activities such as travelling by bus and reconnecting with community and friends (Browning *et al.*, 2008). Although the reasons for laxity in instituting reintegration programs are not documented, the study by Browning *et al.* (2008) was among the first evidence in the region addressing issues affecting women with fistula.

A systematic literature review of 10 qualitative studies relating to rehabilitation and lived experiences of women with fistula in sub-Saharan Africa (Lombard *et al.*, 2015), demonstrated that women focused their discussions on the importance of their social functions/roles. Women reported that fulfilment of social roles was their most important rehabilitating factor, followed by counselling and health education. Because the review was restricted to only African studies, experiences from Asia and other regions were omitted, leaving out crucial information that could inform future programmes.

In recent years, there has been increased focus and interest in reintegration of fistula patients in East Africa and indeed in sub-Saharan Africa as evidenced by the number of studies being

published on this subject (Donnelly *et al.*, 2015; Wilson *et al.*, 2015; Khisa *et al.*, 2016; Lavender *et al.*, 2016; Watt *et al.*, 2015; Mselle *et al.*, 2016; Baragaine *et al.*, 2015). In Tanzania, the available latest literature points towards quantification of the psychological sequela of fistula women, especially after repair (Pope and Bangser, 2015; Wilson *et al.*, 2015; Siddle, 2017). In the same year, Wilson *et al.* (2015) compared the psychosocial effects of fistula with gynaecological conditions; as would be expected, the findings show higher traumatic events in fistula patients than the comparison group, raising design issues in this study. The individualistic approach in addressing psychosocial issues in women with fistula is wanting. Building a block of regional research teams with both surgeons and social scientists would unravel the psychosocial issues affecting the women because each team would bring on board their unique professional knowledge and skills.

Given that all the studies reported in the region were observational by design, it was felt that a randomised trial could yield other important factors in the care of the women with fistula. This observation prompted a short trial run on a Cognitive Behavioural Technology model (CBT), successful in management of other chronic diseases, with a view to incorporating it into the standard routine management of the fistula patients (Watt *et al.*, 2014). The researchers further suggested that a randomised clinical trial will be useful to evaluate the efficacy of this intervention technology before its application in practice (Watt *et al.*, 2015).

In Ethiopia, there have been suggestions to create a continuum of care from the time of discharge coupled with regular community visits over a period, to understand and aid rehabilitation and reintegration of these women (Donnelly *et al.*, 2016). The quest to have this has been necessitated by the fact that the women continue to suffer psychological trauma way after surgery (Donnelly *et al.*, 2015; Khisa *et al.*, 2017; Wilson *et al.*, 2016; Pope *et al.*, 2011). Other studies in West Africa agree that reintegration and rehabilitation of these women is essential (EngenderHealth Reports, 2003; Mwini-Nyaledzigbor *et al.*, 2012).

The complexities surrounding mobilisation of fistula, its treatment and social reintegration of the women demanded a more comprehensive pragmatic approach to resolve these issues (Mohammad, *et al.*, 2009; Pope *et al.*, 2011).

2.6.11: Gaps Identified

It was clear from the literature reviewed that the uni-dimensional findings of individual studies may not be adequate to inform strategies for predicting successful fistula healing. Findings regarding predictors of fistula healing have been reported based on clinical judgement alone; the role of African culture in fistula healing or its influence in the quality of lives for these women remains unexplored. The role of behavioural and motivational theories in helping women achieves self-esteem and self-worth has also not been studied. In addressing these issues, a research method that would help validate or corroborate study findings was desired.

In this regard, a mixed-method approach to the current research was preferred because integrating quantitative and qualitative approaches would bridge these gaps and provide a better understanding of the predictors of fistula healing as well as the lived experiences of the affected women. Mixing the methods was chosen to understand predictors of surgical fistula closure (social demographic, fistula characteristics, and childbirth characteristics) together with the complementary issues of lived experiences among fistula women.

2.7: Summary

Most of the papers reviewed described descriptive studies carried out in single settings. Predictors of successfulness of fistula surgery were primarily based only on clinical features, without any long-term follow-up. This meant that potentially meaningful outcomes, such as psychological impact, were not adequately explored. Developmental and environmental theories relating to fistula healing and community reintegration were also not applied in the papers reviewed. By using single methodological approaches, cultural practices that facilitate/hinder fistula or healing were not revealed. Thus, evidence on rehabilitation after obstetric fistula repair is lacking. A holistic approach to researching the care of women pre and post fistula repair is essential if meaningful strategies are to be developed.

Chapter 3: Research Methodology

3.1: Introduction

The chapter has been divided in two parts. Part one presents the theoretical frameworks related to the different paradigms, including postpositivism/positivism, interpretivism/constructivism and pragmatism. The section discusses the appropriateness of each paradigm and justification of the pragmatic paradigm chosen. Part two of the chapter presents the mixed methods approach which guided the study design. This section includes the rationale for using mixed methods and details the decisions made regarding the methods chosen and how they have been combined. These descriptions lay the foundation for the next chapter, where research methods are described in detail.

Part One: Theoretical Framework

3.2: Overview of Theoretical Framework

In designing a research proposal, one needs to assess the knowledge claims brought to the study. Also, it is important to consider the strategy of inquiry that was used, and to identify specific methods. Creswell (2003) states that it is fundamental that the researcher is able to identify either the quantitative, qualitative or mixed methods approach to inquiry.

Research can be described as a systematic investigation (Burns, 1997) or inquiry, whereby data are collected, analysed and interpreted in some way in an effort to understand, describe, predict or control an educational or psychological phenomenon or to empower individuals in such context (Mertens, 2005). Mertens (2005) emphasises that the exact nature of research is influenced by the researcher's theoretical framework, which is the paradigm defined in section 3.1.2. This idea is particularly relevant in Vesicovaginal Fistula where a gap in knowledge exists regarding the predictors of success of fistula closure and the impact on the lives of these women.

In order to shape practice and policy about VVF care, it may be necessary to consider a variety of sources of information such as patient and fistula characteristics, and the context in which the patient experiences this condition. The latter was needed to address the lived experience of the patient before and after fistula repair. Thus, a combination of these approaches provided a deeper understanding of the fistula problem.

As explained in the next section, a pragmatic framework was appropriate for this study as it provided an opportunity for different approaches and perspectives to address the problem of

Vesicovaginal Fistula; both quantitatively and at a later stage, qualitatively. Rather than having a theoretical philosophy, this study was guided more by personal training, practical experience and research questions.

3.3: Research Paradigms and Debates

Paradigms are defined as a 'loose collection of logically related assumptions, concepts, or propositions that orient thinking and research' (Bogdan and Biklen, 1998, p.22) or the philosophical intent or motivation for undertaking a study (Cohen and Manion, 1994). The main paradigms that are traditionally opposed are postpositivism/positivism and constructivism/interpretivism (Creswell and Plano Clark, 2007). Whilst positivism underlies quantitative research, interpretivism underlies qualitative research.

Contrary to more recent thinking, there are still very strong advocates of each paradigm who believe theirs is the better way to approach research. Indeed, positivism and interpretivism still dominate methodological textbooks and epistemological debates in social sciences. Important advances have been made by feminist, postmodernist, poststructuralist, critical researchers and many more nuanced positions within these broad frameworks (Hughes and Sharrock, 2007; Teddlie and Tashakkori, 2003).

According to Creswell (2003), several developments in recent years have caused a re-examination of positivism and interpretivism as the only paradigms citing many approaches to research. Other philosophical assumptions such as critical perspective, participatory perspectives and pragmatism are being extensively utilised today (Lincoln and Guba, 2000; Tashakkori and Teddlie, 1998). The situation today is less of quantitative versus qualitative and more on how research practices lie somewhere on a continuum between the two (Newman and Benz, 1998).

Finally, the practice of research and proposal writing involves much more than just philosophical assumptions. Philosophical ideas must be combined with broad approaches to research strategies and implemented by specific procedures. Methodology is commonly defined as an overall approach to research and is linked to a paradigm or theoretical framework. Methods refer to systematic modes, procedures or tools used for collection and analysis of data (Mackenzie and Knipe, 2006). Hence, a transparent framework is needed that combines the three elements of research: paradigm, methodology and methods.

3.3.1: Pragmatic Paradigm

Rather than positivist or interpretive paradigms, which either start or develop a theory, pragmatic paradigms are not committed to any system of philosophy or reality. With the research question 'central', data collection and analysis methods are chosen as those most likely to provide insight into the question without philosophical loyalty to any specific paradigm (Tashakkori and Teddlie, 2003). Pragmatism, as a paradigm, relates directly to the research as an epistemological stance. Thus, it directs the research efforts and serves to reassert itself to the exclusion of other paradigms and to articulate theories it already established (Kuhn, 1962). This removes the prescriptive nature of paradigms of requiring particular research methods, while excluding others. The pragmatic paradigm prevents constraints on intellectual curiosity and creativity and limitations on the 'sociological imagination' (Feilzer, 2010). There are many debates surrounding paradigms and research discussing the advantages and disadvantages of quantitative versus qualitative research.

3.3.2: Post positivism/Positivism

Positivism is also referred to as 'scientific method' or 'doing science' research, empirical science or quantitative research. It is based on the rationalistic, empiricist philosophy that originated with Francis Bacon (Mertens, 2005, p.7). It 'reflects a deterministic philosophy in which causes probably determine effects or outcomes' (Creswell, 2003). As such, the problems studied by Positivists reflect a need to examine causes that influence outcomes. These issues are examined in experiments. This paradigm was dominant from 1950s to mid-1970s and held the view that true scientific knowledge is based on 'pure observation'. In addition, the observation is free of the interests, values, purposes and psychological schemata of individuals' (Howe, 1988).

Positivists believe that serious scientific inquiry should not search for ultimate causes derived from outside or some unidentifiable source rather must confine itself to the study of relationships that exist between facts, which are directly accessible to observation. Knowledge is based on exploration of natural phenomena (Crosby, 2006). Positivists use methods that are objective while testing theories through generation and falsification of hypotheses in order to assemble facts.

A criticism of the positivist paradigm is that although they claim that methods and procedures are done objectively, positivists forget to consider the many subjective decisions that are made throughout the research process, such as deciding what to study, what tests to be applied,

interpreting conclusions from data collected and so on. Some would argue that the concept of objective, value free research is a myth and not achievable in real world research (Johnson and Onwuegbuzie, 2004).

Positivists are seen as reductionists because their intent is to reduce the ideas into small, discrete sets of ideas to test such as variables that constitute hypotheses and research questions. They believe there are laws or theories that govern the world that needs to be tested or verified and refined so that we can understand the world. Thus, in a scientific method, the accepted approach would be that the individual starts with a theory, collects data that either supports or refutes the theory and then makes necessary revisions before additional test are conducted.

In contrast to positivism, O'Leary (2004) provides a definition of postpositivism which, to some extent, aligns with ideas from the constructivist paradigm. Postpositivists see the world as ambiguous, variable and multiple in realities; what might be the truth for one person or cultural group may not be the 'truth for another'. This suggests that postpositivism is intuitive and holistic, inductive and exploratory with findings that incorporate qualitative inquiry; this contradicts the definition of Mertens (2005). This research methodology is commonly aligned with quantitative methods of data collection but does acknowledge the benefits of qualitative research.

Postpositivists, like positivists aim to test a theory (O'Leary, 2004) but challenge the traditional notion of absolute truth of knowledge (Phillips and Burbules, 2000), recognising that we cannot be absolutely sure of claims of knowledge when studying the behaviour and actions of humans.

3.3.3: The Interpretivist/Constructivist Paradigm

This approach evolved from the underpinning philosophy of Edmund Husserl's phenomenology, and Wilhelm Dilthey's and other German philosophers' study of interpretive understanding called hermeneutics (Mertens, 2005,). Their intention was to understand 'the world of human experience' (Cohen and Manion, 1994) suggesting that 'reality is socially constructed' (Mertens, 2005,).

Researchers aligned to this paradigm place value and rely upon the 'participants' own views (Creswell, 2003,). Generally, they do not start with a theory; rather they generate or inductively develop a theory or pattern of meanings throughout the research process (Creswell, 2003, p.9). They utilise qualitative data collection methods and analysis, or mixed methods approach, where

quantitative data is utilised to support or expand upon qualitative data and effectively deepen the description. Constructivists believe meanings are varied and multiple and hence cannot be assigned into just a few categories or ideas. For the researcher to allow the participant to construct a meaning of the situation they live in and how they interact with other persons, the questions must be broad and general or more open-ended to allow participants to express their views.

These subjective meanings must be negotiated socially and historically i.e. they are not imprinted on a person but are formed through interaction with others and through cultural norms that operate in a person's life (Creswell, 2003). Using this paradigm, the researcher is able to appreciate that their own background shapes their interpretation; hence they align themselves in the research with the intention of making sense of or interpret the meanings others have about the world. This view has not been without criticisms. It is thought that rather than being 'multiple realities' it is better to say multiple perspectives or opinions or beliefs (Creswell, 2007; Robson, 2011), hence they should be considered as subjective realities. Considering the foregoing criticisms, quality, rigour and relevance in qualitative research have been crucial so as to avoid potential biases inherent in this paradigm.

As a result of this divergence of views, the pragmatic paradigm and mixed methods research have become alternative compromises of these two opposing paradigms; views that are shared by writers like Howe (1988) and Holmes (1994). According to Creswell (2003), pragmatism provides a basis for the following knowledge claims:

- a) Pragmatism is not committed to any one system of philosophy and reality. They draw from inquiries from both quantitative and qualitative liberally hence its application to mixed methods.
- b) Researchers have freedom to choose the methods, techniques, and procedures that best meet their needs and purposes.
- c) Like mixed methods they look at many approaches rather than subscribing to one particular method.
- d) Truth is what matters at the time. Mixed method researchers use both quantitative and qualitative data to provide the best understanding of the research problem.
- e) They look at 'what' and 'how' to research. There is need to establish a purpose for the 'mixing' in the first place.

- f) Finally, they agree that research always occurs in social, political and other contexts. This way, mixed methods studies are reflexive of social justice and political aims. Pragmatism opens the door to mixed methods researchers to use multiple methods, different world views and different assumptions as well as to different forms of data collection and analysis in the mixed methods.

Despite all this, pragmatists do appreciate the strengths and weaknesses of these two major paradigms. In 2004, Johnson and Onwuegbuzie summarised them as follows:

Postpositivists/positivist methods have strengths that include:

- i) Numeric data which is precise
- ii) One can study large numbers
- iii) Involves testing & validating theories and hypothesis
- iv) Elimination of confounding variable to show cause & effect
- v) Enable quantitative predictions
- vi) Research findings independent of researcher
- vii) Generalisation of findings which are credible with political and financial powers

Associated weaknesses may include the fact that knowledge gained may be abstract without applicability; and the theories and categorisation applied may not reflect understanding and experience.

The strengths of the interpretative approach include the idea that data is based on participants' categories of meanings; therefore is important in studying phenomena in depth. Also, the researcher can identify contextual factors and respond as the study progresses. Thus this approach is responsive to local situations, conditions and needs; findings can provide rich understanding of personal perspectives in context.

The interpretivist approach also has weaknesses. It is difficult to generalise the knowledge gained, and to make quantitative predictions. The findings of interpretivist research are more prone to researcher bias and not easily applicable when testing theories and hypotheses. In fact, some administrators and commissioners find the results less credible. In order to avoid confusion created when authors use different terms to discuss paradigms, a summary table (Table 3.1) was created (Mackenzie and Knipe, 2006, p.5).

Table 3.1: Paradigms: Language Commonly Associated with Major Research Paradigm

Positivist/Postpositivist	Interpretivist/Constructivist	Transformative	Pragmatism
Experimental Quasi-experimental Correlation Reductionism Theory verification Causal Comparative Determination Normative	Naturalistic Phenomenological Hermeneutic Interpretivist Ethnographic Multiple participant meanings Social and historical construction Theory generation Symbolic interaction	Critical theory Neo-Marxist Feminist Critical Race Theory Freirean Participatory Emancipatory Advocacy Grand Narrative Empowerment Issue oriented Change-oriented Interventionist Queer theory Race specific Political	Consequences of actions Problem-centred Pluralistic Real-world practice oriented Mixed methods
Adapted from Mertens, p7, (2005) and Creswell(2003)			

In research, paradigms must be matched with the right methods for the study to draw or measure the effects correctly. For example, Positivist/Postpositivist paradigms tend to predominantly use quantitative approaches and the data collection tools may include experiments, quasi-experiments, tests, scales etc. Interpretivist paradigms use predominantly qualitative approaches and the data collection tools would include interviews, observations, document reviews and visual data analysis. Pragmatic paradigms, however, may employ quantitative and/or qualitative approaches with methods being matched to the specific questions and purpose of the research. Here, tools can be drawn from both positivist and interpretivist paradigms. It may be possible then, for a researcher to utilise any and all paradigms as described in the following section. Given the need to be question-focussed, the pragmatic paradigm informed the methodology for this study.

Part Two

Part two of the chapter concentrates on the mixed methods approach, chosen as the most appropriate for this research.

3.4: Mixed Methods Design

Mixed methods research highlights the practical relevance of philosophical pragmatism to research methodology, in particular, but not exclusively to mixed method research (Feilzer, 2010).

The majority of researchers seem to agree that mixed methods research is an approach that must include both quantitative and qualitative designs (Grafton, 2011). However, many inconsistencies and disagreements seem to originate related to consideration of how these two components are related. Discussions have focussed on whether these components reflect quantitative and qualitative data collection and analysis techniques and/or quantitative and qualitative approaches to research methodologies (Denscombe, 2008; Tashakkori and Creswell, 2007). Other areas of contention have been at what stage of the study the components should be mixed, in which order they should be mixed and where the focus should lay. Researchers like Howe (Tashakkori and Teddlie, 2003) presented a 'compatibility thesis' that illustrates how quantitative and qualitative methods are compatible. However, it should be noted that the exact definition of mixed methods is still 'elusive' (Guba, 1990).

Work by Creswell and Plano Clark (2011) described the mixed methods approach as 'an intuitive way of doing research'. Other findings by Feilzer (2010) add that mixed methods is a practical approach that draws on both the strengths of both qualitative and quantitative methods to answer fully the research questions. Similar arguments were discussed by Morgan (1998).

Creswell and Plano Clark (2011) recommended a definition of mixed methods research that combines methods, philosophy, and research design, orientation with the following core characteristics:

- a) Collects and analyses persuasively and rigorously both qualitative and quantitative data (based on research question).
- b) Mixes (or integrates or links) the two forms of data concurrently by combining them (or merging them), sequentially by having one build on the other or embedding one within the other.
- c) Gives priority to one or both forms of data (in terms of what the research emphasises).
- d) Uses these procedures in a single study or in multiple phases of a program of study.
- e) Frames these procedures within philosophical worldviews and theoretical lenses.
- f) Combines the procedures into specific research designs that direct the plan for conducting the study.

The concept of methods 'triangulation' seems to have emanated with Campbell and Fiske (1959), who proposed the use of more than one research method. This stand was seen as part of the validation strategy to ensure the explained variance is not an artefact of the research method, but a result of the underlying phenomenon (Grafton, 2011). Feilzer (2010) notes that some mixed

methods researchers are still struggling with the true integration in the sense of looking at phenomena for different perspectives and providing an enriched understanding. This is supported by Bryman (2007) who stated that researchers continue to describe quantitative and qualitative elements independently of each other.

3.4.1: **Rationale for Use of Mixed Methods**

Use of mixed methods adds time, complexity of data collection, analysis and writing, and requires knowledge of more than one method of research (Bronstein and Kovacs, 2013). However, mixed methods are useful when either quantitative or qualitative methods alone are inadequate for the complexity of the research question and topic (Creswell, 2009). Mixed methods also allow utilisation of the strength of both paradigms while minimising the weakness of both methods. Furthermore they have the ability to strengthen one method to enhance the performance of the other (Creswell and Plano Clark, 2009).

Rationale for mixing methods has been well outlined. Padgett (2008) classifies the reasons for mixing methods into triangulation, complementarity and expansion.

1. **Triangulation:** comparisons for corroboration or seeks convergence and corroboration of results using different methods and designs (Greene,1998)
2. **Complementarity:** qualitative and quantitative sub studies represent different pieces of puzzle or seek elaboration, enhancement, illustration and clarification of results of one method with another (Greene, 1998).
3. **Expansion:** broader theoretical understanding can come from juxtaposing these two perspectives or expand the breadth and range of research by using different methods for different inquiry component (Greene, 1998).

In the same year, Greene (1998) added two other purposes of mixed methods as follows:

4. **Development:** seeks to use the findings of one method to help inform the other method.
5. **Initiation:** aims to discover paradoxes and contradictions that was lead to the research question being reframed and potentially further research.

For the purpose of this study, the mixed method approach chosen was complementarity. This approach appears to be the 'best fit' with the aims and objectives for the proposed research.

Complementarity uses the results from the qualitative component to illustrate and enhance the quantitative results. For example, this study conducted in-depth interviews among fistula patients. The interviews focused on the lived experiences of fistula patients. This approach may highlight the difficulties of living with the fistula problem in low social economic settings.

3.4.2: **When and How to Mix**

According to Padgett (2008), when and how to mix should be considered as a continuum and weight should be assigned depending on which method is dominant, as follows:

- i) **Sequential** studies indicating which method is dominant (in capitals); QUAL to quan, qual to QUAN, QUAN to qual, Quan to QUAL
- ii) **Sequential** but of equal dominance; QUAL to QUAN, QUAN to QUAL
- iii) **Concurrent or 'Nested'**; QUAL+ quan, QUAN + qual
- iv) **Concurrent 'fully integrated'**; QUAL+ QUAN

When utilising the mixed methods approach, a researcher needs to consider key factors such as paradigms, time ordering and where mixing was actually to occur. Although the researcher is free to develop user specific alternatives, flexibility of mixed methods research is known for facilitating a number of approaches (Creswell, 2003; Robson, 2011). This includes:

- a) Sequential explanatory; involves collection and analysis of quantitative data followed by qualitative data, where priority is given to the quantitative and the qualitative serves to explain quantitative findings.
- b) Sequential exploratory design; involves an initial qualitative phase of data collection and analysis followed by quantitative. Findings are integrated during interpretation but priority is given to qualitative as the purpose of this study is exploring the phenomenon.
- c) Concurrent triangulation design; where the quantitative and qualitative methods are used separately and concurrently and results are compared to assess convergence.
- d) Concurrent nested design; where a secondary method is embedded within a study with one primary method, which may be either quantitative or qualitative.
- e) Sequential transformative design; either quantitative or qualitative method may be conducted first and take priority. This approach is guided by the theoretical perspective and the results are integrated during interpretation.

This study was based on a sequential explanatory design. The results of quantitative component such as duration of leakage of urine, duration before seeking treatment,

divorce/separation and poor education, can only be fully described once you have understood the perspectives and experiences of these women. Unfortunately very few qualitative studies have been conducted in this field, as described in the literature review section in chapter two.

3.4.3: Cohort Studies

Cohort studies are best used to determine incidence and natural history of a condition. They can be prospective or retrospective. A key characteristic of cohort studies is that at the starting point of the study the participants are identified and their exposure to a risk factor is assessed (Euser, 2009). In prospective studies, a group is chosen, i.e. those whose fistula has not closed. The researcher measures a variety of variables that might be relevant to the development of the condition. Over a period of time, the same people in the sample are observed to see whether they develop the outcome of interest. In this study, the sample of women with VVF were recruited and treated. After which, they were observed to see whether their fistula closed or not. Various variables or characteristics were measured at different time points. These were then correlated with the outcome of interest (fistula closure). Those whose fistulas failed to close were used as internal controls.

This approach is unlike retrospective studies where data already collected for other purposes is used. The cohort is followed up retrospectively, with the same methodology.

The advantages of cohort studies are that they enable observation of potential causes which may be unethical or impractical if assessed as part of a randomised controlled trial. They measure potential causes before outcome has occurred, and hence demonstrate that these 'causes' preceded the outcome. This helps avoid the debate as to which is cause and which is effect.

Another advantage is that a single study can examine various outcome variables unlike a case control study, which assess only one outcome variable. Cohorts permit calculation of the effect of each variable on the probability of developing the outcome of interest (relative risk) except where a certain outcome is rare, when prospective cohorts are inefficient (Mann, 2003; Euser, 2009). Prospective and retrospective studies have higher efficiency and accuracy as their respective advantages (Euser, 2009).

There is also a possibility to study multiple exposures and multiple outcomes in one cohort. Besides, the combined effect of multiple exposures on disease risk can be determined e.g. the effect of duration of labour and sex of the infant on severity of VVF lesion. Cohort studies are

considered a relatively easy way to pick up associations between many exposures and outcomes. This way several etiological hypotheses can be generated which could be tested using confirmatory studies such as RCTs (Rothman, 2008). Also, cohort studies have broader inclusion criteria and less exclusion criteria compared to an RCT, often making the results more generalisable to clinical practice.

There are also a number of disadvantages with cohort studies. Large samples are often required as the efficiency of prospective studies increases with the increase in incidence of any particular outcome; this is important when it comes to studying rare conditions. Prospective studies are prone to loss of participants to follow-up. Confounding factors are factors likely to affect outcome which are not under investigation or control, e.g. the skill level of the surgeon and technique of repair, route of repair can affect closure of a fistula. A prospective randomised control study can eliminate the possibility of confounding (assignment of the type of exposure is by chance hence confounding is equally present in both groups). Confounding makes it difficult for cohort studies to establish causal effects.

Cohort studies also suffer from bias, especially selection bias and recall bias. The latter occurs when people with the outcome of interest are more likely to remember certain antecedents, or exaggerate, or minimise what they now consider to be risk factors especially in retrospective designs. Biases can occur in any study. Selection bias may occur at the Kenyatta site: as it is a teaching and referral hospital, this hospital is more likely to receive cases that have been repaired many times before and have failed (referral bias). Selection bias may also be introduced in a cohort study by low response if this non-response is selective i.e. different in those people that have the exposure and an increased risk of developing the disease. Comparable bias can also be introduced in cohort studies, usually not at inclusion but with loss- to follow-up which is hardly ever completely random. This may happen if there is failure to show up because women stopped leaking urine, are too busy or too ill; hence disease status cannot be measured.

When there is a selective difference between index and reference group in the follow up, the results are likely to be biased. Biases reflect the potential that the sample may not be representative of the population. Fortunately, in this study, this selection bias was minimised by the high percentage of participation and close follow-up.

3.4.4: **Prospective Versus Retrospective Designs**

These are two main types of cohort studies. Prospective designs are where exposure is assessed at baseline and the study follows the participants through time to study the development of disease or mortality. In this study, patients diagnosed with VVF were operated and followed to see whether the fistula closed or not. In a retrospective study design, the researcher starts the study at the time follow-up has already been completed. Retrospectively, eligible participants are identified, a cohort is constituted and exposures are assessed at baseline. This is cheaper and faster than a prospective study. In an attempt to avoid confusion in hierarchy of the designs (prospective being higher than retrospective), any follow-up study has been considered prospective by some epidemiologists (Vandenbroucke, 1991). However, it is stated that rather than label a study as retrospective or prospective, the researcher should give an explanation of what exactly has been done in the abstract and method section.

The main strength of a prospective cohort study is the accuracy of the data collection with regard to exposures, confounders, and endpoints. This is realised at the cost of an inevitable loss of efficiency, for this design is both expensive and time-consuming due to a usually long follow-up period (Euser, 2009). In contrast, retrospective designs are very time-efficient and elegant way of answering new questions with existing data. However, one must work with what has been measured in the past, often for another purpose, than the one under investigation (Euser, 2009).

3.4.5: **Cross-sectional Study Designs**

In these designs, all measurements on each participant are made at one point in time (Mann, 2003). They are very good at determining prevalence of a disease or condition i.e. the number of cases in a population at a given point in time. Knowing prevalence influences the likelihood of any diagnosis and the predictive value of any investigation.

This design cannot be used to infer causation. Participants can be assessed to determine whether they were exposed to the relevant agent and whether they have the outcome of interest. However, this design cannot differentiate cause and effect from simple associations, and is prone to confounding (Mann, 2003).

The advantage of this design is that participants are deliberately exposed, treated, or not treated hence there are fewer ethical difficulties. They may be less expensive since the data are collected only once and in one group and multiple outcomes can be studied. This is commonly used in

market research and census. It was not applicable to this study, since the researcher measured multiple variables and outcomes at different time points.

3.4.6: Case-control Design

Case-control designs are usually retrospective. Participants with the outcome of interest are matched with a control group who do not have (Mann, 2003). In rare conditions, it is the most feasible design. It is more cost efficient than cohort or cross-sectional studies as the cases are deliberately chosen since they have the disease. They can determine the relative importance of a predictor variable in relation to the presence or absence of the disease in terms of an odds ratio, which usually approximates to the relative risk when the condition is rare (Mann, 2003). Case-control designs are also affected by confounding (Mann, 2003). The choice of controls is very important in case control studies, when this is done properly, it helps minimise confounding factors. It was not applicable to this study because the outcome was not known at the start of the study.

3.4.7: RCT Randomised Controlled Trials

The Randomised controlled trials (RCT) are study designs where participants are randomly assigned to one of two groups: for instance, one study arm may be allocated a new drug under study (the experimental group). This means that participants will receive the intervention that is being tested, and the other arm being the (the comparison group or control) group; meaning the participants will be receiving an alternative (conventional) treatment. After allotment, follow up is done for both groups to see if there are any differences in outcomes. In part, this explains why RCTs are currently the most rigorous study designs in determining cause-effect relationships between treatments and or outcomes. Over time, health services research has been associated with potential errors that are considered as; bias, confounding, and chance. A bias is said to be a deviation of results from the norm, this may occur either due to systematic error in the research methodology or in selection of study participants.

The main features in RCT designs include: random allocation of treatments, double blinding and the fact that participant outcomes are analysed within the study group; regardless of the outcomes. Usually, the analysis focuses on the differences between predetermined outcomes between intervention groups. Although RCTs are powerful tools in various assessments, their wider use is limited by its ethical and practical concerns particularly in biomedical research. For

instance, an RCT may be ethically sound, but it may present challenges in recruitment of study participants; thereby rendering the design infeasible.

Besides, RCT studies require preliminary findings which guide sample size calculation; meaning that the cost of conducting RCTs may be high compared to other designs. That notwithstanding, new health care interventions should be evaluated using RCTs because of its emphasis on scientific communication, methodological rigour and unbiased outcomes. These key attributes put RCT ahead of other designs in health research.

However, prospective studies are prone to loss of participants to follow-up (Mann, 2003); this would seem especially applicable when patients have a long follow up period, as seen in this study. Confounding factors are also likely to affect outcomes (Mann, 2003); usually such factors are not under investigation or under researcher's control. They include: skill level of the surgeon, technique of fistula repair, route of repair and fistula closure. A prospective randomised controlled study can eliminate the possibility of confounding variables (assignment of the type of exposure is by chance hence confounding is equally present in both groups). However, this concept was difficult to apply in this study since all fistula women have the same desire; alleviating the pain and suffering takes precedence over confounders. This makes it difficult to execute randomised cohort studies to help establish causal effects, particularly in fistula patients. Ethically it would also be difficult to conduct an RCT; to allocate some women to repair and others not would cause significant distress to participants. Also, the researcher in this study was conducting the surgeries himself and documenting intra-operative and post-operative procedures. For these reasons, this single surgeon's experience rendered randomised controlled design inappropriate in this particular study.

3.4.8: Qualitative Designs

This section presents an overview of qualitative research and provides the context to the author's decision to choose in-depth interviews informed by an interpretative hermeneutic phenomenological approach.

Review of the literature by Creswell (2009) and Johnson and Onwuegbuzie (2004) demonstrates that qualitative research utilises: smaller number of respondents, induction, exploration, discovery, meaning, interpretation, words and themes, and reflexivity to answer the research question. Other researchers (e.g. Holloway, 2005) explain that qualitative research provides a

means of exploring the emotions, perceptions, views and experiences of a person experiencing a phenomenon. Ordinarily, this design is individual-centered and may provide an in-depth understanding of a behaviour that has not been experienced before. In a rejoinder, Ring *et al.* (2011) agrees that this investigative approach is best suited in healthcare settings, where patient-centered care is of paramount importance.

Authors point out the fact that qualitative methods can be as rigorous as quantitative methods (Creswell, 2009). Furthermore, within certain paradigms, such as pragmatism, there is an acknowledgment that complex phenomena, such as the lived experiences of women living with fistula, are unlikely to bring forth desired outcomes by using quantitative research alone (Thomas, 2003).

In choosing the method of data collection, the researcher considers the chosen approach to research design. Methods such as focus group discussions and in-depth interviews generate textual data as opposed to statistical data. Such data emanates from participant and the researcher interactions; which in most cases occurs at congruent levels. A review of literature by Avis (2005) indicates that during data collection, the researcher frequently reflects on their own influence on data collection process. In qualitative research, the researcher's personal reflection is known as reflexivity, a key concept in maintaining trustworthiness of data.

It is a common practice in qualitative research to use purposive sampling (Patton, 2002). In keeping with the phenomenological approach chosen, purposive sampling was used to select those women who had experienced the phenomenon, i.e. had lived with a fistula and received a surgical repair.

Due to its small sample size, often in a particular context, qualitative research is often not generalisable, nor is it meant to be. Despite this observation, Lincoln and Guba (2000) explain that the question of trustworthiness of the study can be achieved through rigour. Rigour is a key requirement in demonstrating the worthiness of any study. To achieve this criterion, a researcher must ensure application of the following concepts: credibility, transferability, dependability and confirmability of data collected. However, Van Manen (1990) argues that rigour is an empirical analytical term which does not fit an interpretive pathway as may apply in the context of lived experiences. In part, such writings provide a platform for reviewers who are critical of qualitative publications which cannot prove rigour.

Others suggest that use of a transparent, systematic process in data collection and analysis helps ensure rigour (Barbour, 2001). The debate on how rigour fits in qualitative data becomes complex when reports indicate that even though publications may include details such as audits and strategies for bias minimisation, rigour is not necessarily assured in qualitative research (Morse *et al.*, 2002).

It is argued that to ensure rigour researchers should incorporate strategies for bias minimisation into the entire research process, which includes: protocol development, data collection and data analysis stages. In this context, there must be consistency in the conduct of research, availability of visibly transparent systems, and a way of reporting limitations and reflexivity (Davies and Dodd 2002). The transparent systems which include data interpretation processes and reporting of limitations have been associated with achievement of trustworthiness of data (Davies and Dodd 2002). When findings are trustworthy, and demonstrate transferability, qualitative studies can be replicated in different settings.

Although in the field of fistula surgery qualitative approaches have not been fully embraced, in other healthcare settings, qualitative research has gained prominence; as a step towards ensuring holistic approach to patient care. The common approaches applied to health research include; Ethnography, Grounded theory and Phenomenology.

3.4.9: Ethnography Methodology

Ethnography is a qualitative methodology aimed at exploring cultural phenomena (Denzin, 2005). In practice, the resulting field of study reflects the knowledge and the system of meanings in the lives of a cultural group (Denzin, 2005). The design represents graphically and or in writing, the culture of a people selected for study. Others show that ethnography provides a framework for studying the meanings, patterns, and experiences of a defined cultural group (Polit and Beck 2004).

The typical ethnography is a holistic study, which includes a brief history, an analysis of the terrain, the climate, and the habitat. In all cases it should be reflexive, make substantial contributions toward the understanding of the social life of humans, have an aesthetic impact on the reader, and express a credible reality. Ethnography observes the world from the point of view of the participant, records all observed behaviour, and describes relations using concepts that

avoid casual explanations (Brockopp and Hastings 2003). Ethnography includes both anthropological and historical forms of inquiry (Brockopp and Hastings 2003). The commonly used approach is participant observation as part of the field research. This is whereby the researcher completely immerses herself or himself in the culture as an active participant while recording extensive field notes. The demanding nature of observing patient behaviour could not allow its application in the highly stigmatised world of fistula patients. This is because patients live and continue to live in secrecy; which disallows unbiased observed behaviour.

3.4.10: **Grounded Theory Methodology**

Grounded theory was developed by sociologists Barney Glaser and Anselm Strauss in the late 1960s (Strauss *et al.*, 1987; Charmaz, 2006, Glaser, 1992). Defined as a set of procedures used to generate a theory, this methodology helps explain a process or substantive topic at a broader conceptual level. Researchers commonly use this approach when they desire to generate a theory or when they want to study a process, an action, or an interaction. Many researcher beginners use grounded theory because it offers a step-by-step and systematic procedure in the field of study; this allows a close interaction with data collection and analysis. This characteristic is made possible by the fact that data analysis in grounded theory designs optimise on constant comparative procedures; asking questions about their data, in a way that allows an increase in the levels of abstraction. It is during data analysis that a core category is identified (Strauss, 1987). Despite these good attributes, grounded theorists may encounter ethical challenges ranging from advancing the purpose of the study to effects of the power and authority issues during interview; observations that tend to discourage seasoned researchers in applying the design. This methodology was not chosen because it fails to recognise the unique role of the researcher in the study and thus obscures the researcher's considerable contribution in data construction and interpretation (Bryant and Charmaz, 2007).

3.4.11: **Phenomenology Methodology**

The definition of phenomenology has evolved over time, with the primary focus being the structures of individual experiences and consciousness. Phenomenology is seen as an umbrella term which encompasses both philosophical movement and a wide range of research approaches. A more simplistic definition of phenomenology is offered by Grbich (2007) who states that phenomenology is an approach used to understand the hidden meanings and the essences of an experience; the two dimensions are viewed together. These definitions of phenomenology have

the potential to penetrate deep to the human experience and trace the essence of a phenomenon as seen by individuals who experienced it.

At inception, Husserl formulated his classical phenomenology first as a kind of "descriptive psychology" (sometimes referred to as Realist Phenomenology) and later as a transcendental and eidetic science of consciousness (Transcendental Phenomenology). In his *"Ideas"* of 1913, he established the key distinction between the act of consciousness ("noesis") and the phenomena at which it is directed (the "noemata"). In his later transcendental period, Husserl concentrated more on the ideal, essential structures of consciousness, and introduced the method of phenomenological reduction specifically to eliminate any hypothesis on the existence of external objects. Considering the number of emerging approaches and methods developed following this philosopher, Husserl has been referred to as the founder of the phenomenological movement (Koch, 1995). In 1927, Heidegger criticised and expanded Husserl's phenomenological enquiry (particularly in his "Being and Time") to encompass our understanding and experience of 'Being' itself, and developed his original theory of "Dasein" (the non-dualistic human being, engaged in the world). According to Heidegger, as cited by Koch (1995) philosophy is not at all a scientific discipline, but is more fundamental than science itself (which to him is just one way among many of knowing the world, with no specialised access to truth). Heidegger then took Phenomenology as a metaphysical ontology rather than as the foundational discipline that Husserl believed it to be (Koch, 1995). Husserl charged Heidegger with raising the question of ontology but failing to answer it, but Heidegger's development of Existential Phenomenology greatly influenced the subsequent French Existentialism movement (Koch, 1995). The phenomenological movement was initiated by Husserl (1859-1938) as a radically new way of doing philosophy. However, in later years, Heidegger (1889-1976), recast the phenomenological project, essentially moving away from a philosophical discipline whose initial focus was on consciousness and essence of phenomena towards elaborating existential and hermeneutic (interpretive) dimensions (Koch, 1995).

Heidegger acknowledges that all understanding and interpretation is grounded in prior experiences, fore-sight, fore-conception and time (Heidegger, 1962). Alternatively, Van Manen (1990) considered phenomenology as the most appropriate methodology to explore the phenomena of pedagogical significance, a response to how an individual orients to lived experiences and tends to question the way a person experiences his/her world. In this study the phenomenon of interest being "experiences of women living with fistula". It focuses on individuals' meaning-making as the quintessential element of the human experience (Patton, 2002). Phenomenological researchers agree that this design should be flexible, adapted to suit the

phenomena under study and that it is guided by common guidelines (Van Manen, 1990; Crotty, 1996; Crotty, 1998). The agreement between the philosophers brings to light three fields of phenomenology: Realist, Constitutive, and Existential phenomenology (Crotty, 1998).

3.4.12: **Realist Phenomenology**

Realist Phenomenology is Husserl's early formulation, which is based on the first edition of his "*Logical Investigations*". The aim was to analyse the intentional structures of mental acts as they are directed at both real and ideal objects. This perspective emphasises the search for the universal essences of various sorts of matters, including human behaviour/actions, motives, and selves.

3.4.13: **Transcendental Phenomenology (or Constitutive Phenomenology):**

Husserl's later formulation, which followed his 1913 "*Ideas*", takes the intuitive experience of phenomena as its starting point, and tries to extract from it the generalised essential features of experiences and the essence of what we experience, setting aside questions of any relation to the natural world around us. This phenomenology extends Husserl's original scope to include philosophy of the natural sciences. In later years, this work was continued by Aron Gurwitsch (Gurwitsch, 1974) and Elisabeth Ströker (Ströker, 1987), who were devoted to reflections on phenomenological method, especially the method of transcendental phenomenological reduction.

3.4.14: **Existential Phenomenology**

Heidegger's expanded formulation, as expounded in his "*Being and Time*" of 1927, which takes a stand that the observer cannot separate himself from the world and so cannot have the detached viewpoint that Husserl focused on. It is therefore a combination of the phenomenological method with the importance of understanding man in his existential world. Professionals' ranging from pedagogy and nursing to existential psychology have underpinned their work using all branches of phenomenology. The nature of this methodology is that it attempts to explicate the meaning of structures developed through the experience of the person being questioned. Phenomenology was chosen to underpin the current study because of its sensitivity to individual accounts, which provided rich data on an unexplored area of investigation.

The unique feature of this paradigm is that it allows for exploration of a phenomenon with a heterogeneous group, in this case women with fistula. It's for this reason that Ethnography could not have been a methodology of choice because, by design, it would require the researcher to

spend a lot of time in the villages documenting women's experiences. Such an approach would have increased stigma and stress associated with fistula condition. On the other hand, grounded theory would have required the researcher to collect prior fistula information from family and community members/stakeholders. The knowledge gained could then be used to generate a theory/hypothesis. This approach could have contravened basic principles of biomedical research which requires that: researchers must uphold confidentiality and respect for persons in any study involving human subjects.

Therefore, Heideggerian phenomenology was the most appropriate methodology, because it safeguarded their confidentiality, autonomy and justice, since all women had access to care without prejudice. Being a fistula surgeon meant that it was not possible to 'bracket' prior experience, as such, information gathering occurred prospectively. This was important because the final product of a phenomenological inquiry is a description that presents the essence of the phenomenon. Findings derived from a prospective approach to data collection are important in helping a researcher gain better understanding of a phenomenon as seen through the eyes of those who have experienced it: in this case the fistula women hold the key to understanding the burden of living with the problem for many years.

3.5: Principles of Ethics in human research

The health care of humans by their clinicians must always be of high quality and dispensed with concern for dignity and wellbeing of the patient. The same human values must guide the conduct of research on human research participants (Knudson, 2001).

Normally, conducting biomedical research for the purpose of systematically collecting and analysing data from which generaliseable conclusions may be drawn that aid in improving the care of currently unknown beneficiaries in the future (Kapp, 2006).

Consequently, the research must be designed and carried out in a meritorious and ethical way. It is because of these issues that The Belmont Report (Knudson, 2001) was released to act as a framework for Institutional Review Boards (IRBs) to use when reviewing research protocols. The following are the most salient ethical values implicated by the use of human participants in research:

- **Beneficence/ Non-maleficence** – Always do no harm. This principle guides the IRBS to always make sure that in reaching their decisions, they must be certain that harms have been minimised and benefits maximised in protocols under review. Furthermore, in case

of harm involved (which sometimes is inevitable in studies), the potential benefits must outweigh the potential harm. Hence, the protocols must be accompanied by scientific soundness and the importance of the work justified (Kapp, 2006; Knudson, 2001). The surgical option benefitted all qualifying participants especially to stop leakage of urine and restore continence. This was made clear in the protocol and to the patients as well. The study remained alert in case of the risk of psychological distress by putting in place a distress policy.

- **Justice-** Underlying this principle is the concept of equal distribution of burden and benefits among all possible participants i.e. no exclusion on the basis of socioeconomic class, gender, race ethnicity or age. There are practical challenges in implementation of this principle like: the implication that the risks inherent in the research used to develop new therapeutic device/drugs and procedures should not be borne by the populations unlikely to be the beneficiaries of the applications of the research (Knudson, 2001). In this study, all the patients who turned up and satisfied the criteria for admission were operated on regardless of whether they joined the study or not.
- **Fidelity and Trust-** maintain confidentiality within the investigator/ participant relationship. Confidentiality was maintained throughout the data collection and data handling. Furthermore, the data was kept under lock and key in the surgeon's office. This study utilised a research assistant whose experience was useful in building trust.
- **Personal dignity-** Can be incorporated into the principle of justice. The interviews were conducted in a secure quiet room behind a closed door.
- **Autonomy or Respect for persons-** This pertains to the ability of the potential participant to make an informed, voluntary, competent decision making as to whether they wish to join the research study and the privacy of personal information (Kapp, 2006; Knudson, 2001). In this principle lies the ability to make the choice for participants with diminished autonomy(by reason of disease state, mental illness/retardation, children, the frail elderly etc.) must be afforded additional protection. The investigator must make it clear that no information concerned with the making a considered judgement about participation is withheld. The provision of participant Information sheets and allowing for a question and answer session before signing the consent form enabled autonomy within this study. Additionally, for participants under 18 years, parental consent to participate was obtained. For those unable to write, a thumb print was used instead.

Research must be reviewed and approved initially by an institutional review Board (IRB) recognised by the federal office of human research protector (Kapp, 2006). The research activity becomes then the subject of IRB oversight and at least annual re-approval thereafter.

The approval or renewal approval of the protocol, the IRB must determine that the following requirements are made:

- Physical and psychological risks to the participants are minimised
- Physical and psychological risks to the participants are reasonable in relation to the anticipated benefits to these participants and to the general knowledge that may reasonably be expected to result; Selection of participants is equitable and Informed consent will be obtained, including at least the following items being communicated to the potential participant or their authorised surrogate (Kapp, 2006):
 1. Purposes of the research, its expected duration, and the nature of any interventions/ experiments
 2. Anticipated risks or benefits of participation and the reasonable alternatives to participation in research protocol
 3. Confidentiality provisions relating to the research records
 4. Any compensation and/or treatment available for research related injuries
 5. The right to not participate and to discontinue participation at any time without penalty
 6. Informed consent will be documented appropriately

All these were clearly defined and followed as per protocol. For the study, the consenting was done by a research assistant to separate the surgeon from coercion of the patients and participants which would build their confidence and trust.

It is always important to know, as a researcher, that private lawsuits may be brought by a particular participant against the researchers and protocol sponsors for breach of the common law for standards of care (medical malpractice) in the conduct of research involving harming that participant (Kapp, 2006).

The Belmont Report, however, did not develop a hierarchy among the principles which sometimes leaves the IRBS with the challenge of juggling the competing and overlapping interests of each principle. Also, that efforts must be made by IRBS to disseminate, sensitise and educate investigators about their concerns relating to the study design, recruitment methodologies, coercion (either overt or subtle), setting for the consent process, the maintenance of privacy and

confidentiality of private information, and the reporting of adverse events and problems associated with identifying the inevitable study drifts that occur over time (Knudson, 2001).

3.6: Conclusion

This chapter has presented the paradigms underpinning this research. It has discussed the methodological decisions, including the rationale for using mixed methods. The chapter presents justification for the chosen methods of a cohort study and phenomenological inquiry, providing an argument for their complementarity.

In the next chapter, the author presents, in greater detail, materials and methods applied in the two components of study.

Chapter 4: MATERIALS AND METHODS

4.1: Introduction

This chapter provides a description of material and methods used to collect study information. The data were collected from five East African Countries using observation, physical examination and interview. The study design was set within a pragmatic paradigm which used quantitative approach in a 5-stage study, complemented by an in-depth qualitative study. Each of these stages is presented in chronological order in section 4.1.

Part two of the chapter gives a description of study sites, sample size, sampling, recruitment procedures, data collection and management for the quantitative component of the study. The tool used to collect the quantitative data is in Appendix 4.4. Part three of the chapter focuses on the qualitative component, which documents the lived experiences of women living with fistula condition. Interviews were conducted at two time points, before and after surgery. A semi-structured tool was utilised to guide the interviews (Appendix 4.5). This method was considered appropriate to the exploratory nature of the qualitative component of study as presented in Section 4.4 of the chapter.

4.2: Part One: Quantitative component of the study

4.2.1: Design

Regional training centres offering regular fistula services were selected for the study. A multi-country setting in East Africa was used because of already established fistula networks (Appendix 4.1, Study Map) each country had trained fistula teams, whose role was to provide fistula care in a specialised unit.

4.2.2: The Multi-country Sites

The Seven countries included in the study were Kenya, Uganda, Rwanda, DRC Congo, Southern Sudan, Malawi and Somalia. Countries such as Kenya, Uganda, Rwanda, Malawi and DRC Congo had trained fistula teams whose role was to organise and provide fistula care in their countries, specialised units or fistula outreach camps. Fistula teams comprised of surgeons, nurses, counsellors, anaesthetists, physiotherapists, records clerks, nutritionists and administrators. However, each site presented unique work-related challenges and geographical locations. In some cases such as DRC Congo and Malawi, women travelled to neighbouring countries to access fistula care such as Uganda. Countries such as Somalia referred patients to the referral fistula centres in Kenya. However, Rwanda, Southern Sudan, Uganda and Kenya provided services within their

borders. Detailed description of the five sites included in the study is as follows, three of which were in Kenya

Site 1: Kenyatta National Hospital, Kenya

Kenya is a country in Africa and a founding member of the East African Community (EAC). Kenyatta National Hospital is the oldest hospital in Kenya, founded in 1901. The hospital is located in the capital city, Nairobi, within Nairobi County. The city lies on the Nairobi River in the south of the nation and has an elevation of 1795m above sea-level. The last official population was taken in 2009 and at that time was 3,138,369 in the city, this number has since grown to approximately 3.5 million. Nairobi is one of the fastest growing cities in Africa, quickly becoming the second largest city of the African Great Lakes. The city is growing at a rate of over 4% annually, primarily because of the high birth rates and immigrants that come to Nairobi searching for employment opportunities. The administrative area of Nairobi is 696 km² (269 square miles). In 2017, Fraym Urban Markets Index ranked African cities in terms of economic activity, consumer size and connectivity, Nairobi was ranked number ten, after Cairo (Egypt), Johannesburg (South Africa), Lagos (Nigeria), Luanda (Angola) and Democratic Republic of Congo's Kinshasha.

Kenyatta Hospital, being the country's fistula training centre, receives and manages patients on a daily basis. The hospital has a 2000 bed capacity and a busy 24-hour outpatient department. A designated centre, clinic 66, receives and admits fistula patients as they arrive. At times, due to limited theatre space, patients have to wait for a few days before surgery. Each year, about 500 fistula patients are seen on routine fistula service. Another 1000 are seen during the annual fistula camps, giving a total of 1,500 fistula patients at Kenyatta Hospital yearly. The distinct difference between fistula and other hospital based services is that fistula patients receive care at no cost. All other services such as oncology, medical, surgical and paediatric care are provided at a cost to the patient.

Site 2: Kisii Level 6 Teaching and Referral Hospital, Kenya,

Kisii County is located south Western Kenya with an area of 1,317.4 km² and a population of 1,152,282 (Male – 48 %, Female – 52%). Population Density is at 874.7 people per km², with an annual growth rate of 2.75% (2009) (KDHS, 2014). Kisii (Level 6) General Hospital is the largest government owned health facility in the County, with a 250 bed capacity. It is the most equipped health facility within the county. It offers a wide range of services such as surgery, reproductive health, maternity, paediatrics and other medical care services. The hospital provides care for over 20,000 women per year. The surrounding area is mainly urban and includes some peri-urban and

rural areas where agriculture thrives. In this facility, fistula services are offered on a regular basis with over 100 operations annually. This site was also chosen for the qualitative data collection because of its unique location, accessibility and ease follow up.

Site 3: Coast General Hospital, Kenya

Coast General Hospital is located in Mombasa County. Mombasa County covers an area of 229.7 km² excluding 65 km² of water mass. The county is situated in the South Eastern part of Coast region. It borders Kilifi County to the North, Kwale County to the South West and the Indian Ocean to the East. According to the 2009 Census Report, Mombasa county population stood at 939,370 and was projected to increase to 1,041,928 by end of 2012. Tourism is the main attraction in this country, but most indigenous people are poor peasant farmers.

Coast General Hospital is a government owned hospital, with a bed capacity of 499. The hospital provides care for approximately 4000 women per year, mostly from the local population. The surrounding area is mainly urban and includes some peri urban and rural areas. Fistula services are offered on a regular basis: about 120 fistula operations are performed each year.

Site 4: Wau, Southern Sudan

Southern Sudan was the world's youngest nation at the time of writing this thesis. In 2008, Wau was the third-largest city in South Sudan, by population, behind Juba, the capital in Upper Nile State. The city of Wau is the headquarters of Wau County, in which it lies. It also serves as the capital of Western Bahrel Ghazal State, one of the ten states which constitute the Republic of South Sudan. The city is a culturally, ethnically and linguistically diverse. Its residents include: peoples of Fertit, Dinka, Luo and Arab ethnicity. In 2011, the city's population was estimated at about 151,320.

Wau is the latest addition to the fistula circuits in the East Africa. It is mainly served by the Africa Medical Research Foundation (AMREF) outreach programme, within which fistula care is housed. Through this programme, about 100 fistula patients have their fistulas repaired annually.

Site 5: Kagando Hospital, Uganda

Kagando Hospital is located in Uganda, it serves a population of 300,000 and measures 241,038km². Kagando Hospital was started in 1965 by Africa Inland Missionary named Carl Baker. From its humble beginnings as a leprosarium housed in asbestos bus-like huts, Kagando has

grown to a current 250 bed hospital referral hospital. The hospital supports free fistula services, with 130 patients receiving fistula care each year. Some of the patients seen at this facility come from DRC Congo and Rwanda (see Appendix 4.1, study Map).

4.2.3: Quantitative Component of Study

A prospective, multi-stage cohort study was conducted to assess factors that affect the success of fistula surgery and duration of urine leakage. Data were collected from women attending for fistula surgery from five East African countries. The study employed a multistage design.

4.2.4: Study Population

A study population is defined as a sum total of every potential participant who meets the inclusion criteria for a given study (Creswell, 2018). In the current study, patients presenting with Obstetric Fistula at various fistula centres formed the total study population. Apart from a fistula diagnosis, patients were required to show willingness and consent to participate in the study. Unwilling and non-consenting patients were not eligible for study. The cause of fistula and the duration of leakage were not an entry restriction. In this component, all patients with a history of urine and or stool leakage formed the study population.

4.2.5: Sampling Method

More often, researchers sample study participants because of logistical and time limitations. The process by which a researcher selects participants for study is referred to as sampling. Therefore a sample is described as a subset of the population under study (Kerlinger, 1986). Others suggest that a selected sample size should be as representative of the total population as possible (Burns and Grove, 2005). A representative sample is essential in aiding the researcher to avoid type I and type II errors. Type I error may occur where the researcher rejects a true null hypothesis with a verdict that there is no difference between the groups. In a type II error the researcher erroneously fails to reject the null hypothesis, when in actual fact there are observable differences between the groups. In such events, study outcomes may fail to provide validity and reliability of data. To avoid such pitfalls, larger sample sizes are preferred because they reduce the chances of sampling error.

A multi-stage sampling method was employed in this study. This method presents a high level of flexibility and is effective in instances where primary data collection occurs from diverse

geographical regions, as was the case in our study. However, the method does not yield 100% representation of study population and has a high level of subjectivity. It is acknowledged that multi-stage sampling is not as effective as true random sampling; but it addresses some disadvantages that are associated with random sampling such as high costs and shorter duration. However, other robust experimental designs may opt for random sampling since such studies are conducted under controlled conditions.

Random sampling has been described as a probability sampling strategy that is pure and very straightforward. The approach gives each study participant a specific (but not necessarily equal) chance to participate. Its main advantage is that it removes bias from the selection procedure (Gravetter and Forzano, 2011).

The descriptive nature of this mixed-method study allowed for adaptation of a consecutive sampling method. This non-probability sampling technique may be considered as the best of all non-probability samples (Kendal, 2003). In this sampling approach, every person who meets the inclusion criteria is eligible for study. It gives room for the researcher to recruit until his/her sample size has been achieved or until the period elapses, because it includes all women presenting with urine/stool leakage at the fistula centres. This approach reduces any potential selection bias due to researchers selecting participants they prefer for a study. Such a scenario tends to reflect the true picture of the targeted study population (Kendal, 2003). However, given that consecutive sampling relies on those women who access care, it may have variations in who is seen at the clinic at different times of the year, e.g. women may find it more difficult to travel to a fistula centre during rainy season or during harvesting period. Such self-selection may skew the data unless large sample sizes are achieved.

4.2.6: **Sample Size Calculation for Quantitative Component**

Since the prevalence of VVF in East Africa is unknown, the investigator used a consecutive sampling method, whereby 1,224 fistula patients were recruited over a three-year period. There were no dropouts: hence 1,224 patients provided data for analysis. Assuming a surgery success rate of 80%, this sample allows at most 12 explanatory variables to be included in a logistic regression model for reliable estimation (Peduzzi *et al.*, 1996). For a higher success rate, fewer explanatory variables would be able to be used, so only the most clinically relevant (and timely) variables were used in the in estimating sample size. A sample size of 1224 also allowed an exact

95% CI for a success rate of 80% to be estimated to a precision of at most $\pm 2.4\%$ (Denscombe, 2008).

4.2.7: **Participant Recruitment Approaches**

Community mobilisation followed patient recruitment, poor road network especially in rural areas was a challenge (Appendix 4.2). Radio, electronic and print media were used in raising fistula awareness in communities. Other strategies such as song, dance and drama about fistula problems were used to mobilise communities and destigmatise the women. Individuals with problems of urine leakage following child birth or related surgeries were invited to visit the fistula centres at no cost to the women or their families. Patient recruitment was conducted in two ways.

After admission, patients were recruited at all five sites for the quantitative component of study, followed by qualitative interviews in three selected sites in Kenya. Data collection for this component of the study ran from February 13th 2013 to March 20th 2016. Pertinent ethical considerations including consent processes for the both quantitative and qualitative components of study are described in detail in Section 4.11. The recruitment process for qualitative component of study is also presented in Section 4.10.

In general recruitment was a challenging task especially in sites where the surgeon visited at regular intervals; patient numbers were overwhelming. As this workload was affecting ward occupancy and patient satisfaction, the researcher renegotiated with hospital management teams and sponsors to open up more treatment centres. In Kenya, this request was approved and new centres such as Embu and Kilifi were opened to help decongest Kenyatta and Coast general hospitals (see Appendix 4.2: A Picture of a rural fistula site in Kenya). This allowed the researcher to decongest the wards, recruit, screen and operate patients based on the laid down eligibility criteria.

4.2.8: **Eligibility Criteria**

The eligibility criteria were determined according to criteria used in previous work on predictors of fistula surgery, with the desire to help the women achieve full continence, (Kayondo, 2011: Hategekimana, 2005: Goh *et al.*, 2008). The first contact with the patient occurred at the registration desk which was strategically placed at the main entrance to the clinic. Using an

eligibility checklist, fistula teams screened all patients presenting with a history of urine/stool leakage.

4.2.9: **Inclusion Criteria**

Women presenting with a diagnosis of obstetric fistula at selected fistula centres in East Africa were eligible for study. Willing and consenting women were enrolled for study.

4.2.10: **Exclusion Criteria**

Women were excluded during the screening stage if they had fibroids, cancer of the reproductive system or uterine prolapse. Uterine prolapse occurs when pelvic floor muscles/ligaments stretch and weaken causing providing inadequate support for the uterus. The uterus then slips down and protrudes out of the vagina. Those with fistula diagnosis but were non-consenting were also excluded from the study.

4.2.11: **Consenting Procedures**

The process of obtaining consent begins with provision of study related information which includes: risks, benefits, roles and responsibilities. Participants also must have time for question and answer session, only after their questions are answered to their satisfaction can they sign the consent form. Signing the consent form is a sign that the process was voluntary and it is based on information provided to the participant (Appendix 4.3: Appendix 4.3a). Obtaining informed consent from participants for study prior to conducting the research ensures independency in decision-making, ensuring that individuals have no obligation to participate and do so at their own free will (Robinson, 2011). By respecting women's autonomy, the researcher may be considered compliant with ethical principles that govern biomedical research (Kass *et al.*, 2007).

Women who participated in the qualitative component gave consent at two time points: for the quantitative component of study, consent was obtained only once i.e. at the time of enrolment for study. The consent was to cover the entire study period. The signed consent forms were kept under lock and key in the researcher's office.

4.2.12: **Quantitative Tools and Methods**

An instrument was developed based on literature and study objectives. The tool was pilot tested at a different site to establish its validity and reliability in data collection. The outcome of the pilot

indicated that the initial tool was too long and contained non-fistula specific information such as family planning and cervical cancer screening. Appropriate revisions were made before the tool could be used. Therefore, the new tool was based on past research in terms of how and what was important in measuring successful outcomes of fistula surgery. The instrument was also kept brief, so just a three page questionnaire was produced. This is the tool that was used to collect information from all fistula patients (Appendix 4.5). It is presumed that the design of the tool improved the response rate by being presented in parts and each part not too time-consuming to complete. The practicalities of the data collection were built into the running of the fistula service itself, whereby some data was collected by the fistula team/nurse/medical officer as part of the hospital procedure. This included data on a participant's: date of birth, residence, marital status, dates of referral if they were from another facility and details of next of kin. At this point, data on voluntary counselling and testing were collected from routine HIV testing, a common practice for most patients undergoing surgery. From the researcher's viewpoint, this was a very practical way of collecting data on other factors that may affect fistula outcomes outside fistula characteristics.

4.2.13: **Data Collection Procedures**

Data collection occurred in five stages. Each stage has been described in a chronological order starting with stage one to stage five as presented from Section 4.3.12 to 4.4. Figure 4.1 illustrates the flow of quantitative and qualitative study procedures starting from admission till discharge.

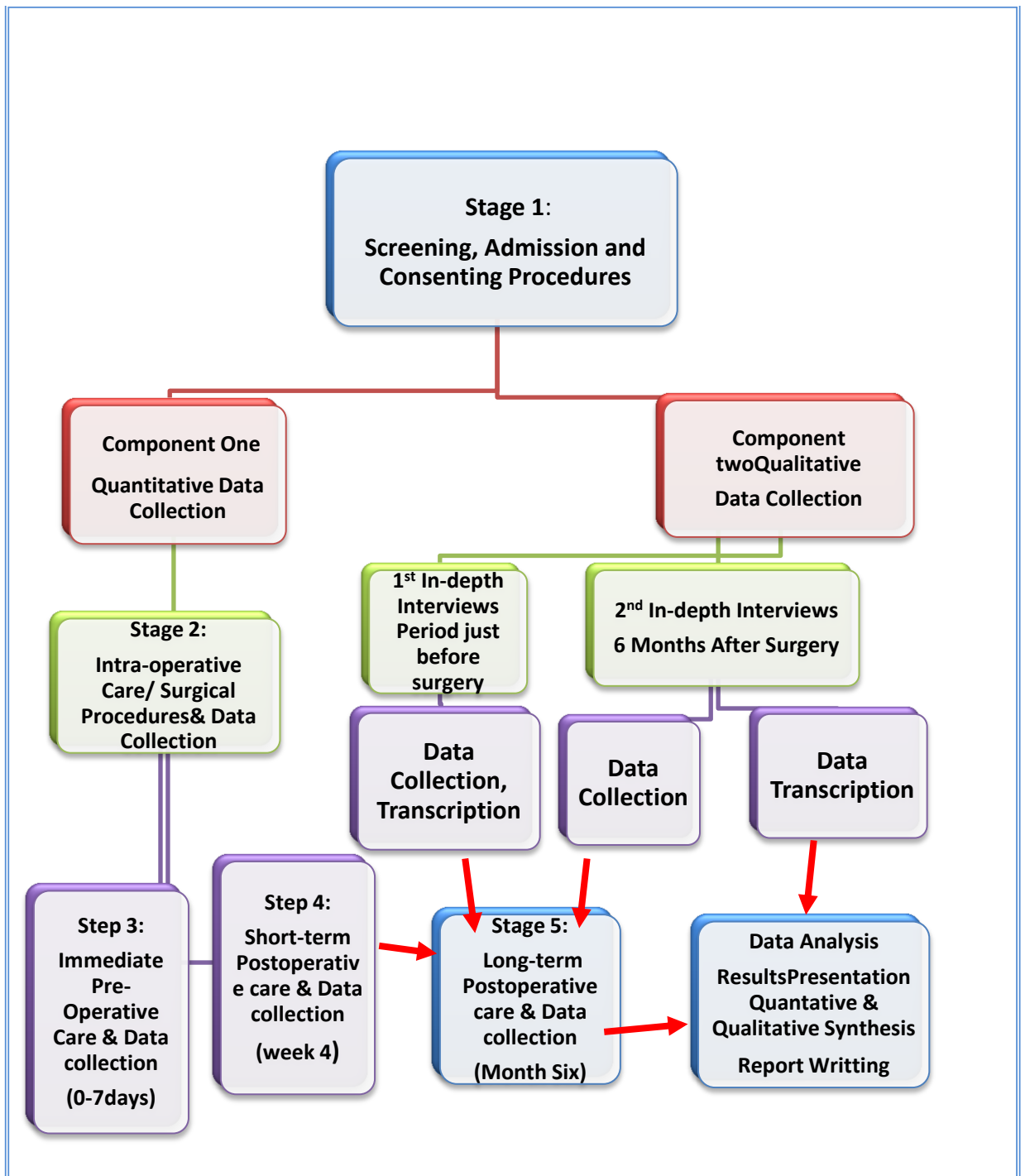


Figure 4.1: Study flow diagram showing step-by-step procedures

4.2.14: Stage 1. Recruitment and Initial Data Collection

The main objective in this stage in the quantitative component was to profile patients who presented with a fistula and establish predictors of successfulness of fistula surgery in East Africa. At the facility level, patients presenting with urine or stool leakage or both were informed about the study and invited to participate in the study. Consecutive sampling was employed in this

study, i.e. every patient that met the inclusion criteria was selected for study until such a time that the required sample size was achieved. This method is relatively easy to use: it is a more representative sample of the whole population and has fewer chances for intentional or unintentional manipulation by clinic staff or errors due to confusion (Polit and Beck, 2011). However, consecutive sampling is not based on randomisation: as such it may present variations as to who is to be seen at fistula clinics at different times of the year. For example, during fistula camps in June, September and November, many women turn up for services compared to any other month. This is because during the fistula camps, transport is provided for those who cannot afford. Transport service is not available during other months. This may hinder other women with fistula from accessing the service; therefore they may not be consecutively recruited for study because they are not reachable.

Willing and consenting women were then assigned study numbers and recruited on a first come first serve basis. Facility and patient profiles were documented using section one of the quantitative data collection form (Appendix 4.5). This section mainly collected sociodemographic information: which included, age, education, parity, marital status, employment, religion, contact details, home/residential address and country of origin. Also, collected in this section were social characteristics of the spouse and whether or not spouse left the relationship because of fistula problem.

Section two of the tool collected information about fistula history, presenting symptoms, (whether patient had urine or stool leakage or both), previous repairs and duration of leakage. Also collected was information about medical history, menstruation patterns, and labour and child birth characteristics.

4.2.15: **Stage 2. Pre-operative Care**

This stage followed stage one as described in Section 4.3.2. Fistula education and supportive counselling were given on a one-to-one basis for all patients in the ward. This is because counselling has been shown to improve compliance for fluid intake, vaginal toileting, and voluntary HIV testing (WHO2004). As part of pre-operative care patients were encouraged to drink 5 litres of fluid daily. As expected, some patients were unwilling to drink the recommended amount of fluid (5 litres) because of fear of increased leakage, but they were advised that a high fluid intake is important intra-operatively as it allows for easy identification of the ureters. Antibiotics were not being given routinely; instead they were administered only where infection

was present, which was rare in this cohort. Oral haematinics and a high-protein diet were instituted to promote wound healing post-operatively.

To assess renal function and suitability for spinal anaesthesia, a minimum of laboratory tests such as the haemogram and serum creatinine were performed. In instances where the patient had a seropositive HIV test, CD4 counts were performed before referring the patient to Comprehensive Care Clinics (CCC) which was located within the hospitals. In all countries, voluntary testing is a routine service; the researcher obtained consent from the patients to allow him use routine data for the study (the consent process is described in section 4.11).

As part of routine practice, all fistula patients were reviewed by the anaesthetist and once the condition was certified as satisfactory, theatre was booked in readiness for fistula repair.

4.2.16: **Stage 3. Intra-Operative Care**

The overriding surgical principle at this stage is that the first attempt at fistula repair offers the best chance for a successful surgery. Upon receiving the patient in theatre, she was made comfortable and settled well in the receiving area. The surgeon then confirmed that consent for surgery had been obtained from the patient and the records were in order. Once all particulars had been confirmed, preloading of the patient with fluids was done, and vital signs confirmed to be normal. Spinal anaesthesia was then administered using bupivacaine at L3L4 lumbar spine region. In some circumstances, an additional drug like fentanyl would be added to improve the effectiveness of bupivacaine. After ten minutes, anaesthesia was confirmed by asking the patient to lift her leg up: if the patient was not able to lift her legs, then she was assumed to be fully anaesthetised.

First, the patient was positioned and placed in an exaggerated lithotomy position; this was to help visualise, classify and assess accessibility of the fistula. This step involved identification and description of the fistula in terms of its location/site, size, extent of damage including circumferential lesions and vaginal stenosis if present. In addition to classifying the fistula, the bladder size and urethral length were also assessed; these assessments are theoretically crucial factors in predicting fistula prognosis. Fistula classification was made based on the Waaldijk (1995) guidelines. Upon classification of the fistula, basic principles in closing the fistula followed. The surgeon ensured that the operation site was adequately exposed, the ureters were protected, the vagina was separated from the bladder and an excision of the scar was made to allow a

tension free closure. The posterior wall of the vagina was also checked for rectal injury and the cervix palpated for any damages. The distance from the external urethral orifice to the distal fistula margin was measured to help estimate the size of the bladder. The surgeon then tapped the interior of the bladder to help detect any calculi. After this, the labia were then sutured laterally to improve access while a swab was sutured to cover the anus.

Thereafter, the vaginal wall distal to the fistula was held with the Allis forceps which was followed by an upward traction: this action brings the fistula into view. The proximal margin of the fistula was then incised through the full thickness of the vaginal wall: great care was taken to avoid bladder injury. This is because if the bladder is closed under any tension/injury, chances of the surgery failing are high. Where necessary, a size 23 blade was used in giving an episiotomy on the lateral walls of the vagina, starting from the left to the right angles of the fistula. The episiotomy facilitates wider access for the dissection of the fistula. When the surgeon was satisfied with the size of the dissection, the reflected tissue was sewn to the labia on each side with a suture. The fistula edge was then trimmed of any scar tissue or residual vaginal skin. After this, the angles were examined again to ensure that they were not tethered to the inferior pubic ramus on either side.

The fistula was then repaired with interrupted size 00 absorbable sutures. To close the fistula, the angles were secured first, taking bites distal, proximal and lateral to the fistula angle. The corner sutures were clipped after tying for identification. During this procedure, uttermost care was taken to ensure that there was no protrusion of bladder mucosa at any point along the suture line. At times, confined location of the vagina made the operation difficult. As such, fish-hook (J) needles or 5/8-circle needles were used because they are small and strong.

Once the fistula was closed, a dye test (Methylene Blue or Gentian Violet) was performed to confirm the closure. After this, the vaginal walls were adapted and haemostasis achieved. A vaginal pack was placed in situ to support drainage. The intra-operative notes and post-operative instructions were clearly written. The surgical findings in this intra-operative component of the study were documented in section 3 of the standard data collection tool. The patient was then handed over to the recovery ward team with clear, written post-operative instructions. Later, when the patient was comfortable, the recovery nurse transferred the patient to the ward.

4.2.17: **Stage 4. The Immediate Post-Operative Care**

This stage of the study covered post-operative care and complications from the time the patient left theatre till the 7th post-operative day. Anticipated complications included catheter blockage and stress incontinence. All complications that were observed after surgery and soon after the patient left theatre were documented in section 4 of the data collection tool.

Fluid intake of more than 5 litres per day was maintained throughout the post-operative period. Removal of the vaginal pack occurred after 24 hours. Patients were advised to have regular sitz baths to ensure perineal hygiene after removal of the vaginal pack. (A sitz bath is a warm salty bath that is used to clean the perineum. It can be used for everyday personal hygiene and or for providing relief from pain or itching in the genital area.) Maintaining a high standard of hygiene helps prevent catheter blockage and secondary infection. At the same time, pelvic floor exercises were initiated to improve continence. Every effort was made to mobilise the patient early because mobilisation allows for good blood circulation on the operation site and prevents deep venous thrombosis. Also, it promotes fluid drainage especially from the operation site which is good for wound healing.

Foley's catheter was left in situ for 14 days to help maintain continuous bladder drainage. This ensures that the damaged bladder muscles rest whilst promoting wound healing. Throughout these processes, the need for follow up visits, family planning and nutrition were communicated to the patients in Kiswahili or other language they best understood. These processes were followed in all sites.

4.2.18: **Stage 5. Long-term Follow up Visit**

Stage 5 dealt with post-operative complications. This stage was further divided into two parts: short and long-term follow up visits. Short-term follow up visits occurred two weeks after discharge while long-term follow up visits occurred from 4 weeks post-surgery. In both instances, the main objective was to assess fistula closure and associated complications. Post-operatively, a dye test was done for every patient at week two: this helped the surgeon in assessing fistula closure and continence. A negative dye test confirmed fistula closure, which allowed for removal of the urethral catheter.

When the fistula failed to close, the dye test turned out positive. As such, the catheter was kept for 1-2 more weeks; if the fistula had not closed after this period, the fistula was considered to

have failed and a second repair was planned. Despite the fistula failing to close, the patient was advised to maintain high fluid intake, continued perineal hygiene and abstain from sexual intercourse. Abstinence allows the raw tissues to rest, which facilitates wound healing.

Required study information was documented using part five of the data collection tool. All the study visits had a 2-4 day window period; this means that if a woman missed her appointment on a certain day she still had a two day chance to be seen within the protocol, within which patients were reviewed and considered to be compliant with protocol. Once consent to join the study was obtained, data on socioeconomic profiles and fistula history was collected using part I and II of the quantitative tool. Patients were told about the qualitative component of the study, it was explained that participating in the in-depth interviews was voluntary: interviews were to be recorded, which they needed to give consent, all information obtained was kept strictly confidential under lock and key by the researcher. (The consent process is described in Section 4.3.9). There was no other eligibility criterion except willingness to participate in the in-depth interviews. An in-depth guide (Appendix 4.6) was used to collect qualitative data. Study stages and procedures are outlined in Figure 4.1.

4.2.19: **Data cleaning from all Sites and Analysis**

Data cleaning helps a researcher avoid incorrect data which if used, may lead to changes in clinical practice, hence introducing unethical procedures. Therefore, various data cleaning strategies were applied. Once data were entered, checking was done using value labels in IBM SPSS Statistics to check for unusual labels or codes. Where this occurred, cross checking with the source document was performed to ensure validity and reliability of data collected. Also, exploratory data analysis was used in data cleaning, an intermediary stage before data analysis. This strategy utilises plots and graphs, which gives an overview of normally distributed data and outliers, thereby giving the researcher a feel for his data. This was the strategy the researcher employed in data cleaning across sites.

4.2.20: **Data Analysis**

Data cleaning was done prior to preliminary data analysis. IBM SPSS Statistics version 20 was used for quantitative data analysis. Once all data collection and cleaning was completed, descriptive methods were used to estimate means, standard deviations, medians and percentages in the study sample, with 95% confidence intervals where appropriate. Frequency tables, bar charts, tables of descriptive statistics and histograms were used to summarise data. Important

characteristics were compared between the five sites. This was done descriptively and inferentially using chi-square tests, Kruskal-Wallis tests and one-way analysis of variance for nominal, ordinal, and highly skewed or approximately normally distributed characteristics respectively. Bivariable analyses such as chi-square tests, chi-square tests for trend, Mann-Whitney U tests, independent-samples t-tests and Kendall's correlation were used to estimate the association of variables with successful surgical repair and duration of urine leakage. Duration of leakage was collected as an ordinal variable as women were not expected to be able to remember the exact number of years of leakage.

Binary multiple logistic regression was used to estimate the adjusted association between predictors and the binary outcome success of surgery. Ordinal and multinomial multiple logistic regressions were used to estimate the adjusted association between predictors and duration of urine leakage. Predictors were included in the regression models for success of surgery and duration of leakage in a two-stage process. Variables were initially included if they showed an unadjusted bivariable association with the outcome variable at a conservative significance level of $\alpha=0.250$. As noted by Hosmer and Lemeshow (2000), this allows independent variables to be included that may not show an important association with the outcome variable on their own but show an association in the presence of other variables. These variables were included in separate multiple regression models based on sociodemographic variables, childbirth-related variables or fistula-related variables. Variables in these regression models were selected for a final model if their adjusted association with the outcome variable was significant at $\alpha=0.10$, or if there were strong theoretical reasons for including them as provided by Hosmer and Lemeshow (2000).

4.2.21: **Summary of Quantitative Component of Study**

The quantitative element aimed at establishing the factors that predict successfulness of fistula surgery and duration of urine leakage in women with fistula. To fulfil this aim a prospective cohort study was conducted in five African countries with a sample size of 1224 women living with fistula. Whilst this approach enabled predictors of successfulness of surgery to be determined, understanding the issues related to pre and post-surgery experiences would require qualitative inquiry. Thus, as part of a mixed methods approach, the next section describes the methods undertaken to gain understanding of the social and psychological contributors to the identified prediction factors.

4.3: Part Two: Qualitative Component of the Study

As outlined in Chapter Three, a phenomenological approach was used to capture the lived experiences of women living with fistula in East Africa. In keeping with the phenomenological approach, in-depth interviews were undertaken. A qualitative research interview is defined by Kvale (p6, 1984) as “an interview whose purpose is to gather descriptions of the life world of the interviewee with respect to the interpretation of the meaning of the described phenomena”. The researcher realised that there were unexplored issues among the women and that it was not possible to capture the lived experiences using a structured quantitative tool. This observation necessitated protocol amendment and resubmission. The amended protocol aimed at documenting the lived experiences of women with fistula using a phenomenological approach, as highlighted in the previous chapter.

The in-depth interview guide was developed by the researcher, informed by the researcher’s experience, the research question and previous literature. The phenomenological approach recognises the importance of individual narratives and depth of data as opposed to large sample sizes. Thus, it was decided that the qualitative data would be obtained only from Kenya. Most of the quantitative data had been obtained from Kenya. In addition, this was a more practical strategy as the researcher was based in this country and local languages may have been an issue in the other countries.

4.3.1: Recruitment for Qualitative Study Participants

Participants for the qualitative interviews were recruited from three sites in Kenya: Kenyatta, Kisii and Coast general hospitals.

Prior to conducting interviews, a comprehensive consent process was under taken as explained in Section 4.5. Women in these sites were interviewed at two time points: the first interviews were conducted before surgery while the second interviews were conducted approximately six months after surgery. Timing of the interviews was crucial for obtaining relevant information regarding lived experiences before and after surgery. The period before surgery captured information about women’s experiences while they lived with the fistula problem. Follow-up interviews at six months were most appropriate because the timing coincided with the long-term post-operative visit, so women did not have to make another visit. In addition, at six months, the fistula would have closed and women may have new experiences.

4.3.2: **Sampling Procedure**

Purposive sampling technique was used in selecting women for the qualitative component of study. As a technique, purposive sampling is widely used in qualitative research for the identification and selection of information-rich cases for the most effective use of limited resources (Patton, 2002). The process involves identification and selection of study participants who are particularly knowledgeable or experienced with the phenomenon of interest (Cresswell *et al.*, 2003). Sixteen women were purposely sampled from the three fistula centres in three county hospitals in Kenya. The centres were chosen because of a high prevalence of fistula, the availability of surgical repair teams and access to the facilities.

4.3.3: **Obtaining Consent for Qualitative component**

All qualifying participants were provided with written and/or verbal information in the local language (Kiswahili). Women presenting with a history of urine and/or faecal leakage, a diagnosis of vesico vaginal/recto vaginal fistula and who had been booked for surgery were included. Women also had to demonstrate the capacity to communicate. Willing and consenting women were then assigned a study number. To provide an environment, free of coercion, the recruitment and consent processes were conducted by a researcher assistant who was not part of the clinical care team. By design, the small (16 participants) sample size was in keeping with the phenomenological approach, whereby the richness of the data took priority over the number of participants. In keeping with phenomenology, data saturation was not sought.

4.3.4: **Data Collection during the Pre and Post-operative Periods**

A broad interview schedule (Appendix 4.6) was developed from prior experience and knowledge of published literature. This helped in gaining content validity: the questions covered the main areas of study. Prior to study initiation, the tool was piloted in a hospital in the Eastern Region of Kenya. Following the piloting, minor changes were made to the tool related to community involvement in fistula care. Women were interviewed at two time points: the first interview was conducted after admission, just before surgery and the second occurred 6 months after surgery. All interviews were conducted in a private clinical room by an experienced Public Health Nurse. On average, the interviews lasted 30-60 minutes per person and focused on experiences before, during and after surgery. The study started on February, 13th 2013 and ended on March, 20th 2016; having completed the month six follow up visits and in-depth interviews.

4.3.5: **Pre-operative Interviews**

Qualitative data collection occurred between February 2013 and March 2016, following ethical approval from the University of Nairobi and The University of Manchester. Within this period, community mobilisation, patient recruitment, data collection and follow up visits occurred. Three sites in Kenya (Kenyatta, Kisii and Mombasa) were selected for this component of study because they shared a common language (Kiswahili) and were accessible for follow-up. In the ward, women who had joined the quantitative component of study, whose demographic characteristics and fistula diagnosis had been confirmed, were invited to participate by the Public Health Nurse. The nurse approached each patient individually explaining the nature of the qualitative study and what participation involved. Women who were willing to be interviewed were provided with a copy of the patient information sheet (Appendix 4.3 or Appendix 4.3a), after which detailed study information was given by the nurse on a one-to-one basis, in a private room at the reproductive health clinic.

This qualitative component of study employed a hermeneutic phenomenological approach, guided by Heidegger's work (Heidegger, 1962). This approach allows a researcher to study women's experiences while recognising that the observations and interpretations will be influenced by one's own prior experiences and beliefs. In this study, the surgeon had many years' experience working with similar patients in the same settings. As such, phenomenology was seen as the most appropriate way of capturing individual women's journeys: before, during and after fistula repair. To achieve this, prospective longitudinal data were collected in the form of women's narratives. The advantage of this approach lies in the recognition and uniqueness of each woman's lived experience. In addition, the approach supports the collective interpretation of data from which a phenomenon can be described. This phenomenon provides clarity to researchers understanding of critical issues which led to drawing of recommendations for practice. The study required a multi-team (obstetrician, midwife, public health nurse and psychologist) approach in the design, implementation and data processing. Considering the team's prior knowledge and experiences, a reflexive stance was therefore adopted, whereby the researchers reflected on how they may have influenced the interpretations.

4.3.6: **Post-operative Interviews**

The post-operative interviews were conducted during a six month follow-up visit. These interviews were a continuation of the first interviews which were conducted during the pre-operative period. Written consent was not required at this stage, however the initial consent to

be followed up was verbally reaffirmed. This part aimed at gathering information on women's lived experiences after surgery and was guided by part two of the interview guide (Appendix 4.6).

All the interviews were recorded and later transcribed and translated verbatim. Pseudonyms were used to maintain anonymity in accordance with robust ethical principles. Each interview lasted about 30-60 minutes. At the end of each interview, the interviewer did a recap to help confirm the interpretations, after which participants were allowed time for comments or suggestions. The interviewer maintained a journal of field notes where all events related to each interview were recorded. These interviews were conducted in accordance with ethical principles that guide qualitative research.

4.3.7: Qualitative Data Processing and Analysis

All in-depth interviews were conducted in Kiswahili, audio-recorded, transcribed verbatim (word by word) and translated to English. Pseudonyms were used to maintain anonymity. To maintain consistency and rigour, initial codes were discussed and agreed with mentors beforehand. A thematic approach was used in data analysis as described by Van Manen (1990). First, transcripts were read and re-read in their entirety, to allow data familiarisation. Then, significant sentences were highlighted, along with clusters of sentences that provided context to the text.

Throughout the process, the whole transcripts were reread to observe any trends in the themes and ensure correct interpretations. This process of hermeneutic reflection and the hermeneutic circle are pivotal to hermeneutic interpretive phenomenology (Heidegger, 1962). Moving backwards and forwards between individual textual sections and whole narratives recognises women's personal experiences while allowing interpretation of the data as a whole. To aid rigour, a research journal (recording researcher's experiences), field notes and an audit trail were kept throughout the process (Walsh, 2004). Furthermore, the primary researcher led the analysis, with input and discussion from the remainder of the team to ensure confirmability of interpretations (Lincoln and Guba, 2000).

4.4: Ethical Issues

The general principles governing ethical conduct in biomedical research were discussed previously in Chapter Three. These principles have been applied in details at every stage of this research. Foremost, prior to study initiation, ethical approval for all sites was obtained from KNH/UON-ERC (Ref: P529/10/2012), see Appendix 6.4.). In ensuring sound consent procedures, the participant

information sheet was translated into Kiswahili, a language that is spoken in most across counties in Kenya. In cases of language barrier, a local translator was called upon to translate the study information as required. Qualifying and willing patients were issued with study information sheet which explained the purpose of the study, procedures, roles and responsibilities of participants and the researcher. Once patients were comfortable with the information and all their questions answered, they were required to give consent using the study consent form (Appendix 4.4). For some illiterate women who could not provide a written consent, a thumb print was allowed. Patients aged below 18 years had their parent's or guardian's consent on their behalf as required by the law.

However, the investigator may not be sure to what extent the trauma and stigma associated with fistula affected consent process since most patients desperately look forward to continence restoration. The time period chosen was to obtain adequate recruitment of participants, but short enough to ensure reduction of potential confounding variables, such as changes in fistula repair techniques. To safeguard confidentiality, patients were allocated a study number and all information was coded to remove any patient identifiers.

4.4.1: Distress Policy in the Study

Across countries, health facilities are at various levels of development and specialisation. Fortunately, each selected site had a structured distress policy, with clear implementation guidelines. For this reason, one could find a counsellor and social worker joining fistula teams wherever a camp was held. In hospitals where fistula services were offered as routine service, e.g. at Kenyatta National hospital, counsellors and social workers are allocated roles and responsibilities at clinic 66, the fistula centre. This kind of arrangements allowed women access to immediate support in case of a crisis.

4.5: Conclusion

This chapter has discussed the methods for the study. The qualitative and quantitative methods were combined to generate a mixed-methods approach. This allowed for a more holistic dataset to be considered that informs comprehensive management of obstetric fistula. The quantitative component identified patient profiles, fistula characteristics and predictors of successfulness of surgery in a five stage design. Data analysis was carried out using SPSS and will be presented in narrative and table form. The qualitative component of the study aimed to document the lived experiences of women living with a fistula in Kenya. The methods adhered to the

phenomenological principles, strengthened by the longitudinal approach, purposive sampling, in-depth interviewing, thematic analysis and reflexivity. The following two chapters will describe the main findings of both elements of the mixed-methods study.

Chapter 5: QUANTITATIVE RESULTS

5.1: Introduction

This chapter presents findings from the quantitative component of the study, a cohort study of patients attending fistula centres across three East African Countries. Section 5.2 summarises characteristics of the participants and their spouses by country of referral, as women referred from different countries were expected to have different characteristics. The section presents findings for sociodemographic variables, childbirth-related variables, fistula-related variables and the outcome variables successfulness of surgery and duration of leakage in a comprehensive description of the recruited sample. Section 5.3 explores multivariate associations of sociodemographic, childbirth-related and fistula-related variables with successfulness of surgery using binary logistic regression modelling. Section 5.4 explores multivariate associations of sociodemographic, childbirth-related and fistula-related variables with duration of leakage using multinomial logistic regression modelling. Finally, Section 5.5 summarises the main findings from the analyses.

5.2: Characteristics of the Participants and their Spouses

5.2.1: Sociodemographic Characteristics by Country of Referral

Table 5.1 summarises sociodemographic characteristics of the women participating in the study by country of referral. Most women (897, 73.3%) had been referred from Kenya, the next most common countries of referral being Uganda (104, 8.5%), Rwanda (75, 6.1%) and Southern Sudan (70, 5.7%). There were smaller numbers referred from the DR Congo (38), Malawi (19) and Somalia (3).

The most common age groups across the total sample were 18-27 years (36.9%) and 28-37 years (34.8%); only 40 women (3.3%) were aged 17 or under, 38 of whom were referred from Kenya. The mean height was 154.7 cm (SD 8.0) and the mean weight was 56.2 kg (SD 10.4), and there was little variation by country. Most women were married (60.9%), one woman in five being single. The percentage single was higher for women referred from Kenya (23.8%) compared with any other country apart from Somali, where two of the three women were single. The percentage separated or divorced was highest for the DR Congo (34.2%), Rwanda (23.0%) and Uganda (21.0%). Almost all women were Christian (94.5%), with the DR Congo having by far the highest percentage of Muslims (39.5%). One in three women (35.3%) had no children currently alive, the ratio being as high as one in two for women referred from the DR Congo and Southern Sudan.

Table 5.2 summarises the highest level of education level of the women and their spouses by country of referral. Most women (62.9%) had only been educated to primary level, 15.3% had a secondary level education, only 54 (4.4%) had been to college and only 5 had been to university. The most common level of education was primary for women referred from Kenya (62.9%), Malawi (73.7%), Rwanda (59.5%), Southern Sudan (57.7%) and Uganda (81.8%), with 71.1% of women from the DR Congo and 2/3 from Somalia having had no education. Level of education was considerably higher in women referred from Kenya, 18.3% of whom had been educated to secondary level, the next highest percentage being 7.5% for Uganda: all the college- and university-educated women were referred from Kenya. Relatively few of the women's spouses had been educated beyond primary level: 24.4% had a secondary level education, 62 (5.1%) had a college education and 16 had been to university.

Table 5.3 summarises the employment status and occupation of the women and their spouses by country of referral. Across the total sample, four out of ten women were unused, the most common occupations being peasant farmer (35.0%), housewife (31.4%) and being engaged in small business (13.7%). Unemployment rates varied by country of referral, ranging from 91.1% for the DR Congo and 76.1% for Southern Sudan to 13.5% for Rwanda and 13.2% for Uganda. Fewer of their spouses were unused (13.5%), the rates also differing by country, the most common occupation being peasant farmer (45.8%) followed by small business (14.4%). Occupations of the women and their spouses also differed by country of referral. Among the women, the most commonly reported occupations were housewife for Kenya (31.1%), the DR Congo (65.8%), Somalia (66.7%) and Southern Sudan (66.2%), and peasant farmer for Malawi (47.4%), Rwanda (79.7%) and Uganda (73.6%). Peasant farmer was the most common occupation for spouses in many countries, the percentage being as high as 86.8% for Uganda and 78.4% for Rwanda. For Southern Sudan, the most common occupation for spouses was pastoralist (31.0%), while almost half of the spouses from the DR Congo had no occupation recorded.

Table 5.1 Demographic characteristics of the women by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Age group	<= 17	38 (4.2%)	0 (0%)	2 (5.3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	40 (3.3%)
	18-27	343 (37.6%)	7 (36.8%)	21 (55.3%)	13 (17.6%)	0 (0%)	35 (49.3%)	33 (31.1%)	452 (36.9%)
	28-37	305 (33.4%)	8 (42.1%)	6 (15.8%)	35 (47.3%)	1 (33.3%)	25 (35.2%)	46 (43.4%)	426 (34.8%)
	38-47	113 (12.4%)	3 (15.8%)	9 (23.7%)	17 (23.0%)	2 (66.7%)	8 (11.3%)	11 (10.4%)	163 (13.3%)
	48-57	63 (6.9%)	0 (0%)	0 (0%)	7 (9.5%)	0 (0%)	2 (2.8%)	13 (12.3%)	85 (6.9%)
	58-67	40 (4.4%)	1 (5.3%)	0 (0%)	0 (0%)	0 (0%)	1 (1.4%)	1 (0.9%)	43 (3.5%)
	>=68	11 (1.2%)	0 (0%)	0 (0%)	2 (2.7%)	0 (0%)	0 (0%)	2 (1.9%)	15 (1.2%)
Height (cm)	mean [SD]	154.7 [8.0]	150.3 [5.2]	153.3 [6.9]	153.6 [7.7]	158.7 [4.0]	154.2 [6.7]	153.1 [7.5]	154.4 [7.8]
Weight (kg)	mean [SD]	56.2 [10.4]	53.7 [7.8]	54.8 [7.5]	55.7 [9.9]	59.0 [2.6]	55.8 [8.3]	55.1 [7.9]	56.0 [10.0]
Marital status	Single	217 (23.8%)	1 (5.3%)	1 (2.6%)	11 (14.9%)	2 (66.7%)	7 (9.9%)	12 (11.3%)	251 (20.5%)
	Married	553 (60.6%)	15 (78.9%)	23 (60.5%)	37 (50.0%)	1 (33.3%)	51 (71.8%)	65 (61.3%)	745 (60.9%)
	Separated	54 (5.9%)	0 (0%)	1 (2.6%)	13 (17.6%)	0 (0%)	5 (7.0%)	7 (6.6%)	80 (6.5%)
	Divorced	34 (3.7%)	3 (15.8%)	12 (31.6%)	4 (5.4%)	0 (0%)	3 (4.2%)	18 (17.0%)	74 (6.0%)
	Widowed	55 (6.0%)	0 (0%)	1 (2.6%)	9 (12.2%)	0 (0%)	5 (7.0%)	4 (3.8%)	74 (6.0%)
Religion	Christian	863 (94.5%)	19 (100%)	23 (60.5%)	74 (100%)	3 (100%)	70 (98.6%)	105 (99.1%)	1157 (94.5%)
	Muslim	50 (5.5%)	0 (0%)	15 (39.5%)	0 (0%)	0 (0%)	1 (1.4%)	1 (0.9%)	67 (5.5%)
Number of children currently alive	0	306 (33.8%)	5 (26.3%)	19 (50.0%)	27 (36.5%)	2 (66.7%)	37 (52.9%)	33 (31.4%)	429 (35.3%)
	1	171 (18.9%)	6 (31.6%)	5 (13.2%)	20 (27.0%)	0 (0%)	9 (12.9%)	24 (22.9%)	235 (19.3%)
	2	158 (17.4%)	3 (15.8%)	3 (7.9%)	11 (14.9%)	0 (0%)	6 (8.6%)	15 (14.3%)	196 (16.1%)
	3	97 (10.7%)	3 (15.8%)	2 (5.3%)	7 (9.5%)	1 (33.3%)	7 (10.0%)	11 (10.5%)	128 (10.5%)
	4	66 (7.3%)	2 (10.5%)	3 (7.9%)	4 (5.4%)	0 (0%)	5 (7.1%)	5 (4.8%)	85 (7.0%)
	5 or more	108 (11.9%)	0 (0%)	6 (15.8%)	5 (6.8%)	0 (0%)	6 (8.6%)	17 (16.2%)	142 (11.7%)
Overall		913 (100%)	19 (100%)	38 (100.0%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)

Table 5.2 Education of the women and their spouses by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Woman's education	None	113 (12.4%)	4 (21.1%)	27 (71.1%)	24 (32.4%)	2 (66.7%)	26 (36.6%)	12 (11.3%)	208 (17.0%)
	Primary	574 (62.9%)	14 (73.7%)	11 (28.9%)	44 (59.5%)	0 (0%)	41 (57.7%)	86 (81.1%)	770 (62.9%)
	Secondary	167 (18.3%)	1 (5.3%)	0 (0%)	6 (8.1%)	1 (33.3%)	4 (5.6%)	8 (7.5%)	187 (15.3%)
	College	54 (5.9%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	54 (4.4%)
	University	5 (0.5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	5 (0.4%)
	Total	913 (100%)	19 (100%)	38 (100.0%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)
Spouse education	None	176 (19.6%)	4 (21.1%)	27 (71.1%)	35 (47.3%)	2 (66.7%)	23 (32.4%)	14 (13.3%)	281 (23.3%)
	Primary	390 (43.5%)	9 (47.4%)	9 (23.7%)	30 (40.5%)	0 (0%)	35 (49.3%)	80 (76.2%)	553 (45.8%)
	Secondary	262 (29.2%)	6 (31.6%)	1 (2.6%)	8 (10.8%)	1 (33.3%)	7 (9.9%)	10 (9.5%)	295 (24.4%)
	College	56 (6.2%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	4 (5.6%)	1 (1.0%)	62 (5.1%)
	University	13 (1.4%)	0 (0%)	1 (2.6%)	0 (0%)	0 (0%)	2 (2.8%)	0 (0%)	16 (1.3%)
	Total	897 (100%)	19 (100%)	38 (100%)	75 (100%)	3 (100%)	70 (100%)	104 (100%)	1224 (100%)

Table 5.3 Employment status and occupation of the women and their spouses by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Woman Unemployed	Yes	368 (40.3%)	8 (42.1%)	35 (92.1%)	10 (13.5%)	2 (66.7%)	54 (76.1%)	14 (13.2%)	491 (40.1%)
	No	545 (59.7%)	11 (57.9%)	3 (7.9%)	64 (86.5%)	1 (33.3%)	17 (23.9%)	92 (86.8%)	733 (59.9%)
Woman Occupation	Business person	152 (16.6%)	1 (5.3%)	0 (0%)	3 (4.1%)	1 (33.3%)	4 (5.6%)	7 (6.6%)	168 (13.7%)
	Casual labourer	31 (3.4%)	1 (5.3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (0.9%)	33 (2.7%)
	Employed (general work)	86 (9.4%)	0 (0%)	2 (5.3%)	2 (2.7%)	0 (0%)	5 (7.0%)	6 (5.7%)	101 (8.3%)
	Housewife	284 (31.1%)	7 (36.8%)	25 (65.8%)	6 (8.1%)	2 (66.7%)	47 (66.2%)	13 (12.3%)	384 (31.4%)
	Pastoralist	2 (0.2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (0.2%)
	Peasant farmer	274 (30.0%)	9 (47.4%)	1 (2.6%)	59 (79.7%)	0 (0%)	8 (11.3%)	78 (73.6%)	429 (35.0%)
	Retired	1 (0.1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (0.1%)
	Student	32 (3.5%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	2 (2.8%)	0 (0%)	35 (2.9%)
	No occupation	51 (5.6%)	1 (5.3%)	10 (26.3%)	3 (4.1%)	0 (0%)	5 (7.0%)	1 (0.9%)	71 (5.8%)
Total		913 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)
Spouse Unemployed	Yes	125 (13.7%)	0 (0%)	18 (47.4%)	3 (4.1%)	1 (33.3%)	16 (22.5%)	2 (1.9%)	165 (13.5%)
	No	786 (86.3%)	19 (100%)	20 (52.6%)	71 (95.9%)	2 (66.7%)	55 (77.5%)	104 (98.1%)	1057 (86.5%)
Spouse Occupation	Business person	148 (16.2%)	2 (10.5%)	7 (18.4%)	6 (8.1%)	1 (33.3%)	5 (7.0%)	7 (6.6%)	176 (14.4%)
	Casual labourer	106 (11.6%)	3 (15.8%)	3 (7.9%)	2 (2.7%)	0 (0%)	2 (2.8%)	1 (0.9%)	117 (9.6%)
	Employed (general work)	142 (15.6%)	3 (15.8%)	2 (5.3%)	5 (6.8%)	1 (33.3%)	9 (12.7%)	4 (3.8%)	166 (13.6%)
	Musician	1 (0.1%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (0.1%)
	Pastoralist	14 (1.5%)	0 (0%)	1 (2.6%)	0 (0%)	0 (0%)	22 (31.0%)	0 (0%)	37 (3.0%)
	Peasant farmer	375 (41.2%)	11 (57.9%)	7 (18.4%)	58 (78.4%)	0 (0%)	17 (23.9%)	92 (86.8%)	560 (45.8%)
	Retired	4 (0.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	5 (0.4%)
	Student	13 (1.4%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	3 (4.2%)	0 (0%)	17 (1.4%)
No occupation	108 (11.9%)	0 (0%)	18 (47.4%)	2 (2.7%)	1 (33.3%)	12 (16.9%)	0 (0%)	143 (11.7%)	
Total		911 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1222 (100%)

Table 5.4 summarises the impact of the fistula on the women by country of referral. Most spouses did not leave the women after the occurrence of fistula (78.1%). The percentage of husbands leaving was highest for the DR Congo (36.8%) followed by Southern Sudan (33.8%), compared with only 18.6% for Kenya. Just over half of the women continued to live with their spouses (53.1%) after the fistula developed, with 11.9% living on their own.

Radio (49.6%) was the most common source of camp information, followed by hospital referrals (39.7%) while 4.4% were informed by their parents or siblings. Only 1.2% of the women heard about the fistula camp through television and only 2.2% heard from other fistula patients. This is understandable given that television is more expensive to own and that fistula patients are isolated. Most people in East Africa own a basic mobile phone with radio capability giving radio communication a very high penetration. Radio was the most common source for Kenya, Malawi, Rwanda, Southern Sudan and Uganda, but hospital referral was the most common source for countries affected by war (the DR Congo 37/38 and Somalia 3/3) where the infrastructure had been affected.

Table 5.5 summarises the relationship between how the woman first knew about the fistula camp and her level of education. Women with primary or secondary education were more likely to have heard about the camp from the radio, while college- and university-educated women were more likely to have been referred from hospital. Slightly more women with no education were referred from hospital (47.6%) than heard from the radio (44.2%). The higher education confers possibility and potentiality of being employed with financial capability to own a TV unlike the lower education who may afford a radio or better a mobile phone which runs radio service. Many of these radios transmit in the local vernacular languages making them more popular in the rural areas.

Table 5.4 Impact of fistula on the women by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Whether husband left	Yes	170 (18.6%)	4 (21.1%)	14 (36.8%)	24 (32.4%)	0 (0%)	24 (33.8%)	32 (30.2%)	268 (21.9%)
	No	743 (81.4%)	15 (78.9%)	24 (63.2%)	50 (67.6%)	3 (100%)	47 (66.2%)	74 (69.8%)	956 (78.1%)
Who do you live with now?	Self	97 (10.6%)	1 (5.3%)	4 (10.5%)	17 (23.0%)	0 (0%)	8 (12.7%)	18 (17.0%)	146 (11.9%)
	Spouse	489 (53.6%)	15 (78.9%)	15 (39.5%)	31 (41.9%)	3 (100%)	38 (53.5%)	58 (54.7%)	649 (53.1%)
	Parents	155 (17.0%)	2 (10.5%)	4 (10.5%)	16 (21.6%)	0 (0%)	13 (18.3%)	25 (23.6%)	215 (17.6%)
	Siblings	86 (9.4%)	1 (5.3%)	6 (15.8%)	3 (4.1%)	0 (0%)	7 (9.9%)	4 (3.7%)	107 (8.7%)
	Relatives/ Friends	66 (7.2%)	0 (0%)	9 (23.7%)	6 (8.1%)	0 (0%)	2 (2.8%)	1 (0.9%)	84 (6.9%)
	Employer/ neighbour	14 (1.5%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	1 (1.4%)	0 (0%)	16 (1.3%)
	Own children	5 (0.5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	6 (0.5%)
How did you first know of the camp?	Radio	411 (45.0%)	13 (68.4%)	0 (0%)	63 (85.1%)	0 (0%)	32 (45.1%)	88 (83.0%)	607 (49.6%)
	TV	14 (1.5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	15 (1.2%)
	Referral from hospital	395 (43.3%)	6 (31.6%)	37 (97.4%)	7 (9.5%)	3 (100%)	24 (33.8%)	14 (3.2%)	486 (39.7%)
	Parents/siblings	46 (5.0%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	7 (9.9%)	0 (0%)	54 (4.4%)
	Friends/relative s/neighbours	30 (3.3%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	3 (4.2%)	1 (0.9%)	35 (2.9%)
	Other fistula patient	17 (1.9%)	0 (0%)	1 (2.6%)	2 (2.7%)	0 (0%)	4 (5.6%)	3 (2.8%)	27 (2.2%)
Overall		913 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)

Table 5.5 Source of information of fistula camp by education level of woman

How did you first know of the camp?	None	Primary	Secondary	College	University	Total
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Radio	92 (44.2%)	411 (53.4%)	85 (45.5%)	18 (33.3%)	1 (20.0%)	607 (49.6%)
TV	1 (0.5%)	5 (0.6%)	9 (4.8%)	0 (0%)	0 (0%)	15 (1.2%)
Referral from hospital	99 (47.6%)	278 (36.1%)	70 (40.1%)	30 (55.6%)	4 (80.0%)	486 (39.7%)
Parents/siblings	8 (3.8%)	34 (4.4%)	9 (4.8%)	3 (5.6%)	0 (0%)	54 (4.4%)
Friends/relatives/neighbours	5 (2.4%)	25 (3.2%)	4 (2.1%)	1 (1.9%)	0 (0%)	35 (2.9%)
Other fistula patient	3 (1.4%)	17 (2.2%)	5 (2.7%)	2 (3.7%)	0 (0%)	27 (2.2%)
Total	208 (100%)	770 (100%)	187 (100%)	54 (100%)	5 (100%)	1224 (100%)

Table 5.6 shows the health status of women at surgery by country of referral. Overall, only half of the women (52.0%) were still menstruating at the time of operation. This percentage varied by

country of referral, with many more still menstruating in the DR Congo (84.2%) and fewer in Malawi (43.1%). A good general condition is a preoperative requirement to promote healing and success of any surgical condition. HIV status is not a contraindication for surgery so long as the general condition is good. Most women were in good general condition at surgery (77.9%), the highest percentages being for Malawi (100%), DR Congo (92.1%) and Rwanda (91.9%). Relatively more women were referred from Southern Sudan (22.5%) and Uganda (14.2%) in poor condition. Overall, the HIV prevalence was low at 6.0%, Uganda (9.4%) and Rwanda (8.1%) having the highest prevalence with none of the 71 women referred from Southern Sudan being HIV positive. These results are in line with HIV prevalence in the general population in this region of Africa (UNAIDS, 2015)

Table 5.7 shows the general condition and HIV status of women at surgery by centre of referral. Within this sample, there were variations in general condition and HIV status between centres, especially within Kenya. For example, there were relatively more women referred from Coast General and Kisii with a poor general condition (13.0% and 13.5% respectively); Kisii had the highest prevalence of HIV (10.1%) and Garissa and Webuye the lowest (0%).

Table 5.6 General health status of the women by country

Country		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Menstruating regularly	Yes	461 (51.0%)	8 (42.1%)	32 (84.2%)	47 (63.5%)	2 (66.7%)	32 (45.1%)	49 (46.7%)	631 (52.0%)
	No	443 (49.0%)	11 (57.9%)	6 (15.8%)	27 (36.5%)	1 (33.3%)	39 (54.9%)	56 (53.3%)	583 (48.0%)
General condition	Poor	63 (6.9%)	0 (0%)	1 (2.6%)	5 (6.8%)	0 (0%)	16 (22.5%)	15 (14.2%)	100 (8.2%)
	Fair	154 (16.9%)	0 (0%)	2 (5.3%)	1 (1.4%)	0 (0%)	2 (2.8%)	11 (10.4%)	170 (13.9%)
	Good	695 (76.2%)	19 (100%)	35 (92.1%)	68 (91.9%)	3 (100%)	53 (74.6%)	80 (75.5%)	953 (77.9%)
HIV status	Positive	55 (6.0%)	1 (5.3%)	1 (2.6%)	6 (8.1%)	0 (0%)	0 (0%)	10 (9.4%)	73 (6.0%)
	Negative	857 (94.0%)	18 (94.7%)	37 (97.4%)	68 (91.9%)	3 (100%)	71 (100%)	96 (90.6%)	1150 (94.0%)
Overall		912 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1223 (100%)

Table 5.7 General condition and HIV status of the women by centre

Country of centre	Centre	General condition			HIV status		Overall
		Poor	Fair	Good	Positive	Negative	
		N (%)	N (%)	N (%)	N (%)	N (%)	
Kenya	Coast General	12 (13.0%)	13 (14.1%)	67 (72.8%)	1 (1.1%)	91 (98.9%)	92 (100%)
	Garissa	0 (0%)	2 (14.3%)	12 (85.7%)	0 (0%)	14 (100%)	14 (100%)
	Kisii	23 (13.5%)	28 (16.5%)	119 (70.0%)	17 (10.1%)	152 (89.9%)	170 (100%)
	Kenyatta NH	27 (4.8%)	92 (16.3%)	446 (78.9%)	30 (5.3%)	536 (94.7%)	566 (100%)
	New Nyanza	2 (2.0%)	21 (20.6%)	79 (77.5%)	9 (8.8%)	93 (91.2%)	101 (100%)
	Webuye	0 (0%)	0 (0%)	12 (100%)	0 (0%)	12 (100%)	12 (100%)
	Total	64 (6.7%)	156 (16.3%)	735 (77.0%)	57 (6.0%)	898 (94.0%)	955 (100%)
Malawi	Blantyre	0 (0%)	0 (0%)	1 (100%)	0 (0%)	1 (100%)	1 (100%)
	Lilongwe	0 (0%)	0 (0%)	18 (100%)	1 (5.6%)	17 (94.4%)	18 (100%)
	Total	0 (0%)	0 (0%)	19 (100%)	1 (5.3%)	18 (94.7%)	19 (100%)
Rwanda	CHUK	4 (7.1%)	0 (0%)	52 (92.9%)	4 (7.1%)	52 (92.9%)	56 (100%)
	Ruhengeri	2 (10.5%)	1 (5.3%)	16 (84.2%)	2 (10.5%)	17 (89.5%)	19 (100%)
	Total	6 (8.0%)	1 (1.3%)	68 (90.7%)	6 (8.0%)	69 (92.0%)	75 (100%)
Southern Sudan	Juba	0 (0%)	0 (0%)	4 (100%)	0 (0%)	4 (100%)	4 (100%)
	Rumbek	16 (88.9%)	2 (11.1%)	0 (0%)	0 (0%)	18 (100%)	18 (100%)
	Wau	0 (0%)	0 (0%)	48 (100%)	0 (0%)	48 (100%)	48 (100%)
	Total	16 (22.9%)	2 (2.9%)	52 (74.3%)	0 (0%)	70 (100%)	70 (100%)
Uganda	Kagando	14 (13.9%)	11 (10.9%)	76 (75.2%)	9 (8.9%)	92 (91.1%)	101 (100%)
	Mulago	0 (0%)	0 (0%)	3 (100%)	0 (0%)	3 (100%)	3 (100%)
	Total	14 (13.5%)	11 (10.6%)	79 (76.0%)	9 (8.7%)	95 (91.3%)	104 (100%)
Overall		100 (8.2%)	170 (13.9%)	953 (77.9%)	73 (6.0%)	1150 (94.0%)	1223 (100%)

5.2.2: **Childbirth-related Characteristics by Country of Referral**

Table 5.8 shows childbirth-related characteristics of the women by country of referral. Duration of labour was often reported in days, so there were peaks at 24, 48 and 72 hours. Overall, the mean duration of labour was 46.7 hours (median 48 hours) with a mean birth weight of 3.53 kg. Duration of labour varied considerably by country of referral, reflecting local practices. The longest labours were in Southern Sudan (mean 78.9, median 72) and the DR Congo (mean 77.9, median 72), while the shortest were in Malawi (mean 29.6, median 24) and Somalia (mean 32.0, median 24). Birthweight also varied by country, with the highest mean in Somalia (3.87) and the lowest means in the DR Congo (3.20) and Southern Sudan (3.25).

In this sample of women, male babies were far more common than female babies (58.2% v 41.8%), the imbalance being most marked for Southern Sudan (66.2% v 33.8%). More than half of the babies (62.5%) had died, perinatal mortality in this sample being highest for Southern Sudan (81.7%) and Rwanda (71.6%).

Leakage of urine following birth was most common in women referred from Southern Sudan (97.5%), Rwanda (95.9%) and Uganda (94.3%). Obstetric problems are a major cause of fistula in this region. Some women had childbirth injuries with a third (32.4%) having with leg weakness after birth. This percentage ranged from 52.4% for Uganda and 43.7% for Southern Sudan to 24.3% for Rwanda and 18.4% for the DR Congo. Just over half of the women (55.0%) had catheter insertion after birth as a means of prevention and treatment. Catheter insertion was most common in women referred from Rwanda (63.5%) and least common for Malawi and the DR Congo (both 36.8%).

Table 5.9 shows attendance at birth for the women by country of referral. Most women (70.3%) gave birth under the care of a skilled birth attendant: 27.7% were attended by a midwife only, 32.9% were attended by a doctor only and 9.7% were attended by both doctor and midwife. One in five women (19.2%) had a traditional birth attendant during childbirth, 5.9% had only a relative present while 93 (7.6%) women gave birth alone. Midwives were most common at childbirth in women referred from Rwanda (41.9%) and least present for Southern Sudan (29.6%), while traditional birth assistants were most common in the DR Congo (32.4%) and Southern Sudan (35.2%) and least common in Malawi (10.2%), Rwanda (9.5%) and Uganda (12.3%). Skilled attendance at birth was most common among women referred from Uganda (91.1%) and Rwanda (79.7%) and least common for the DR Congo (57.9%) and Southern Sudan (54.9%). Giving birth with no-one in attendance was most common in women referred from Malawi (4/19, 21.1%).

Table 5.8 Childbirth-related characteristics of the women by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Duration of labour	mean [SD]	43.3 [49.3]	29.6 [21.2]	77.9 [53.6]	49.6 [35.4]	32.0 [25.0]	78.9 [47.9]	42.9 [29.2]	46.7 [47.8]
	median {range}	24 {1 to 504}	24 {4 to 72}	72 {5 to 240}	48 {6 to 168}	24 {12 to 60}	72 {3 to 192}	48 {1 to 168}	48 {1 to 504}
Birth weight	mean [SD]	3.57 [0.87]	3.40 [0.69]	3.20 [0.70]	3.31 [0.75]	3.87 [0.23]	3.25 [0.60]	3.65 [1.06]	3.53 [0.87]
Gender of infant	Male	526 (59.3%)	11 (57.9%)	17 (45.9%)	33 (44.6%)	1 (33.3%)	47 (66.2%)	62 (58.5%)	697 (58.2%)
	Female	361 (40.7%)	8 (42.1%)	20 (54.1%)	41 (55.4%)	2 (66.7%)	24 (33.8%)	44 (41.5%)	500 (41.8%)
Infant still alive	Yes	361 (40.5%)	6 (31.6%)	13 (35.1%)	21 (28.4%)	0 (0%)	13 (18.3%)	37 (34.9%)	451 (37.5%)
	No	531 (59.5%)	13 (68.4%)	24 (64.9%)	53 (71.6%)	3 (100%)	58 (81.7%)	69 (65.1%)	751 (62.5%)
Leakage after birth	Yes	807 (88.9%)	17 (89.5%)	33 (86.8%)	71 (95.9%)	3 (100%)	69 (97.2%)	100 (94.3%)	1100 (90.2%)
	No	101 (11.1%)	2 (10.5%)	5 (13.2%)	3 (4.1%)	0 (0%)	2 (2.8%)	6 (5.7%)	119 (9.8%)
Leg weakness after Birth	Yes	275 (30.5%)	6 (31.6%)	7 (18.4%)	18 (24.3%)	1 (33.3%)	31 (43.7%)	55 (52.4%)	393 (32.4%)
	No	627 (69.5%)	13 (68.3%)	31 (81.6%)	56 (75.7%)	2 (66.7%)	40 (56.3%)	50 (47.6%)	819 (67.6%)
Catheter inserted after birth	Yes	504 (55.9%)	7 (36.8%)	14 (36.8%)	47 (63.5%)	1 (33.3%)	30 (42.3%)	63 (59.4%)	666 (55.0%)
	No	397 (44.1%)	12 (63.2%)	24 (63.2%)	27 (36.5%)	2 (66.7%)	41 (57.7%)	43 (40.6%)	546 (45.0%)
Overall		913 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)

Table 5.9 Attendance at birth for the women by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Midwife present at birth	Yes	345 (38.3%)	7 (36.8%)	14 (38.8%)	31 (41.9%)	2 (66.7%)	21 (29.6%)	38 (35.8%)	458 (37.9%)
	No	555 (61.7%)	12 (3.2%)	23 (62.2%)	43 (58.1%)	1 (33.3%)	50 (70.4%)	68 (64.2%)	752 (62.1%)
Doctor present at birth	Yes	389 (43.2%)	5 (26.3%)	12 (32.4%)	36 (48.6%)	0 (0%)	20 (28.2%)	60 (56.6%)	522 (43.1%)
	No	511 (58.6%)	14 (73.7%)	25 (67.6%)	38 (51.4%)	3 (100%)	51 (71.8%)	46 (43.4%)	688 (56.9%)
Relative present at birth	Yes	80 (8.9%)	1 (5.3%)	6 (16.2%)	18 (24.3%)	0 (0%)	6 (8.5%)	9 (8.5%)	120 (9.9%)
	No	820 (91.1%)	18 (94.7%)	31 (83.8%)	56 (75.7%)	3 (100%)	65 (91.5%)	97 (91.5%)	1090 (90.1%)
Traditional birth assistant present at birth	Yes	172 (19.1%)	2 (10.5%)	12 (32.4%)	7 (9.5%)	1 (33.3%)	25 (35.2%)	13 (12.3%)	232 (19.2%)
	No	728 (80.9%)	17 (89.5%)	25 (67.6%)	67 (90.5%)	2 (66.7%)	46 (64.8%)	93 (87.7%)	978 (80.8%)
Skilled attendance at birth	Yes	641 (70.2%)	12 (63.2%)	22 (57.9%)	59 (79.7%)	2 (66.7%)	39 (54.9%)	86 (91.1%)	861 (70.3%)
	No	272 (29.8%)	7 (36.8%)	16 (42.1%)	15 (20.3%)	1 (33.3%)	32 (45.1%)	20 (18.9%)	363 (29.7%)
Skilled attendant at birth	Midwife & doctor	93 (10.2%)	0 (0%)	4 (10.5%)	8 (10.8%)	0 (0%)	2 (2.8%)	12 (11.3%)	119 (9.7%)
	Midwife only	252 (27.6%)	7 (36.8%)	10 (26.3%)	23 (31.1%)	2 (66.7%)	19 (26.8%)	26 (24.5%)	339 (27.7%)
	Doctor only	296 (32.4%)	5 (26.3%)	8 (21.1%)	28 (37.8%)	0 (0%)	18 (25.4%)	48 (45.3%)	403 (32.9%)
	Neither	272 (29.8%)	7 (36.8%)	16 (42.1%)	15 (20.3%)	1 (33.3%)	32 (45.1%)	20 (18.9%)	363 (29.7%)
Only relative present at birth	Yes	53 (5.8%)	1 (5.3%)	3 (7.9%)	6 (8.1%)	0 (0%)	5 (7.0%)	4 (3.8%)	72 (5.9%)
	No	860 (94.2%)	18 (94.7%)	35 (92.1%)	68 (91.9%)	3 (100%)	66 (93.0%)	102 (96.2%)	1152 (94.1%)
No-one present at birth	Yes	74 (8.1%)	4 (21.1%)	0 (0%)	4 (5.4%)	0 (0%)	3 (4.2%)	8 (7.5%)	93 (7.6%)
	No	839 (91.9%)	15 (78.9%)	38 (100%)	70 (94.6%)	3 (100%)	68 (95.8%)	98 (92.5%)	1131 (92.4%)
Overall		913 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)

5.2.3: Fistula-related Characteristics by Country of Referral

Table 5.10 shows fistula-related details and symptoms of the women by country of referral. The mean haemoglobin level among this cohort was 12.4 g/dl, which is good for post-operative healing. The highest mean level was found among women from Rwanda (13.3) while the lowest levels were in Southern Sudan (11.3), Malawi (11.8) and DR Congo (11.9). The most common parity for the women was 1+0 (44.6%), the highest being referred from DR Congo (50.0%)

followed closely by Kenya (45.9%). This confirmed that for many women fistula occurred during the first birth.

The majority of the women (80.7%) presented with a urine problem and 60.1% could not pass urine normally. These percentages also varied by country: the percentage presenting with urine problems ranged from 90.5% for Rwanda to 78.8% for Kenya, while the percentage who could not pass urine normally ranged from 77.5% for Southern Sudan to 52.6% for Malawi. Faecal leakage, which is a less debilitating condition, was present in 25.2% of the women, ranging from 34.2% for the DR Congo to 13.5% for Rwanda. Over 90% (90.2%) of women presented with leakage of urine following birth with more than 1/3 (36.4%) having leaked urine for up to 12 months and more than a quarter (26.1%) for more than 9 years.

Table 5.11 shows fistula-related characteristics of the women by country of referral. The mean fistula size was 2.15 cm in diameter with most fistulas 1-2 cm from the external urethral orifice (EUO) or urethral meatus. The mean size was larger in women referred from the DR Congo; the fistula position among women from that country was more likely to be 1-2 cm from the EUO compared with other countries (73.0% v overall percentage of 59.9%). Few women (77, 6.3%) presented with multiple fistula (more than 1 fistula). A quarter of the women (27.5%) had undergone a previous attempt at fistula repair at the time of joining the study: 25.6% had a previous vaginal repair while 4.0% had a previous rectal repair. Repairs were more common in women from Rwanda (45.9%) or Uganda (43.4%). Vaginal stenosis/scarring was very common (72.4%) while vulvar excoriation was mostly mild (61.2%) or moderate (35.4%).

Table 5.12 shows fistula classification by country of referral. The most common vaginal fistula classifications occurring were VVF 11Aa (25.1%) followed by VVF1 (20.6%). The most commonly occurring recto-vaginal fistula classification was RVF11b (11.0%). There were few combined fistulas (VVF/RVF) (3.0%). The pattern of classification was similar for women referred from different countries, although there were more women from the DR Congo (23.7%) and Southern Sudan (23.9%) with VVF IIAb fistulas than average (12.5%) and more women from Uganda with VVF III fistulas than average (12.3% v 6.3%).

Table 5.10 Fistula-related details of the women by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Haemoglobin	mean [SD]	12.4 [1.9]	11.8 [1.3]	11.9 [1.8]	13.3 [1.8]	12.1 [1.9]	11.3 [1.7]	12.5 [1.6]	12.4 [1.9]
Parity when fistula developed	0	8 (0.9%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (1.0%)	9 (0.8%)
	1	410 (45.9%)	6 (31.6%)	19 (50.0%)	32 (45.7%)	0 (0%)	28 (45.2%)	34 (34.0%)	529 (44.6%)
	2	160 (17.9%)	3 (15.8%)	7 (18.4%)	9 (12.9%)	0 (0%)	14 (22.6%)	20 (20.0%)	213 (18.0%)
	3	127 (14.2%)	3 (15.8%)	1 (2.6%)	13 (18.6%)	1 (33.3%)	2 (3.2%)	12 (12.0%)	159 (13.4%)
	4	74 (8.3%)	3 (15.8%)	0 (0%)	3 (4.3%)	0 (0%)	6 (9.7%)	9 (9.0%)	95 (8.0%)
	5 or more	114 (12.8%)	4 (21.1%)	11 (28.9%)	13 (18.6%)	2 (66.7%)	12 (19.4%)	24 (24.0%)	180 (15.2%)
Problem with urine	Yes	719 (78.8%)	16 (83.2%)	31 (81.6%)	67 (90.5%)	2 (66.7%)	61 (85.9%)	91 (85.8%)	987 (80.7%)
	No	193 (21.2%)	3 (15.8%)	7 (18.4%)	7 (9.5%)	1 (33.3%)	10 (14.1%)	15 (14.2%)	236 (19.3%)
Problem with faeces	Yes	235 (25.7%)	3 (15.8%)	13 (34.2%)	10 (13.5%)	1 (33.3%)	18 (25.4%)	28 (26.4%)	308 (25.2%)
	No	678 (74.3%)	16 (84.2%)	25 (65.8%)	64 (86.5%)	2 (66.7%)	53 (74.6%)	78 (73.6%)	916 (74.8%)
Pass urine normally	Yes	381 (41.7%)	10 (52.6%)	18 (47.4%)	22 (29.7%)	1 (33.3%)	16 (22.5%)	40 (37.7%)	488 (39.9%)
	No	532 (58.3%)	9 (47.4%)	20 (52.6%)	52 (70.3%)	2 (66.7%)	55 (77.5%)	66 (62.3%)	736 (60.1%)
Duration of leakage	Up to 12 months	354 (39.0%)	5 (26.3%)	15 (39.5%)	11 (14.9%)	3 (100%)	20 (28.2%)	34 (33.7%)	442 (36.4%)
	13-60 months	194 (21.4%)	4 (21.1%)	17 (44.7%)	20 (27.0%)	0 (0%)	26 (37.1%)	22 (21.8%)	283 (23.3%)
	61-108 months	122 (13.5%)	6 (31.6%)	3 (7.9%)	13 (17.6%)	0 (0%)	12 (17.1%)	15 (14.9%)	171 (14.1%)
	Over 108 months	237 (26.1%)	4 (21.1%)	3 (7.9%)	30 (40.5%)	0 (0%)	13 (18.3%)	30 (29.7%)	317 (26.1%)
Overall		913 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)

Table 5.11 Fistula-related characteristics of participants by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Fistula size	mean	2.13	2.34	2.45	2.12	2.67	2.26	2.07	2.15
	[SD]	[1.35]	[1.31]	[1.29]	[1.09]	[1.02]	[1.37]	[1.200]	[1.32]
Fistula position from EUO	< 1 cm	113 (13.1%)	0 (0%)	2 (5.4%)	5 (6.9%)	0 (0%)	7 (9.9%)	13 (12.5%)	140 (12.0%)
	1-2 cm	511 (59.2%)	12 (63.2%)	27 (73.0%)	45 (62.5%)	3 (100%)	44 (62.0%)	58 (55.8%)	700 (59.9%)
	2.1-3 cm	137 (15.9%)	5 (26.3%)	6 (16.2%)	17 (23.6%)	0 (0%)	13 (18.3%)	18 (17.3%)	196 (16.8%)
	> 3 cm	102 (11.8%)	2 (10.5%)	2 (5.4%)	5 (6.9%)	0 (0%)	7 (9.9%)	15 (14.4%)	133 (11.4%)
Multiple fistula	Yes	58 (6.4%)	1 (5.3%)	1 (2.6%)	5 (6.8%)	0 (0%)	6 (8.5%)	7 (5.7%)	77 (6.3%)
	No	847 (93.6%)	18 (94.7%)	37 (97.4%)	69 (93.2%)	3 (100%)	65 (91.5%)	100 (94.2%)	1139 (93.1%)
Location of multiple fistula	None	847 (93.6%)	18 (94.7%)	37 (97.4%)	69 (93.2%)	3 (100%)	65 (91.5%)	100 (94.2%)	1139 (93.1%)
	Vaginal only	27 (3.0%)	1 (5.3%)	1 (2.6%)	5 (6.8%)	0 (0%)	4 (5.6%)	3 (2.8%)	41 (3.4%)
	Vaginal & rectal	31 (3.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (2.8%)	3 (2.8%)	36 (3.0%)
Previous repair (vaginal)	Yes	203 (22.2%)	6 (31.6%)	9 (23.7%)	34 (45.9%)	1 (33.3%)	16 (22.5%)	44 (41.5%)	313 (25.6%)
	No	710 (77.8%)	13 (68.4%)	29 (76.3%)	40 (54.1%)	2 (66.7%)	55 (77.5%)	62 (58.5%)	911 (74.4%)
Previous repair (rectal)	Yes	43 (4.7%)	0 (0%)	0 (0%)	1 (1.4%)	0 (0%)	1 (1.4%)	4 (3.8%)	49 (4.0%)
	No	870 (95.3%)	19 (100%)	38 (100%)	73 (98.6%)	3 (100%)	70 (98.6%)	102 (96.2%)	1175 (96.0%)
Previous repair (either vaginal or rectal)	Yes	224 (24.5%)	6 (31.6%)	9 (23.7%)	34 (45.9%)	1 (33.3%)	16 (22.5%)	46 (43.4%)	336 (27.5%)
	No	689 (75.5%)	13 (68.4%)	29 (76.3%)	40 (54.1%)	2 (66.7%)	55 (77.5%)	60 (56.6%)	888 (72.5%)
Vaginal stenosis	Yes	642 (70.5%)	17 (89.5%)	23 (60.5%)	46 (62.2%)	2 (66.7%)	67 (94.4%)	88 (83.0%)	885 (72.4%)
	No	269 (29.5%)	2 (10.5%)	15 (39.5%)	28 (37.8%)	1 (33.3%)	4 (5.6%)	18 (17.0%)	337 (27.6%)
Severity of excoriation	Mild	577 (63.3%)	8 (42.1%)	27 (71.1%)	37 (50.0%)	3 (100%)	34 (47.9%)	62 (58.5%)	748 (61.2%)
	Moderate	299 (32.8%)	11 (57.9%)	11 (28.9%)	37 (50.0%)	0 (0%)	34 (47.9%)	41 (38.7%)	433 (35.4%)
	Severe	35 (3.8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	3 (4.2%)	3 (2.8%)	41 (3.4%)
Overall		913 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1224 (100%)

EUO=external urethral orifice

Table 5.12 Fistula classification by country

Classification	Kenya	Malawi	DR Congo	Rwanda	Somalia	South Sudan	Uganda	Total
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
VVF I	193 (21.3%)	4 (21.1%)	9 (23.7%)	13 (17.6%)	0 (0%)	10 (14.1%)	22 (20.8%)	251 (20.6%)
VVF II Aa	228 (25.2%)	5 (26.3%)	10 (26.3%)	24 (32.4%)	0 (0%)	12 (16.9%)	26 (24.5%)	305 (25.1%)
VVF II Ab	102 (11.3%)	2 (10.5%)	9 (23.7%)	14 (18.9%)	0 (0%)	17 (23.9%)	8 (7.5%)	152 (12.5%)
VVF II Ba	57 (6.3%)	2 (10.5%)	1 (2.6%)	2 (2.7%)	1 (33.3%)	6 (8.5%)	10 (9.4%)	79 (6.5%)
VVF II Bb	38 (4.2%)	2 (10.5%)	1 (2.6%)	3 (4.1%)	1 (33.3%)	2 (2.8%)	3 (2.8%)	50 (4.1%)
VVF III	57 (6.3%)	0 (0%)	1 (2.6%)	2 (2.7%)	0 (0%)	3 (4.2%)	13 (12.3%)	76 (6.3%)
Combined VVF and RVF	31 (3.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (2.8%)	3 (2.8%)	36 (3.0%)
RVF Ia	8 (0.9%)	0 (0%)	1 (2.6%)	0 (0%)	0 (0%)	0 (0%)	3 (2.8%)	12 (1.0%)
RVF Ib	23 (2.5%)	0 (0%)	2 (5.2%)	3 (4.1%)	0 (0%)	1 (1.4%)	1 (0.9%)	30 (2.5%)
RVF 1c	13 (1.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2 (2.8%)	1 (0.9%)	16 (1.3%)
RVF IIa	53 (5.9%)	1 (5.3%)	1 (2.6%)	6 (8.1%)	1 (33.3%)	4 (5.6%)	5 (4.7%)	71 (5.8%)
RVF IIb	98 (10.8%)	3 (15.8%)	3 (7.9%)	7 (9.5%)	0 (0%)	12 (16.9%)	11 (10.4%)	134 (11.0%)
RVF III	4 (0.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	4 (0.3%)
Total	905 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	106 (100%)	1216 (100%)

5.2.4: Outcome Variables

The two outcome variables for this study were duration of leakage and successfulness of surgery. Figure 5.1 shows the way in which duration of leakage was recorded in intervals of months and the numbers of women reporting duration in each interval. Each of the first nine intervals covered 12 months while the tenth interval was for any duration larger than 108 months.

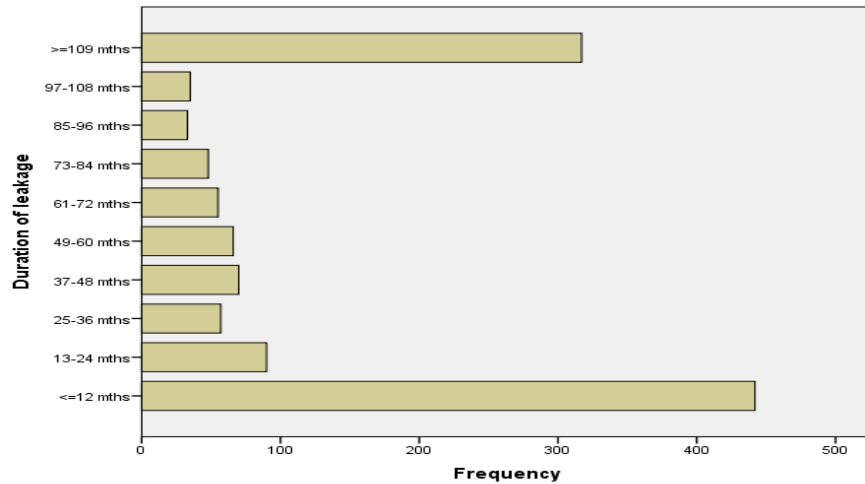


Figure 5.1 Bar chart of duration of leakage (n=1213)

There were two clear peaks at ≤ 12 months and ≥ 109 months with a gradual increase in frequency between the peaks. Out of the 1213 women who reported a duration, 442 (36.4%) had experienced up to 12 months of leakage before surgery, while 317 (26.1%) had experienced leakage for over 108 months. This indicated that duration of leakage could not be treated as a continuous variable with an approximately normal distribution for statistical analysis. For analysis, duration of leakage was grouped into four intervals: up to 12 months, 13-60 months, 61-108 months and over 108 months, as shown in Figure 5.2.

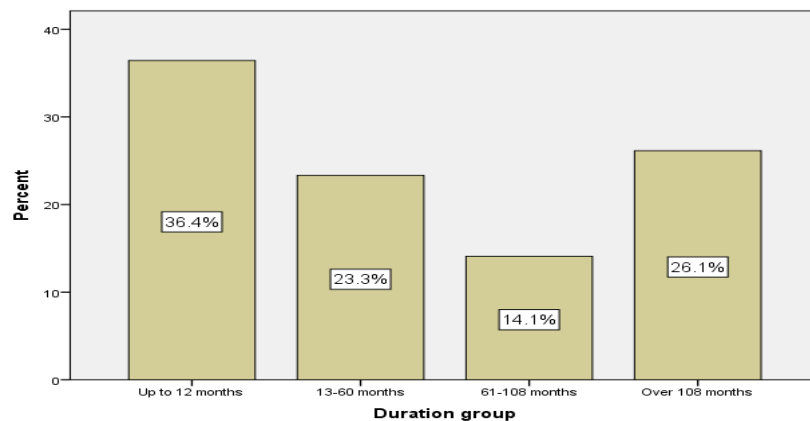


Figure 5.2 Bar chart of duration of leakage group (n=1213)

Successfulness of surgery was recorded for 1199 women, of whom 1128 (94.1%) had a successful surgery with 71 (5.9%) having an unsuccessful surgery (Figure 5.3). The low failure rate also had

implications for statistical analysis as the approach used for modelling factors predictive of a successful surgery, binary logistic regression, has a sample size requirement based on the number of participants in each outcome category (see Section 5.3 of Chapter five).

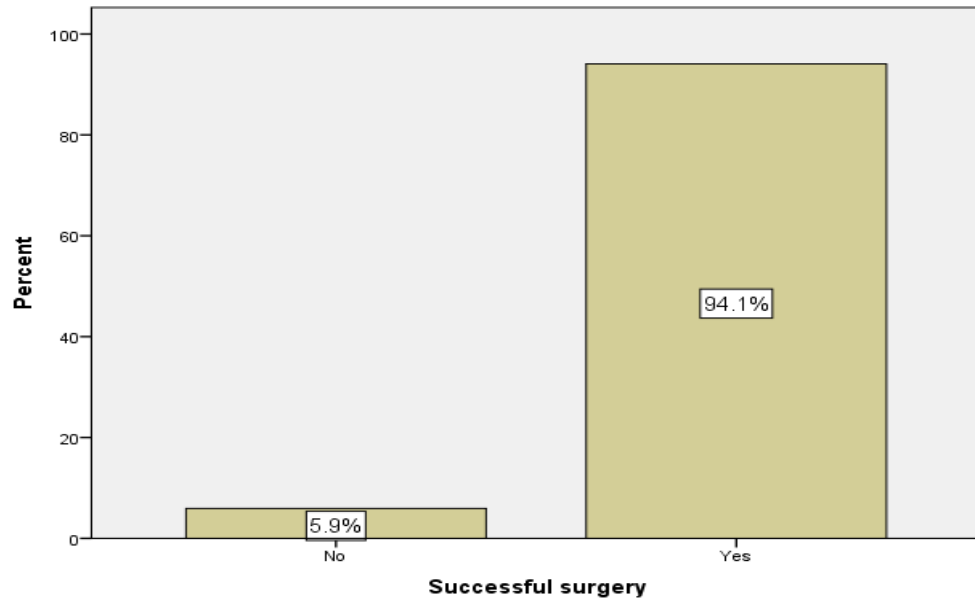


Figure 5.3 Bar chart of successfulness of surgery (n=1199)

Table 5.13 gives a breakdown of duration of leakage of urine (in months and grouped) and successfulness of surgery by country of referral. Duration of leakage varied from country to country. Apart from the three Somalis who all had a leakage lasting 12 months or less, the highest percentage within a country who had presented within one year was for women referred from Kenya (39.0%) and the DR Congo (39.5%); the lowest was for Rwanda (14.9%). The percentage of women whose leakage had lasted more than 108 months varied from 7.9% for the DR Congo to 40.5% for Rwanda. The successfulness of surgery also varied by country of referral. Apart from the three women referred from Somalia all of whom had a successful operation, the highest success rates were for Kenya (96.5%) and Uganda (93.2%), with lower than average success rates for Malawi (77.8%), the DR Congo (81.1%), Southern Sudan (84.3%) and Rwanda (84.9%).

Table 5.13 Duration of leakage and successfulness of surgery by country

Characteristic		Kenya	Malawi	DR Congo	Rwanda	Somalia	Southern Sudan	Uganda	Total
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Duration of leakage (months)	≤ 12	354 (39.0%)	5 (26.3%)	15 (39.5%)	11 (14.9%)	3 (100%)	20 (28.2%)	34 (33.7%)	442 (36.4%)
	13-24	56 (6.2%)	2 (10.5%)	7 (18.4%)	11 (14.9%)	0 (0%)	5 (7.0%)	9 (8.9%)	90 (7.4%)
	25-36	40 (4.4%)	0 (0%)	2 (5.3%)	2 (2.7%)	0 (0%)	9 (12.7%)	4 (4.0%)	57 (4.7%)
	37-48	53 (5.8%)	1 (5.3%)	1 (2.6%)	4 (5.4%)	0 (0%)	6 (8.5%)	5 (5.0%)	70 (5.8%)
	49-60	45 (5.0%)	1 (5.3%)	7 (18.4%)	3 (4.1%)	0 (0%)	6 (8.5%)	4 (4.0%)	66 (5.4%)
	61-72	42 (4.6%)	0 (0%)	1 (2.6%)	3 (4.1%)	0 (0%)	4 (5.6%)	5 (5.0%)	55 (4.5%)
	73-84	35 (3.9%)	1 (5.3%)	1 (2.6%)	5 (6.8%)	0 (0%)	3 (4.2%)	3 (3.0%)	48 (4.0%)
	85-96	22 (2.4%)	3 (15.8%)	1 (2.6%)	1 (1.4%)	0 (0%)	4 (5.6%)	2 (2.0%)	33 (2.7%)
	97-108	23 (2.5%)	2 (10.5%)	0 (0%)	4 (5.4%)	0 (0%)	1 (1.4%)	5 (5.0%)	35 (2.9%)
	≥ 109	237 (26.1%)	4 (21.1%)	3 (7.9%)	30 (40.5%)	0 (0%)	13 (18.3%)	30 (29.7%)	317 (26.1%)
Duration of leakage (grouped)	Up to 12 months	354 (39.0%)	5 (26.3%)	15 (39.5%)	11 (14.9%)	3 (100%)	20 (28.2%)	34 (33.7%)	442 (36.4%)
	13-60 months	194 (21.4%)	4 (21.1%)	17 (44.7%)	20 (27.0%)	0 (0%)	26 (21.8%)	22 (21.8%)	283 (23.3%)
	61-108 months	122 (13.5%)	6 (31.6%)	3 (7.9%)	13 (17.6%)	0 (0%)	12 (16.9%)	15 (14.9%)	171 (14.1%)
	Over 108 months	237 (26.1%)	4 (21.1%)	3 (7.9%)	30 (40.5%)	0 (0%)	13 (18.3%)	30 (29.7%)	317 (26.1%)
	Total	907 (100%)	19 (100%)	38 (100%)	74 (100%)	3 (100%)	71 (100%)	101 (100%)	1213 (100%)
Successfulness of surgery	No	31 (3.5%)	4 (22.2%)	7 (18.9%)	11 (15.1%)	0 (0%)	11 (15.7%)	7 (6.8%)	71 (5.9%)
	Yes	864 (96.5%)	14 (77.8%)	30 (81.1%)	6 (84.9%)	3 (100%)	59 (84.3%)	96 (93.2%)	1128 (94.1%)
	Total	895 (100%)	18 (100%)	37 (100%)	73 (100%)	3 (100%)	70 (100%)	103 (100%)	1199 (100%)

Across all 1224 women, 268 (21.9%) reported that the husband left because of the fistula. Tables 5.14 and 5.15 summarise the relationship between duration of leakage and whether the husband left because of the fistula where duration was known. The percentage of husbands leaving generally increased as duration of leakage increased. For women whose leakage had lasted up to a year, 14.7% of husbands had left while for those whose leakage had lasted over 9 years, 26.8% of husbands had left. The percentage leaving peaked in the fifth year after the fistula had developed, suggesting that husbands may have been giving up hope of the fistula healing.

Table 5.14 Duration of leakage in months by whether the husband left because of fistula

Duration of leakage in months	Whether husband left because of fistula		
	Yes	No	Total
	N (%)	N (%)	N (%)
≤ 12	65 (14.7%)	377 (85.3%)	442 (100%)
13-24	19 (21.1%)	71 (78.9%)	90 (100%)
25-36	13 (22.8%)	44 (77.2%)	57 (100%)
37-48	16 (22.9%)	54 (77.1%)	70 (100%)
49-60	24 (36.4%)	42 (63.6%)	66 (100%)
61-72	15 (27.3%)	40 (72.7%)	55 (100%)
73-84	13 (27.1%)	35 (72.9%)	48 (100%)
85-96	9 (27.3%)	24 (72.7%)	33 (100%)
97-108	6 (17.1%)	29 (82.9%)	35 (100%)
≥ 109	85 (26.8%)	232 (73.2%)	317 (100%)
Total	265 (21.8%)	948 (78.2%)	1213 (100%)

Table 5.15 Duration of leakage (grouped) by whether the husband left because of fistula

Duration of leakage (grouped)	Whether husband left because of fistula		
	Yes	No	Total
	N (%)	N (%)	N (%)
Up to 1 year	65 (14.7%)	377 (85.3%)	442 (100%)
2-5 years	72 (25.4%)	211 (74.6%)	283 (100%)
6-9 years	43 (25.1%)	128 (74.9%)	171 (100%)
10 or more years	85 (26.8%)	232 (73.2%)	317 (100%)
Total	265 (21.8%)	948 (78.2%)	1213 (100%)

5.3: Bivariate Associations with Successfulness of Surgery

This section presents the results of analyses of relationships between successfulness of surgery and individual sociodemographic or clinical variables. These analyses do not take into account any concurrent relationships with other variables.

5.3.1: Sociodemographic Characteristics by Successfulness of Surgery

Table 5.16 shows the association between successfulness of surgery and centre of referral. The centres are grouped by country but the analysis is across all centres. The success rate was lower at three centres: Rumbek (76.5%), CHUK (82.1%) and Wau (85.4%). However, the difference between the 15 centres was not statistically significant ($p=0.702$), possibly due to the large number of centres some of which had small numbers of women. There were no significant differences between centres within the same country.

Table 5.16 Centre of referral by successfulness of surgery

Country of centre	Centre	Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Kenya	Coast General	2 (2.2%)	89 (97.8%)	91 (100%)	Fisher's exact	0.702
	Garissa	1 (7.7%)	12 (92.3%)	13 (100%)		
	Kisii	5 (3.0%)	162 (97.0%)	167 (100%)		
	Kenyatta NH	26 (4.7%)	528 (95.3%)	554 (100%)		
	New Nyanza	4 (4.0%)	97 (96.0%)	101 (100%)		
	Webuye	0 (0%)	11 (100%)	11 (100%)		
Malawi	Blantyre	0 (0%)	1 (100%)	1 (100%)		
	Lilongwe	4 (4.0%)	13 (77.8%)	14 (100%)		
Rwanda	CHUK	10 (17.9%)	46 (82.1%)	56 (100%)		
	Ruhengeri	1 (5.6%)	17 (94.4%)	18 (100%)		
Southern Sudan	Juba	0 (0%)	4 (100%)	4 (100%)		
	Rumbek	4 (23.5%)	13 (76.5%)	17 (100%)		
	Wau	7 (14.6%)	41 (85.4%)	48 (100%)		
Uganda	Kagando	7 (7.1%)	91 (92.9%)	98 (100%)		
	Mulago	0 (0%)	3 (100%)	3 (100%)		
Total		71 (5.9%)	1128 (94.1%)	1199 (100%)		

Comparisons of centres within country of referral: Kenya – Fisher's exact $p=0.956$; Rwanda – Fisher's exact $p=0.524$; Southern Sudan – Fisher's exact $p=0.589$; Uganda – Fisher's exact $p>0.999$

Table 5.17 shows the association between successfulness of surgery and country of referral. The success rate was highest for Kenya (96.5%) and low for Malawi (77.8%), the DR Congo (81.1%), Southern Sudan (84.3%) and Rwanda (84.9%). The association with country of referral was statistically significant ($p < 0.001$), indicating very strong evidence of a difference between the countries. This might be expected, given that there are differences between countries in the level of fistula care that can be provided.

Table 5.17 Country of referral by successfulness of surgery

Country	Unsuccessful	Successful	Total	Test results	P
	N (%)	N (%)	N (%)		
Kenya	31 (3.5%)	864 (96.5%)	895 (100%)	Fisher's exact	<0.001
Malawi	4 (22.2%)	14 (77.8%)	18 (100%)		
DR Congo	7 (18.9%)	30 (81.1%)	37 (100%)		
Rwanda	11 (15.1%)	62 (84.9%)	73 (100%)		
Somalia	0 (0%)	3 (100%)	3 (100%)		
Southern Sudan	11 (15.7%)	59 (84.3%)	70 (100%)		
Uganda	7 (6.8%)	96 (93.2%)	103 (100%)		
Total	71 (5.9%)	1128 (94.1%)	1199 (100%)		

Table 5.18 shows the association between successfulness of surgery and a number of demographic variables. Successfulness was not associated with age group, height, weight, marital status and religion but there was a near significant association with number of children currently alive when the order present in this variable was ignored ($p = 0.060$). This was due to an increase in the success rate for 2 children (97.9%) and a decrease in the success rate for 3 children (90.5%) currently alive compared with the overall success rate of 94.1%.

Table 5.18 Demographic characteristics of the women by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Age group	<= 17	4 (10.3%)	35 (89.7%)	39 (100%)	$\chi^2_{\text{trend}}=0.65$, df=1 $\chi^2=5.58$, df=6	0.420 0.472
	18-27	29 (6.5%)	418 (93.5%)	447 (100%)		
	28-37	22 (5.3%)	392 (94.7%)	414 (100%)		
	38-47	10 (6.2%)	151 (93.8%)	161 (100%)		
	48-57	2 (2.4%)	82 (97.6%)	84 (100%)		
	58-67	2 (5.0%)	38 (95.0%)	40 (100%)		
	>=68	2 (14.3%)	12 (85.7%)	14 (100%)		
Height (cm)	mean [SD]	153.1 [8.9]	154.5 [7.7]	154.4 [5.8]	t=-1.50, df=1188	0.135
Weight (kg)	mean [SD]	55.1 [9.3]	56.0 [10.0]	56.0 [10.0]	t=-0.75, df=1188	0.453
Marital status	Single	10 (4.0%)	237 (96.0%)	247 (100%)	Fisher's exact	0.533
	Married	46 (6.3%)	685 (93.7%)	731 (100%)		
	Separated	4 (5.1%)	75 (94.9%)	79 (100%)		
	Divorced	5 (6.9%)	67 (93.1%)	72 (100%)		
	Widowed	6 (8.6%)	64 (91.4%)	70 (100%)		
Religion	Christian	68 (6.0%)	1064 (94.0%)	1132 (100%)	Fisher's exact	0.793
	Muslim	3 (4.5%)	64 (95.5%)	67 (100%)		
Number of children currently alive	0	30 (7.2%)	387 (92.8%)	417 (100%)	$\chi^2_{\text{trend}}=1.35$, df=1 $\chi^2=10.59$, df=5	0.245 0.060
	1	14 (6.0%)	218 (94.0%)	232 (100%)		
	2	4 (2.1%)	187 (97.9%)	181 (100%)		
	3	12 (9.5%)	114 (90.5%)	126 (100%)		
	4	5 (5.9%)	80 (94.1%)	85 (100%)		
	5 or more	5 (3.6%)	134 (96.4%)	139 (100%)		
Overall		71 (5.9%)	1128 (94.1%)	1199 (100%)		

Table 5.19 shows the association between successfulness of surgery and the education level of the women and their spouses. Neither variable showed a significant association.

Table 5.19 Education of the women and their spouses by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Woman's education	None	15 (7.4%)	188 (92.6%)	203 (100%)	$\chi^2_{\text{trend}}=1.05,$ df=1 $\chi^2=5.00,$ df=4	0.306 0.287
	Primary	46 (6.1%)	707 (93.9%)	753 (100%)		
	Secondary	6 (3.2%)	179 (96.8%)	185 (100%)		
	College	3 (5.7%)	50 (94.3%)	53 (100%)		
	University	1 (20.0%)	4 (80.0%)	5 (100%)		
	Total	71 (5.9%)	1128 (94.1%)	1199 (100%)		
Spouse's education	None	20 (7.3%)	253 (92.7%)	273 (100%)	$\chi^2_{\text{trend}}=1.94,$ df=1 Fisher's exact	0.164 0.205
	Primary	31 (5.7%)	511 (94.3%)	542 (100%)		
	Secondary	18 (6.2%)	274 (93.8%)	292 (100%)		
	College	0 (0%)	59 (100%)	59 (100%)		
	University	1 (6.3%)	15 (93.8%)	16 (100%)		
	Total	70 (5.9%)	1112 (94.1%)	1182 (100%)		

Table 5.20 shows the association between successfulness of surgery and the employment status and occupation of the women and their spouses. The employment status of the women was significantly associated with successfulness of surgery ($p=0.004$): there was strong evidence that women who were unemployed were more likely have an unsuccessful outcome than those who were employed; although the observed difference was only 4.0%, the failure rate for unemployed women (8.3%) was almost double that for employed women (4.3%). A woman's ability to be employed may be limited by the severity of her fistula-related symptoms. The woman's occupation and her spouse's employment status and occupation were not significantly associated with successfulness of surgery.

Table 5.20 Employment status and occupation of the women and their spouses by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Woman unemployed	Yes	40 (8.3%)	440 (91.7%)	480 (100%)	$\chi^2=8.36$, df=1	0.004
	No	31 (4.3%)	688 (95.7%)	719 (100%)		
Woman occupation	Business person	8 (4.8%)	157 (95.2%)	165 (100%)	Fisher's exact	0.193
	Casual labourer	1 (3.0%)	32 (97.0%)	33 (100%)		
	Employed (general work)	2 (2.0%)	98 (98.0%)	100 (100%)		
	Housewife	32 (8.5%)	343 (91.5%)	375 (100%)		
	Pastoralist	0 (0%)	2 (100%)	2 (100%)		
	Peasant farmer	20 (4.8%)	399 (95.2%)	419 (100%)		
	Retired	0 (0%)	1 (100%)	1 (100%)		
	Student	3 (8.8%)	31 (91.2%)	34 (100%)		
	No occupation	5 (7.1%)	65 (92.9%)	70 (100%)		
	Total	71 (5.9%)	1128 (94.1%)	1199 (100%)		
Spouse unemployed	Yes	13 (8.0%)	149 (92.0%)	162 (100%)	$\chi^2=1.47$, df=1	0.225
	No	58 (5.6%)	977 (94.4%)	1035 (100%)		
Spouse occupation	Business person	5 (2.9%)	167 (97.1%)	172 (100%)	Fisher's exact	0.437
	Casual labourer	7 (6.1%)	108 (93.9%)	115 (100%)		
	Employed (general work)	7 (4.3%)	157 (95.7%)	164 (100%)		
	Musician	0 (0%)	1 (100%)	1 (100%)		
	Pastoralist	3 (8.1%)	34 (91.9%)	37 (100%)		
	Peasant farmer	36 (6.6%)	510 (93.4%)	546 (100%)		
	Retired	0 (0%)	5 (100%)	5 (100%)		
	Student	1 (6.3%)	15 (93.8%)	16 (100%)		
	No occupation	12 (8.5%)	129 (91.5%)	141 (100%)		
Overall		71 (5.9%)	1126 (94.1%)	1197 (100%)		

Table 5.21 shows the association between successfulness of surgery and a number of variables indicating the impact of fistula on the women. There were no significant associations with whether the husband had left because of the fistula, the persons the woman currently lived with or how she found out about the fistula camp.

Table 5.21 Impact of fistula on the women by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Whether husband left	Yes	14 (5.3%)	249 (94.7%)	263 (100%)	$\chi^2=0.22$, df=1	0.642
	No	57 (6.1%)	879 (93.9%)	936 (100%)		
Who do you live with now?	Self	8 (5.5%)	137 (94.5%)	145 (100%)	Fisher's exact	0.879
	Spouse	41 (6.4%)	597 (93.6%)	638 (100%)		
	Parents	12 (5.8%)	196 (94.2%)	208 (100%)		
	Siblings	7 (6.6%)	99 (93.4%)	106 (100%)		
	Relatives/ friends	2 (2.5%)	77 (97.5%)	79 (100%)		
	Employer/ neighbour	1 (6.3%)	15 (93.8%)	16 (100%)		
	Own children	0 (0%)	6 (100%)	6 (100%)		
How did you first know of the camp?	Radio	32 (5.4%)	557 (94.6%)	589 (100%)	Fisher's exact	0.427
	TV	1 (6.7%)	14 (93.3%)	15 (100%)		
	Referral from hospital	33 (6.9%)	447 (93.1%)	40 (100%)		
	Parents/ siblings	1 (1.9%)	53 (98.1%)	54 (100%)		
	Friends/ relatives/ neighbours	1 (2.9%)	33 (97.1%)	34 (100%)		
	Other fistula patient	3 (11.1%)	24 (88.9%)	27 (100%)		
	Overall		71 (5.9%)	1128 (94.1%)		

Table 5.22 shows the association between successfulness of surgery and the woman's health status. Women who were menstruating regularly were slightly more likely to have an unsuccessful surgery, but the association was not significant. Although women with a poor general condition and those who were HIV positive were slightly more likely to have unsuccessful surgery, neither variable showed a statistically significant association.

Table 5.22 Health status of the women by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Menstruating regularly	Yes	38 (6.2%)	575 (93.8%)	613 (100%)	$\chi^2=0.36$, df=1	0.547
	No	31 (5.4%)	545 (94.6%)	576 (100%)		
General condition	Poor	7 (7.0%)	93 (93.0%)	100 (100%)	$\chi^2_{trend}=0.01$, df=1	0.909
	Fair	7 (4.3%)	157 (95.7%)	164 (100%)		
	Good	57 (6.1%)	877 (93.9%)	934 (100%)		
HIV status	Positive	6 (8.7%)	63 (91.3%)	69 (100%)	$\chi^2=1.01$, df=1	0.316
	Negative	65 (5.8%)	1064 (94.2%)	1129 (100%)		
Overall		71 (5.9%)	1128 (94.1%)	1199 (100%)		

5.3.2: Childbirth-related Characteristics by Successfulness of Surgery

Table 5.23 shows the association between successfulness of surgery and a number of childbirth-related characteristics of the women, while Table 5.24 shows the association with attendance at birth. None of duration of labour, birthweight, gender of infant, leakage after birth, leg weakness after birth, catheter insertion after birth, having a midwife or doctor present at the birth alone or in combination, having a traditional birth assistant at birth or giving birth alone were significantly associated with successfulness of surgery. Two variables showed a near significant association: whether the infant was still alive ($p=0.064$) and having only a relative present at birth ($p=0.067$). There was weak evidence that the success rate was lower when the infant had died and when only a relative was present at birth. Having a relative at birth (possibly in combination with others) was the only variable showing a significant association ($p=0.014$): when a relative present, the failure rate doubled from 5.3% to 10.9%. Having a relative present at childbirth may indicate that there were problems during the labour, with the woman herself unable to make decisions or access appropriate facilities.

Table 5.23 Childbirth-related characteristics of the women by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Duration of labour (hours)	mean [SD]	50.8 [47.6]	46.4 [48.0]	46.7 [47.8]	M-W U=30185.5	0.695
	median {range}	30 {2 to 168}	48 {1 to 504}	48 {1 to 504}		
Birthweight (kg)	mean [SD]	3.45 [0.77]	3.53 [0.85]	3.53 [0.87]	t=-0.67, df=1093	0.503
Gender of infant	Male	38 (5.6%)	643 (94.4%)	681 (100%)	$\chi^2=0.45$, df=1	0.504
	Female	32 (6.5%)	459 (93.5%)	491 (100%)		
Infant still alive	Yes	19 (4.3%)	423 (95.7%)	442 (100%)	$\chi^2=3.44$, df=1	0.064
	No	51 (6.9%)	684 (93.1%)	735 (100%)		
Leakage after birth	Yes	63 (5.8%)	1014 (94.2%)	1077 (100%)	$\chi^2=0.18$, df=1	0.668
	No	8 (6.8%)	109 (93.2%)	117 (100%)		
Leg weakness after birth	Yes	28 (7.3%)	356 (92.7%)	384 (100%)	$\chi^2=1.98$, df=1	0.158
	No	42 (5.2%)	761 (94.8%)	803 (100%)		
Catheter inserted after birth	Yes	32 (4.9%)	619 (95.1%)	651 (100%)	$\chi^2=2.12$, df=1	0.145
	No	37 (6.9%)	499 (93.1%)	536 (100%)		
Overall		71 (5.9%)	1128 (94.1%)	1199 (100%)		

Table 5.24 Attendance at birth for the women by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Midwife present at birth	Yes	23 (5.1%)	430 (94.9%)	453 (100%)	$\chi^2=0.91$, df=1	0.340
	No	47 (6.4%)	685 (93.6%)	732 (100%)		
Doctor present at birth	Yes	28 (5.5%)	479 (94.5%)	507 (100%)	$\chi^2=0.24$, df=1	0.627
	No	42 (6.2%)	636 (93.8%)	678 (100%)		
Relative present at birth	Yes	13 (10.9%)	106 (89.1%)	119 (100%)	$\chi^2=5.99$, df=1	0.014
	No	57 (5.3%)	1009 (94.7%)	1066 (100%)		
Traditional birth assistant present at birth	Yes	16 (7.0%)	213 (93.0%)	229 (100%)	$\chi^2=0.60$, df=1	0.440
	No	54 (5.6%)	902 (94.4%)	956 (100%)		
Skilled attendance at birth	Yes	44 (5.2%)	798 (94.8%)	842 (100%)	$\chi^2=2.46$, df=1	0.117
	No	27 (7.6%)	330 (92.4%)	357 (100%)		
Skilled attendant at birth	Midwife & doctor	7 (5.9%)	111 (94.1%)	118 (100%)	$\chi^2=2.71$, df=3	0.439
	Midwife only	16 (4.8%)	319 (95.2%)	335 (100%)		
	Doctor only	21 (5.4%)	368 (94.6%)	389 (100%)		
	Neither	27 (7.6%)	330 (92.4%)	357 (100%)		
Only relative present at birth	Yes	8 (11.1%)	64 (88.9%)	72 (100%)	Fisher's exact	0.067
	No	63 (5.6%)	1064 (94.4%)	1127 (100%)		
No-one present at birth	Yes	7 (7.9%)	82 (92.1%)	89 (100%)	$\chi^2=0.65$ df=1	0.419
	No	64 (5.8%)	1046 (94.2%)	1110 (100%)		
Overall		71 (5.9%)	1128 (94.1%)	1199 (100%)		

5.3.3: Fistula-related Characteristics by Successfulness of Surgery

Table 5.25 shows the association between successfulness of surgery and fistula-related details of the women. Although the mean haemoglobin level was slightly lower in women with unsuccessful surgery (12.0 v 12.4 g/dl), haemoglobin level was not significantly associated with successfulness of surgery ($p=0.101$). The association with parity when the fistula first developed was almost significant when order was excluded ($p=0.087$). This was skewed by the low success rate for women with parity 0 (7/9 successes); when this category was excluded, the near significance disappeared ($p=0.267$). Neither problem with urine nor problem passing urine normally was significantly associated with successfulness of surgery.

For duration of leakage, the success rate was lowest for 13-60 months (92.8%), but the difference between the four intervals used for duration was not significant. The only variable where the association approached significance was problem with faeces (p=0.052): there was weak evidence that women with such a problem had a lower failure rate (the observed difference being 3.1%, 3.6% v 6.7%).

Table 5.25 Fistula-related details of the women by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Haemoglobin	mean [SD]	12.0 [2.0]	12.4 [1.9]	12.4 [1.9]	t=-1.64, df=1196	0.101
Parity when fistula developed [†]	0	2 (22.2%)	7 (77.8%)	9 (100%)	$\chi^2_{\text{trend}}=0.45,$ df=1 $\chi^2=9.60,$ df=5	0.501 0.087
	1	22 (4.2%)	496 (95.8%)	518 (100%)		
	2	16 (7.7%)	193 (92.3%)	209 (100%)		
	3	12 (7.7%)	144 (92.3%)	156 (100%)		
	4	4 (4.3%)	90 (95.7%)	94 (100%)		
	5 or more	11 (6.3%)	163 (93.7%)	174 (100%)		
Problem with urine	Yes	61 (6.3%)	906 (93.7%)	967 (100%)	$\chi^2=1.31,$ df=1	0.252
	No	10 (4.3%)	221 (95.7%)	231 (100%)		
Problem with faeces	Yes	11 (3.6%)	291 (96.4%)	302 (100%)	$\chi^2=3.76,$ df=1	0.052
	No	60 (6.7%)	837 (93.3%)	897 (100%)		
Pass urine normally	Yes	28 (5.8%)	452 (94.2%)	480 (100%)	$\chi^2=0.01,$ df=1	0.916
	No	43 (6.0%)	676 (94.0%)	719 (100%)		
Duration of leakage	Up to 12 months	28 (6.5%)	406 (93.5%)	434 (100%)	$\chi^2_{\text{trend}}=2.19,$ df=1 $\chi^2=3.24,$ df=3	0.139 0.356
	13-60 months	20 (7.2%)	259 (92.8%)	279 (100%)		
	61-108 months	10 (6.0%)	158 (94.0%)	168 (100%)		
	Over 108 months	12 (3.9%)	295 (96.1%)	307 (100%)		
Overall		71 (5.9%)	1128 (94.1%)	1199 (100%)		

[†] excluding parity=0: $\chi^2_{\text{trend}}=0.96,$ df=1, p=0.327; $\chi^2=5.20,$ df=4, p=0.267

Table 5.26 shows the association between successfulness of surgery and fistula-related characteristics of the women. None of fistula size, having a multiple fistula, type of multiple fistula, previous fistula repairs or severity of excoriation were significantly associated with successfulness of surgery. The association with fistula position was nearly significant when order was ignored (p=0.063), and there was weak evidence that the success rate was lower when the fistula was 2.1-3 cm from the external urethral orifice. The only variable showing a significant association was vaginal stenosis (p=0.018), with some evidence that women with vaginal stenosis were more likely to have unsuccessful surgery; while the difference was only 3.6% (6.9% v 3.3%), the failure rate for women with stenosis was more than double that for women without stenosis.

Vaginal stenosis is a measure of complexity of the fistula and the severity of the lesion both at presentation and surgery, and may make it difficult for the surgeon to repair the fistula. It may also indicate the ability of the women to comply with clinical instructions, as those who do not comply may have symptoms that result in severe scarring and poor healing.

Table 5.26 Fistula-related characteristics of the women by successfulness of surgery

Characteristic		Unsuccessful	Successful	Total	Test results	P
		N (%)	N (%)	N (%)		
Fistula size	mean [SD]	2.25 [1.51]	2.15 [1.32]	2.15 [1.32]	t=0.62, df=1164	0.538
Fistula position from EUO	< 1 cm	8 (5.8%)	131 (94.2%)	139 (100%)	$\chi^2_{trend}=2.32,$ df=1 $\chi^2=7.31,$ df=3	0.128
	1-2 cm	33 (4.8%)	651 (95.2%)	684 (100%)		0.063
	2.1-3 cm	19 (10.1%)	170 (89.9%)	189 (100%)		
	> 3 cm	9 (6.8%)	123 (93.2%)	132 (100%)		
Multiple fistula	Yes	5 (6.8%)	69 (93.2%)	74 (100%)	$\chi^2=0.09,$ df=1	0.765
	No	66 (5.9%)	1051 (94.1%)	1117 (100%)		
Type of multiple fistula	None	66 (5.9%)	1051 (94.1%)	1117 (100%)	Fisher's exact	0.789
	Vaginal only	3 (7.7%)	36 (92.3%)	39 (100%)		
	Vaginal & rectal	2 (5.7%)	33 (94.3%)	35 (100%)		
Previous repair (vaginal)	Yes	15 (5.0%)	287 (95.0%)	302 (100%)	$\chi^2=0.66,$ df=1	0.416
	No	56 (6.2%)	841 (93.8%)	897 (100%)		
Previous repair (rectal)	Yes	1 (2.0%)	48 (98.0%)	49 (100%)	Fisher's exact	0.358
	No	70 (6.1%)	1080 (93.9%)	1150 (100%)		
Previous repair (either vaginal or rectal)	Yes	16 (4.9%)	309 (95.1%)	325 (100%)	$\chi^2=0.80,$ df=1	0.372
	No	55 (6.3%)	819 (93.7%)	874 (100%)		
Vaginal stenosis	Yes	60 (6.9%)	806 (93.1%)	866 (100%)	$\chi^2=5.58,$ df=1	0.018
	No	11 (3.3%)	320 (96.7%)	331 (100%)		
Severity of excoriation	Mild	39 (5.3%)	694 (94.7%)	733 (100%)	$\chi^2_{trend}=0.81,$ df=1 $\chi^2=1.55,$ df=2	0.368
	Moderate	30 (7.1%)	394 (92.9%)	424 (100%)		0.461
	Severe	2 (5.0%)	38 (95.0%)	40 (100%)		
Overall		71 (5.9%)	1128 (94.1%)	1199 (100%)		

EUO=external urethral orifice

Table 5.27 shows the association between successfulness of surgery and fistula classification. The success rate ranged from 100% for RVF I and RVF III fistulas and 98.6% for RVF IIa fistulas down to 88.5% for VVF IIAb fistulas. However, differences between the 13 classifications were not statistically significant (p=0.187). Table 5.28 shows the association between successfulness of surgery and fistula classification group. Differences between the seven groups were not statistically significant either (p=0.335), the lowest success rate being for VVF III fistulas.

Table 5.27 Fistula classification by successfulness of surgery

Classification	Unsuccessful	Successful	Total	Test results	P		
	N (%)	N (%)	N (%)				
VVF I	13 (5.3%)	234 (94.7%)	247 (100%)	Fisher's exact	0.187		
VVF IIaA	17 (5.6%)	284 (94.4%)	301 (100%)				
VVF IIAb	17 (11.5%)	131 (88.5%)	148 (100%)				
VVF IIBa	3 (3.8%)	76 (96.2%)	79 (100%)				
VVF IIBb	2 (4.3%)	45 (95.7%)	47 (100%)				
VVF III	8 (10.8%)	66 (89.2%)	74 (100%)				
Combined VVF and RVF	2 (5.7%)	33 (94.3%)	35 (100%)				
RVF Ia	1 (8.3%)	11 (91.7%)	12 (100%)				
RVF Ib	1 (3.6%)	27 (96.4%)	28 (100%)				
RVF 1c	0 (0%)	16 (100%)	16 (100%)				
RVF IIa	1 (1.4%)	69 (98.6%)	70 (100%)				
RVF IIb	6 (4.6%)	124 (95.4%)	130 (100%)				
RVF III	0 (0%)	4 (100%)	4 (100%)				
Total	71 (6.0%)	1120 (94.0%)	1191 (100%)				

Table 5.28 Fistula classification group by successfulness of surgery

Classification	Unsuccessful	Successful	Total	Test results	P		
	N (%)	N (%)	N (%)				
VVF I	13 (5.3%)	234 (94.7%)	247 (100%)	Fisher's exact	0.335		
VVF II	39 (6.8%)	536 (93.2%)	575 (100%)				
VVF III	8 (10.8%)	66 (89.2%)	74 (100%)				
Combined VVF and RVF	2 (5.7%)	33 (94.3%)	35 (100%)				
RVF I	2 (3.6%)	11 (96.4%)	56 (100%)				
RVF II	7 (3.5%)	193 (96.5%)	200 (100%)				
RVF III	0 (0%)	4 (100%)	4 (100%)				
Total	71 (6.0%)	1120 (94.0%)	1191 (100%)				

5.3.4 Variables showing statistically significant associations with successfulness of surgery

Table 5.29 lists the variables that were significantly associated with successfulness of surgery at a highly conservative significance level of $\alpha=0.25$. Centres of referral were not significantly different within countries; the association due to centre was due to differences between country of referral, the success rates for women referred from outside Kenya generally being lower than those referred from within Kenya.

Table 5.29 Variables significantly associated with successfulness of surgery at $p<0.250$

Block	Variable	Coefficients potentially in model	P
Sociodemographic	Country of referral	6	<0.001
	Centre of referral	14	<0.001
	Woman unemployed	1	0.004
	Number of children currently alive	5	0.060
	Height	1	0.135
	Spouse education	4	0.164
	Woman's occupation	8	0.193
	Spouse unemployed	1	0.225
Childbirth-related	Relative present at birth	1	0.014
	Infant still alive	1	0.064
	Relative only present at birth	1	0.067
	Skilled attendance at birth	1	0.117
	Catheter inserted after birth	1	0.145
	Leg weakness after birth	1	0.158
Fistula-related	Vaginal stenosis	1	0.018
	Problem with faeces	1	0.052
	Fistula position	3	0.063
	Parity when fistula developed	5	0.087
	Haemoglobin	1	0.101
	Duration of leakage	3	0.139
	Fistula classification	12	0.187

5.4: Bivariate Associations with Duration of Leakage

This section presents the results of analyses of relationships between duration of leakage and individual sociodemographic or clinical variables. For these analyses, duration of leakage was grouped into four intervals: up to 12 months, 13-60 months, 61-108 months and over 108 months. As in the associations with successfulness of surgery, these analyses do not take into account any concurrent relationships with other variables.

5.4.1: Sociodemographic Characteristics by Duration of Leakage

Table 5.30 shows the associations between centre of referral and duration of leakage. The distribution of duration of leakage differed significantly between centres ($p < 0.001$).

In Kenya, more than three quarters of the women referred from Garissa (78.6%), slightly more than half referred from Coast General (52.2%) and slightly under half referred from Kenyatta NH (44.7%) presented with leakage of up to 12 months, all well above the overall average of 36.4%. Only 3/14 women from Garissa presented with leakage lasting 13 months or more, while only 20/92 from Coast General had leakage of 61 months or more. Fewer women than average presented with leakage lasting up to 12 months from Kisii (18.5%) and New Nyanza (27.5%); women from Kisii were more likely to have leakage lasting 13-60 months (30.4%) or over 108 months (39.9%) while those from New Nyanza were more likely to have leakage lasting over 108 months.

Outside Kenya, fewer women than average presented with leakage of up to 12 months from all centres. Instead, more women than average presented with leakages of 13-60 months at Juba (75.0%), Rumbek (44.4%) and Wau (31.3%), with leakages of 61-108 months at Lilongwe (33.3%), Rumbek (33.3%) and CHUK (21.4%), and with leakages over 108 months at Ruhengeri (52.6%) and CHUK (37.5%).

These differences were also largely reflected in a comparison by country of referral (Table 5.31), where the difference between countries was also significant ($p < 0.001$). The imbalances within Kenya balanced each other out, but for Malawi, there were fewer leakages up to 12 months (26.3%) and more of 61-108 months (31.6% and) than average; for Southern Sudan, there were fewer leakages up to 12 months (28.2%) and more of 13-60 months (36.6%); for the DR Congo, there were more of 13-60 months (44.7%); and for Rwanda, there were more lasting more than 108 months (40.5%).

Table 5.30 Centre of referral by duration of leakage

Country of centre	Centre	Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Kenya	Coast General	48 (52.2%)	24 (26.1%)	8 (8.7%)	12 (13.0%)	92 (100%)	Fisher's exact	<0.001
	Garissa	11 (78.6%)	1 (7.1%)	1 (7.1%)	1 (7.1%)	14 (100%)		
	Kisii	31 (18.5%)	51 (30.4%)	19 (11.3%)	67 (39.9%)	168 (100%)		
	Kenyatta NH	251 (44.7%)	112 (19.9%)	80 (14.2%)	119 (21.2%)	562 (100%)		
	New Nyanza	28 (27.5%)	21 (20.6%)	16 (15.7%)	37 (36.3%)	102 (100%)		
	Webuye	5 (41.7%)	2 (16.7%)	1 (8.3%)	4 (33.3%)	12 (100%)		
Malawi	Blantyre	0 (0%)	0 (0%)	0 (0%)	1 (100%)	1 (100%)		
	Lilongwe	5 (27.8%)	4 (22.2%)	6 (33.3%)	3 (16.7%)	18 (100%)		
Rwanda	CHUK	7 (12.5%)	16 (28.6%)	12 (21.4%)	21 (37.5%)	56 (100%)		
	Ruhengeri	4 (21.1%)	4 (21.1%)	1 (5.3%)	10 (52.6%)	19 (100%)		
Southern Sudan	Juba	1 (25.0%)	3 (75.0%)	0 (0%)	0 (0%)	4 (100%)		
	Rumbek	2 (11.1%)	8 (44.4%)	6 (33.3%)	2 (11.1%)	18 (100%)		
	Wau	16 (33.3%)	15 (31.3%)	6 (12.5%)	11 (22.9%)	48 (100%)		
Uganda	Kagando	33 (34.4%)	21 (21.9%)	14 (14.6%)	28 (29.2%)	96 (100%)		
	Mulago	0 (0%)	1 (33.3%)	1 (33.3%)	1 (33.3%)	3 (100%)		
Total		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

Table 5.31 Country of referral by duration of leakage

Country	Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
	N (%)	N (%)	N (%)	N (%)	N (%)		
Kenya	354 (39.0%)	194 (21.4%)	122 (13.5%)	237 (26.1%)	907 (100%)	Fisher's exact	<0.001
Malawi	5 (26.3%)	4 (21.1%)	6 (31.6%)	4 (21.1%)	19 (100%)		
DR Congo	15 (39.5%)	17 (44.7%)	3 (7.9%)	3 (7.9%)	38 (100%)		
Rwanda	11 (14.9%)	20 (27.0%)	13 (17.6%)	31 (40.5%)	74 (100%)		
Somalia	3 (100%)	0 (0%)	0 (0%)	0 (0%)	3 (100%)		
Southern Sudan	20 (28.2%)	26 (36.6%)	12 (16.9%)	13 (18.3%)	71 (100%)		
Uganda	34 (33.7%)	22 (21.8%)	15 (14.9%)	30 (29.7%)	101 (100%)		
Total	442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

Comparisons of centres within country of referral: Kenya – Fisher's exact $p < 0.001$; Rwanda – Fisher's exact $p = 0.441$; Southern Sudan – Fisher's exact $p = 0.128$; Uganda – Fisher's exact $p = 0.803$

Table 5.32 shows the associations between demographic characteristics of the women and duration of leakage. As would be expected, younger women tended to have significantly shorter duration of leakage ($p < 0.001$), with 75.0% of those aged 17 or under and 44.2% of those aged 18-27 having a leakage of up to 12 months and only 7.5% of those aged 17 or under and less than a quarter of those aged 18-27 having a leakage lasting 61 months or more. At least 60% of the women aged 48-57, 58-67 and 68 or over had a leakage lasting over 108 months. There was no significant association between duration of leakage and height, weight or number of children currently alive, but there were significant associations with marital status ($p < 0.001$) and religion ($p = 0.005$). Single women were more likely to have durations of up to 12 months (42.1%) and less likely to have duration of over 108 months (14.2%). Women who were separated, divorced or widowed were less likely to have durations of up to 12 months; instead, the most common duration of leakage for divorced women was 13-60 months (42.5%) while that for separated and widowed women was over 108 months (41.3% and 64.4% respectively). Muslim women were more likely to have duration of up to 12 months (47.8%) and less likely to have duration over 108 months (11.9%).

Table 5.33 shows the associations between the level of education of the women and their spouses and duration of leakage. The association with the women's level of education was particularly significant ($p < 0.001$). Women with secondary and college educations were more

likely to have surgery with leakage of up to 12 months (47.3% and 60.4% respectively) and less likely to have leakage of over 108 months (19.6% and 3.8%). There was some evidence that the spouses education was associated with duration of leakage ($p < 0.05$), the most noticeable effect being for those with a college education, where their wives were more likely to have leakage up to 60 months and less likely to have leakage over 108 months.

Table 5.34 shows associations between the employment status and occupation of the women and their spouses with duration of leakage. The association with the woman's employment status was significant ($p < 0.001$), with unemployed women being more likely to have a duration of up to 12 months (43.1%) and less likely to have a duration over 108 months (20.0%). The association with the woman's occupation was significant too ($p < 0.001$), with women who were employed in general work (53.6%) or who were housewives (43.1%) or students (60.0%) more likely to have a duration of up to 12 months and less likely to have a duration over 108 months (12.1%, 12.4% and 5.7%). In particular, 33/35 students had a duration up to 60 months. Peasant farmers were the only occupation more likely to have duration over 108 months (38.8%). The pattern was similar for the spouse's employment status and occupation. Again, peasant farmers were the only occupation where the wife was more likely to have duration over 108 months.

Table 5.32 Demographic characteristics of the women by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Age group	<= 17	30 (75.0%)	7 (17.5%)	1 (2.5%)	2 (5.0%)	40 (100%)	$\chi^2_{trend}=159.9, df=1$ Kendall's $\tau=0.30$ Fisher's exact	<0.001 <0.001 <0.001
	18-27	199 (44.2%)	141 (31.3%)	79 (17.6%)	31 (6.9%)	450 (100%)		
	28-37	147 (34.8%)	87 (20.6%)	60 (14.2%)	129 (30.5%)	423 (100%)		
	38-47	44 (27.2%)	30 (18.5%)	23 (14.2%)	65 (30.5%)	162 (100%)		
	48-57	11 (13.6%)	11 (13.6%)	6 (7.4%)	53 (65.4%)	81 (100%)		
	58-67	6 (14.3%)	6 (14.3%)	2 (4.8%)	28 (66.7%)	42 (100%)		
	>=68	5 (33.3%)	1 (6.7%)	0 (0%)	9 (60.0%)	15 (100%)		
Height (cm)	mean [SD]	154.8 [7.1]	154.2 [8.9]	153.3 [8.6]	154.5 [7.1]	154.4 [7.8]	F=1.44, df=3,529.0	0.229
Weight (kg)	mean [SD]	55.6 [9.6]	56.4 [9.7]	56.0 [10.4]	55.9 [10.4]	55.9 [10.0]	F=0.32, df=3,1201	0.811
Marital status	Single	104 (42.1%)	68 (27.5%)	40 (16.2%)	35 (14.2%)	247 (100%)	Fisher's exact	<0.001
	Married	294 (39.7%)	158 (21.4%)	108 (14.6%)	180 (24.3%)	740 (100%)		
	Separated	20 (25.0%)	15 (18.8%)	12 (15.0%)	33 (41.3%)	80 (100%)		
	Divorced	16 (21.9%)	31 (42.5%)	4 (5.5%)	22 (30.1%)	73 (100%)		
	Widowed	8 (11.0%)	11 (15.1%)	7 (9.6%)	47 (64.4%)	73 (100%)		
Religion	Christian	410 (35.8%)	265 (23.1%)	162 (14.1%)	309 (27.0%)	1146 (100%)	$\chi^2_{trend}=7.91, df=1$	0.005
	Muslim	32 (47.8%)	18 (26.9%)	9 (13.4%)	9 (11.9%)	67 (100%)		
Number of children currently alive	0	141 (33.2%)	106 (24.9%)	62 (14.6%)	116 (27.3%)	425 (100%)	$\chi^2_{trend}=1.15, df=1$ Kendall's $\tau=0.01$ $\chi^2=19.76, df=15$	0.283 0.735 0.181
	1	101 (43.0%)	57 (24.3%)	28 (11.9%)	49 (20.9%)	235 (100%)		
	2	74 (37.8%)	47 (24.0%)	32 (16.3%)	43 (21.9%)	196 (100%)		
	3	50 (39.4%)	20 (15.7%)	21 (16.5%)	36 (28.3%)	127 (100%)		
	4	28 (33.3%)	18 (21.4%)	9 (10.7%)	29 (34.5%)	84 (100%)		
	5 or more	44 (31.9%)	34 (24.6%)	18 (13.0%)	42 (30.4%)	138 (100%)		
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

Table 5.33 Education of the women and their spouses by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Woman's education	None	66 (31.7%)	53 (25.5%)	26 (12.5%)	63 (30.3%)	208 (100%)	$\chi^2_{\text{trend}}=18.87, df=1$ Kendall's $\tau=-0.11$ $\chi^2=39.12, df=12$	<0.001 <0.001 <0.001
	Primary	256 (33.6%)	184 (24.1%)	108 (14.2%)	215 (28.2%)	763 (100%)		
	Secondary	87 (47.3%)	35 (19.0%)	26 (14.1%)	36 (19.6%)	184 (100%)		
	College	32 (60.4%)	10 (18.9%)	9 (17.0%)	2 (3.8%)	53 (100%)		
	University	1 (20.0%)	1 (20.0%)	2 (40.0%)	1 (20.0%)	5 (100%)		
	Total	442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		
Spouse's education	None	86 (30.6%)	76 (27.0%)	38 (13.5%)	81 (28.8%)	281 (100%)	$\chi^2_{\text{trend}}=3.97, df=1$ Kendall's $\tau=-0.05$ $\chi^2=23.79, df=12$	0.046 0.027 0.022
	Primary	205 (37.5%)	118 (21.6%)	74 (13.5%)	150 (27.4%)	547 (100%)		
	Secondary	115 (39.2%)	64 (21.8%)	41 (14.0%)	73 (24.9%)	293 (100%)		
	College	25 (41.7%)	18 (30.0%)	11 (18.3%)	6 (10.0%)	60 (100%)		
	University	3 (18.8%)	4 (25.0%)	6 (37.5%)	3 (18.8%)	16 (100%)		
	Total	434 (36.3%)	280 (23.4%)	170 (14.2%)	313 (26.1%)	1197 (100%)		

Table 5.34 Employment status and occupation of the women and their spouses by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Woman unemployed	Yes	211 (43.1%)	124 (25.3%)	57 (11.6%)	98 (20.0%)	490 (100%)	$\chi^2_{trend}=25.64,$ df=1 $\chi^2=26.65,$ df=3	<0.001 <0.001
	No	231 (32.0%)	159 (22.0%)	114 (15.8%)	219 (30.3%)	723 (100%)		
Woman's occupation	Business person	66 (39.3%)	35 (20.8%)	28 (16.7%)	39 (23.2%)	168 (100%)	Fisher's exact	<0.001
	Casual labourer	13 (39.4%)	12 (36.4%)	4 (12.1%)	4 (12.1%)	33 (100%)		
	Employed (general work)	52 (53.6%)	14 (14.4%)	19 (19.6%)	12 (12.4%)	97 (100%)		
	Housewife	165 (43.1%)	90 (23.5%)	43 (11.2%)	85 (22.2%)	383 (100%)		
	Pastoralist	1 (50.0%)	0 (0%)	1 (50.0%)	0 (0%)	2 (100%)		
	Peasant farmer	99 (23.4%)	98 (23.2%)	62 (14.7%)	164 (38.8%)	423 (100%)		
	Retired	1 (100%)	0 (0%)	0 (0%)	0 (0%)	1 (100%)		
	Student	21 (60.0%)	12 (34.3%)	0 (0%)	2 (5.7%)	35 (100%)		
	No occupation	24 (33.8%)	22 (31.0%)	14 (19.7%)	11 (15.5%)	71 (100%)		
	Total	442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		
Spouse unemployed	Yes	71 (43.6%)	48 (29.4%)	16 (9.8%)	28 (17.2%)	163 (100%)	$\chi^2_{trend}=11.15,$ df=1 $\chi^2=13.92,$ df=3	0.001 0.003
	No	370 (35.3%)	235 (22.4%)	155 (14.8%)	289 (27.6%)	1049 (100%)		
Spouse's occupation	Business person	80 (45.5%)	38 (21.6%)	25 (14.2%)	33 (18.8%)	176 (100%)	Fisher's exact	<0.001
	Casual labourer	51 (43.6%)	27 (23.1%)	18 (15.4%)	21 (17.9%)	117 (100%)		
	Employed (general work)	67 (40.6%)	36 (21.8%)	25 (15.2%)	37 (22.4%)	165 (100%)		
	Musician	0 (0%)	1 (100%)	0 (0%)	0 (0%)	1 (100%)		
	Pastoralist	17 (45.9%)	9 (24.3%)	2 (5.4%)	9 (24.3%)	37 (100%)		
	Peasant farmer	155 (28.0%)	124 (22.4%)	85 (15.4%)	189 (34.2%)	553 (100%)		
	Retired	1 (20.0%)	2 (40.0%)	2 (40.0%)	0 (0%)	5 (100%)		
	Student	8 (47.1%)	9 (52.9%)	0 (0%)	0 (0%)	17 (100%)		
	No occupation	62 (44.0%)	37 (26.2%)	14 (9.9%)	28 (19.9%)	141 (100%)		
	Total	441 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.2%)	1212 (100%)		

Table 5.35 shows associations between variables indicating the impact of the fistula on the women with duration of leakage. Associations with whether the husband left and who the woman lived with were very strongly significant ($p < 0.001$). Women whose husband had left were less likely to have a duration up to 12 months (24.5%) and more likely to have a duration over 108 months (32.1%). Those living on their own were less likely to have a duration of up to 12 months (16.9%) or 13-60 months (18.3%) and more likely to have a duration over 108 months (47.9%). Those living with parents (29.6%), relatives or friends (32.1%) or an employer or neighbour (37.5%) were more likely than average to have duration of 13-60 months. The source of knowledge of the fistula camp was also very strongly related to duration of leakage ($p < 0.001$). Among the two largest groups, those learning from the radio were less likely to have a duration up to 12 months (21.8%) and more likely to have a duration over 108 months (37.6%), while those referred from hospital were more likely to have a duration up to 12 months (55.7%) and less likely to have a duration over 108 months (11.9%). Perhaps because of the isolation, among those learning of the camp from other fistula patients, one third (9/27) had a duration over 108 months.

Table 5.36 shows the associations between the women's health status and duration of leakage. The association with menstruating regularly was significant when the ordering of duration was ignored ($p < 0.001$), but this appeared to be due to those with a duration of 13-60 months, where more than average (28.2% compared with 23.3%) were menstruating regularly. The associations of the woman's general condition and HIV status with duration of leakage were not statistically significant.

Table 5.35 Impact of fistula on the women by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Whether husband left	Yes	65 (24.5%)	72 (27.2%)	43 (16.2%)	85 (32.1%)	265 (100%)	$\chi^2_{\text{trend}}=15.58, \text{df}=1$ $\chi^2=21.01, \text{df}=3$	<0.001 <0.001
	No	377 (39.8%)	211 (22.3%)	128 (13.5%)	232 (24.5%)	948 (100%)		
Who do you live with now?	Self	24 (16.9%)	26 (18.3%)	24 (16.9%)	68 (47.9%)	142 (100%)	Fisher's exact	<0.001
	Spouse	259 (40.2%)	138 (21.4%)	92 (14.3%)	156 (24.2%)	645 (100%)		
	Parents	81 (38.0%)	66 (29.6%)	27 (12.7%)	42 (19.7%)	213 (100%)		
	Siblings	43 (40.6%)	22 (20.8%)	14 (13.2%)	27 (25.5%)	106 (100%)		
	Relatives/ friends	29 (34.5%)	27 (32.1%)	9 (10.7%)	19 (22.6%)	84 (100%)		
	Employer/ neighbour	4 (25.0%)	6 (37.5%)	5 (31.3%)	1 (6.3%)	16 (100%)		
	Own children	2 (33.3%)	1 (16.7%)	0 (0%)	3 (50.0%)	6 (100%)		
How did you first know of the camp?	Radio	131 (21.8%)	152 (25.3%)	92 (15.3%)	226 (37.6%)	601 (100%)	Fisher's exact	<0.001
	TV	8 (53.3%)	1 (6.7%)	5 (33.3%)	1 (6.7%)	15 (100%)		
	Referral from hospital	268 (55.7%)	103 (21.4%)	53 (11.0%)	57 (11.9%)	481 (100%)		
	Parents/ siblings	12 (22.2%)	16 (29.6%)	8 (14.8%)	18 (33.3%)	54 (4.5%)		
	Friends/ relatives/ neighbours	13 (37.1%)	8 (22.9%)	8 (22.9%)	6 (17.1%)	35 (100%)		
	Other fistula patient	10 (37.0%)	3 (11.1%)	5 (18.5%)	9 (33.3%)	27 (2.2%)		
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

Table 5.36 Health status of the women by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Menstruating regularly	Yes	207 (33.0%)	177 (28.2%)	93 (14.8%)	150 (23.9%)	627 (100%)	$\chi^2_{\text{trend}}=0.01, df=1$ $\chi^2=20.77, df=3$	0.944 <0.001
	No	232 (40.2%)	104 (18.0%)	76 (13.2%)	165 (28.6%)	577 (100%)		
General condition	Poor	38 (39.6%)	24 (25.0%)	12 (12.5%)	22 (22.9%)	96 (100%)	$\chi^2_{\text{trend}}=0.73, df=1$ Kendall's $\tau=0.02$ $\chi^2=1.66, df=6$	0.392 0.453 0.948
	Fair	63 (37.7%)	35 (21.0%)	25 (15.0%)	44 (26.3%)	167 (100%)		
	Good	340 (35.8%)	224 (23.6%)	134 (14.1%)	251 (26.4%)	949 (100%)		
HIV status	Positive	21 (28.8%)	18 (24.7%)	11 (15.1%)	23 (31.5%)	73 (100%)	$\chi^2_{\text{trend}}=2.03, df=1$ $\chi^2=2.25, df=3$	0.154 0.522
	Negative	421 (37.0%)	265 (23.3%)	160 (14.0%)	293 (25.7%)	1139 (100%)		
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

5.4.2: Childbirth-related Characteristics by Duration of Leakage

Table 5.37 shows associations between childbirth-related characteristics of the women and Table 5.38 shows associations between attendance at birth and duration of leakage. The correlation with duration of labour was small and positive but statistically significant (Kendall's $\tau=0.14, p<0.001$), a longer labour being associated with a longer period of leakage. The correlation with birthweight was very small and positive but statistically significant (Kendall's $\tau=0.06, p=0.015$), a heavier baby also being associated with a longer period of leakage. However, the differences in mean birthweight were small (3.43 to 3.65 kg). Leakage after birth was significantly associated with duration ($p=0.002$ allowing for ordering), with more women without leakage after birth having a duration up to 12 months (50.9%). There was no significant association with leg weakness after birth but there was with catheter insertion after birth ($p<0.001$): more women who had catheter insertion had duration up to 12 months (41.8%).

Duration of leakage was not significantly associated with the gender of the infant, whether the infant was still alive, whether a midwife or a traditional birth assistant was present at birth, whether there was skilled attendance at birth or whether the woman gave birth on her own. Two attendance factors did appear to be important: the presence of a doctor at the birth ($p=0.001$ ignoring order) and the presence of a relative at birth ($p=0.005$ ignoring order). When a doctor was present, the woman was more likely to attend for surgery with a leakage

of up to 12 months (41.7%); when a relative was present, the woman was more likely to have duration of 13-60 months (32.8%) or 108 months or more (31.1%). When only the relative was present at birth ($p < 0.001$ ignoring order), a duration of 13-60 months was more likely again (43.7%).

Table 5.37 Childbirth-related characteristics of the women by duration of leakage.

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Duration of labour	mean [SD]	39.5 [42.6]	46.5 [38.6]	46.1 [43.6]	57.5 [60.9]	46.9 [47.9]	K-W $\chi^2=7.11$, df=3 Kendall's $\tau=0.14$	0.069 <0.001
	median {range}	24 {1 to 432}	48 {2 to 192}	39 {2 to 336}	48 {1 to 504}	48 {1 to 504}		
Birth weight	mean [SD]	3.43 [0.80]	3.53 [0.76]	3.65 [1.01]	3.61 [0.95]	3.53 [0.87]	F=3.45, df=3,492.5 Kendall's $\tau=0.06$	0.017 0.015
Gender of infant	Male	241 (34.8%)	159 (23.0%)	102 (14.7%)	190 (27.5%)	692 (100%)	$\chi^2_{trend}=2.16$, df=1 $\chi^2=2.28$, df=3	0.142 0.516
	Female	188 (37.9%)	120 (24.2%)	67 (13.5%)	121 (24.4%)	496 (100%)		
Infant still alive	Yes	174 (39.0%)	104 (23.3%)	65 (14.6%)	103 (23.1%)	446 (100%)	$\chi^2_{trend}=3.40$, df=1 $\chi^2=4.06$, df=3	0.065 0.255
	No	258 (34.5%)	177 (23.7%)	104 (13.9%)	208 (27.8%)	747 (100%)		
Leakage after birth	Yes	380 (34.8%)	259 (23.7%)	160 (14.6%)	294 (16.9%)	1093 (100%)	$\chi^2_{trend}=9.89$, df=1 $\chi^2=12.38$, df=3	0.002 0.006
	No	59 (50.9%)	24 (20.7%)	11 (9.5%)	22 (19.0%)	116 (100%)		
Leg weakness after birth	Yes	149 (38.3%)	78 (20.1%)	60 (15.4%)	102 (26.2%)	389 (100%)	$\chi^2_{trend}=0.01$, df=1 $\chi^2=4.17$, df=3	0.913 0.240
	No	287 (35.3%)	204 (25.1%)	110 (13.5%)	212 (26.1%)	813 (100%)		
Catheter inserted after birth	Yes	278 (41.8%)	142 (21.4%)	87 (13.1%)	158 (23.8%)	665 (100%)	$\chi^2_{trend}=12.96$, df=1 $\chi^2=18.75$, df=3	<0.001 <0.001
	No	160 (29.7%)	138 (25.7%)	83 (15.4%)	157 (29.2%)	538 (100%)		
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

Table 5.38 Attendance at birth for the women by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Midwife present at birth	Yes	164 (36.0%)	109 (23.9%)	61 (13.4%)	122 (26.8%)	456 (100%)	$\chi^2_{trend}=0.02, df=1$ $\chi^2=0.51, df=3$	0.880 0.916
	No	271 (36.4%)	172 (23.1%)	109 (14.7%)	192 (25.8%)	744 (100%)		
Doctor present at birth	Yes	217 (41.7%)	96 (18.5%)	71 (13.7%)	136 (26.2%)	520 (100%)	$\chi^2_{trend}=2.28, df=1$ $\chi^2=17.40, df=3$	0.131 0.001
	No	218 (32.1%)	185 (27.2%)	99 (14.6%)	178 (26.2%)	680 (100%)		
Relative present at birth	Yes	27 (22.7%)	39 (32.8%)	16 (13.4%)	37 (31.1%)	119 (100%)	$\chi^2_{trend}=4.66, df=1$ $\chi^2=12.91, df=3$	0.031 0.005
	No	408 (37.7%)	242 (22.4%)	154 (14.2%)	277 (25.6%)	1081 (100%)		
Traditional birth attendant present at birth	Yes	77 (33.6%)	51 (22.3%)	33 (14.4%)	68 (29.7%)	229 (100%)	$\chi^2_{trend}=1.91, df=1$ $\chi^2=2.06, df=3$	0.167 0.561
	No	358 (36.9%)	230 (23.7%)	137 (14.1%)	246 (25.3%)	971 (100%)		
Skilled attendance at birth	Yes	322 (37.6%)	187 (21.8%)	121 (14.1%)	227 (26.5%)	857 (100%)	$\chi^2_{trend}=0.03, df=1$ $\chi^2=4.03, df=3$	0.857 0.259
	No	120 (33.7%)	96 (27.0%)	50 (14.0%)	90 (25.3%)	356 (100%)		
Skilled attendant at birth	Midwife & doctor	59 (49.6%)	18 (15.1%)	11 (9.2%)	31 (26.1%)	119 (100%)	$\chi^2=22.43, df=9$	0.008
	Midwife only	105 (31.2%)	91 (27.0%)	50 (14.8%)	91 (27.0%)	337 (100%)		
	Doctor only	158 (39.4%)	78 (19.5%)	60 (15.0%)	105 (26.2%)	401 (100%)		
	Neither	120 (33.7%)	96 (27.0%)	50 (14.0%)	90 (25.3%)	356 (100%)		
Only relative present at birth	Yes	14 (19.7%)	31 (43.7%)	7 (9.9%)	19 (26.8%)	71 (100%)	$\chi^2_{trend}=0.97, df=1$ $\chi^2=20.12, df=3$	0.324 <0.001
	No	428 (37.5%)	252 (22.1%)	164 (14.4%)	298 (26.1%)	1142 (100%)		
No-one present at birth	Yes	38 (36.0%)	20 (22.2%)	16 (17.8%)	16 (17.8%)	90 (100%)	$\chi^2_{trend}=2.35, df=1$ $\chi^2=4.48, df=3$	0.125 0.215
	No	404 (36.0%)	263 (23.4%)	155 (13.8%)	301 (26.8%)	1123 (100%)		
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

5.4.3: **Fistula-related Characteristics by Duration of Leakage**

Table 5.39 shows associations between fistula-related details and symptoms of the women with duration of leakage. The association with haemoglobin level was statistically significant ($p=0.007$) but this appeared to be an artefact of the large sample size because the mean levels in the four groups (12.2 to 12.6 g/dl) were not clinically different. The association with parity was statistically significant using three different tests incorporating or ignoring order ($p=0.002$ to 0.027). Women with parities of 0, 2, 3 and 4 (50%, 42.4%, 46.8% and 43.2% respectively) were more likely while those with a parity of 1 (30.0%) were less likely to have a duration of up to 12 months. Women with parities of 2 and 3 were less likely to duration of over 108 months (20.5% and 20.9%). There were no significant associations with problems with urine or faeces, while the association with passing urine normally was significant when the ordering of duration was again ignored ($p=0.015$). Slightly more women than average had a duration of 13-60 months and slightly less than average had a duration over 108 months.

Table 5.40 shows associations between fistula-related characteristics of the women with duration of leakage. There was no significant association between fistula size, fistula position, having a multiple fistula or vaginal stenosis and duration of leakage. There were significant associations with having a previous fistula repair. Those with previous vaginal repairs ($p<0.001$) were less likely to have a duration up to 12 months (22.4%) and more likely to have a duration over 108 months (39.0%). Those with previous rectal repairs ($p<0.001$) were less likely to have durations up to 12 months (19.1%) or 13-60 months (14.9%) and more likely to have durations of 61-108 months (19.1%) or over 108 months (46.8%). Severity of excoriation was significantly associated with duration of leakage ($p<0.001$): women with mild excoriation were more likely to have a duration up to 12 months (40.0%) and less likely to have a duration over 108 months (22.0%), while those with moderate excoriation were less likely to have a duration up to 12 months (30.4%) and more likely to have a duration over 108 months (33.4%).

Table 5.39 Fistula-related details of the women by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Haemoglobin	mean [SD]	12.2 [1.8]	12.3 [2.0]	12.6 [1.9]	12.6 [1.9]	12.4 [1.9]	F=4.11, df=3,1208	0.007
Parity when fistula developed [†]	0	4 (50.0%)	2 (25.0%)	0 (0%)	2 (25.0%)	8 (100%)	$\chi^2_{trend}=5.13, df=1$ Kendall's $\tau=-0.08$ $\chi^2=27.21, df=15$	0.023 0.002 0.027
	1	158 (30.0%)	131 (24.9%)	84 (15.9%)	154 (29.2%)	527 (100%)		
	2	89 (42.4%)	46 (21.9%)	32 (15.2%)	43 (20.5%)	210 (100%)		
	3	74 (46.8%)	33 (20.9%)	18 (11.4%)	33 (20.9%)	158 (100%)		
	4	41 (43.2%)	19 (20.0%)	10 (10.5%)	25 (26.3%)	95 (100%)		
	5 or more	65 (36.7%)	45 (25.4%)	21 (11.9%)	46 (26.0%)	177 (100%)		
Problem with urine	Yes	355 (36.2%)	224 (22.9%)	133 (13.6%)	268 (27.3%)	980 (100%)	$\chi^2_{trend}=1.53, df=1$ $\chi^2=4.28, df=3$	0.216 0.233
	No	87 (37.5%)	58 (25.0%)	38 (16.4%)	49 (21.1%)	232 (100%)		
Problem with faeces	Yes	103 (33.9%)	83 (27.3%)	40 (13.2%)	78 (25.7%)	304 (100%)	$\chi^2_{trend}=0.01, df=1$ $\chi^2=3.76, df=3$	0.912 0.289
	No	339 (37.3%)	200 (22.0%)	131 (14.4%)	239 (26.3%)	909 (100%)		
Pass urine normally	Yes	176 (36.6%)	130 (27.0%)	70 (14.6%)	105 (21.8%)	481 (100%)	$\chi^2_{trend}=3.76, df=1$ $\chi^2=10.44, df=3$	0.053 0.015
	No	266 (36.6%)	153 (20.9%)	101 (13.8%)	212 (29.0%)	732 (100%)		
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

Table 5.40 Fistula-related characteristics of the women by duration of leakage

Characteristic		Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
		N (%)	N (%)	N (%)	N (%)	N (%)		
Fistula size	mean [SD]	2.15 [1.33]	2.28 [1.35]	2.01 [1.23]	2.13 [1.34]	2.15 [1.32]	F=1.53, df=3,1177	0.206
Fistula position from EUO	< 1 cm	61 (44.9%)	25 (18.4%)	17 (12.5%)	33 (24.3%)	136 (100%)	$\chi^2_{trend}=0.00$, df=1 Kendall's $\tau=0.01$ $\chi^2=12.18$, df=9	0.993
	1-2 cm	242 (34.7%)	174 (25.0%)	94 (13.5%)	187 (26.8%)	697 (100%)		0.788
	2.1-3 cm	70 (36.1%)	42 (21.6%)	37 (19.1%)	45 (23.2%)	194 (100%)		0.203
	> 3 cm	51 (38.3%)	35 (26.3%)	14 (10.5%)	33 (24.8%)	133 (100%)		
Multiple fistula	Yes	30 (40.5%)	13 (17.6%)	12 (16.2%)	19 (25.7%)	74 (100%)	$\chi^2_{trend}=0.30$, df=1 $\chi^2=1.68$, df=3	0.863
	No	411 (36.3%)	268 (23.7%)	159 (14.1%)	293 (25.9%)	1131 (100%)		0.641
Type of multiple fistula	None	411 (36.3%)	268 (23.7%)	159 (14.1%)	293 (25.9%)	1131 (100%)	$\chi^2=3.97$, df=6	0.681
	Vaginal only	14 (35.9%)	8 (20.5%)	5 (12.8%)	12 (30.8%)	39 (100%)		
	Vaginal and rectal	16 (45.7%)	5 (14.3%)	7 (20.0%)	7 (20.0%)	35 (100%)		
Previous repair (vaginal)	Yes	70 (22.4%)	74 (23.6%)	47 (15.0%)	122 (39.0%)	313 (100%)	$\chi^2_{trend}=47.74$, df=1 $\chi^2=49.83$, df=3	<0.001
	No	372 (41.3%)	209 (23.2%)	124 (13.8%)	195 (21.7%)	900 (100%)		<0.001
Previous repair (rectal)	Yes	9 (19.1%)	7 (14.9%)	9 (19.1%)	22 (46.8%)	47 (100%)	$\chi^2_{trend}=13.56$, df=1 $\chi^2=14.39$, df=3	<0.001
	No	433 (37.1%)	276 (23.7%)	162 (13.9%)	295 (25.3%)	1166 (100%)		0.002
Previous repair (either vaginal or rectal)	Yes	76 (22.8%)	78 (23.4%)	49 (14.7%)	131 (39.2%)	334 (100%)	$\chi^2_{trend}=51.53$, df=1 $\chi^2=54.01$, df=3	<0.001
	No	366 (41.6%)	205 (23.3%)	122 (13.9%)	186 (21.2%)	879 (100%)		<0.001
Vaginal stenosis	Yes	314 (35.8%)	202 (23.1%)	122 (13.9%)	238 (27.2%)	876 (100%)	$\chi^2_{trend}=1.48$, df=1 $\chi^2=1.93$, df=3	0.225
	No	128 (38.2%)	80 (23.9%)	49 (14.6%)	78 (23.3%)	335 (100%)		0.588
Severity of excoriation	Mild	297 (40.0%)	171 (23.0%)	111 (15.0%)	163 (22.0%)	742 (100%)	$\chi^2_{trend}=11.31$, df=1 Kendall's $\tau=0.10$ $\chi^2=21.81$, df=6	0.001
	Moderate	130 (30.4%)	100 (23.4%)	55 (12.9%)	143 (33.4%)	428 (100%)		<0.001
	Severe	15 (36.6%)	11 (26.8%)	5 (12.2%)	10 (24.4%)	41 (100%)		0.001
Overall		442 (36.4%)	283 (23.3%)	171 (14.1%)	317 (26.1%)	1213 (100%)		

EUO=external urethral orifice.

[†] excluding parity=0: $\chi^2_{trend}=5.63$, df=1, p=0.018; Kendall's $\tau=-0.08$, p=0.001; $\chi^2=25.69$, df=12, p=0.012

Table 5.41 shows associations between fistula classification and duration of leakage. While the overall association was not statistically significant, women with four classifications were more likely to have duration of leakage up to 12 months: VVF IIBb (50.0%), combined VVF and RVF (45.7%), RVF Ib (46.7%) and RVF 1c (50.0%). Two classifications were more likely to be associated with durations over 108 months: RVF Ib (36.7%) and RVF IIa (31.4%).

Table 5.42 shows associations between fistula classification groups and duration of leakage. Again while the overall association was not statistically significant, combined VVF and RVF (45.7%) continued to be associated with a duration of up to 12 months, as did RVF I (43.1%).

Table 5.41 Fistula classification by duration of leakage

Classification	Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P
	N (%)	N (%)	N (%)	N (%)	N (%)		
VVF I	86 (34.4%)	53 (21.2%)	44 (17.6%)	67 (26.8%)	250 (100%)	Fisher's exact	0.131
VVF IIAa	95 (31.4%)	82 (27.1%)	42 (13.9%)	84 (27.7%)	303 (100%)		
VVF IIAb	60 (39.7%)	43 (28.5%)	15 (9.9%)	33 (21.9%)	151 (100%)		
VVF IIBa	28 (35.4%)	15 (19.0%)	17 (21.5%)	19 (24.1%)	79 (100%)		
VVF IIBb	25 (50.0%)	6 (12.0%)	6 (12.0%)	13 (26.0%)	50 (100%)		
VVF III	29 (38.7%)	17 (22.7%)	7 (9.3%)	22 (29.3%)	75 (100%)		
Combined VVF and RVF	16 (45.7%)	5 (14.3%)	7 (20.0%)	7 (20.0%)	35 (100%)		
RVF Ia	3 (25.0%)	5 (41.7%)	1 (8.3%)	3 (25.0%)	12 (100%)		
RVF Ib	14 (46.7%)	4 (13.3%)	1 (3.3%)	11 (36.7%)	30 (100%)		
RVF 1c	8 (50.0%)	4 (25.0%)	1 (6.3%)	3 (18.8%)	16 (100%)		
RVF IIa	23 (32.9%)	12 (17.1%)	13 (18.6%)	22 (31.4%)	70 (100%)		
RVF IIb	51 (38.9%)	35 (26.7%)	17 (13.0%)	28 (21.4%)	131 (100%)		
RVF III	3 (100%)	0 (0%)	0 (0%)	0 (0%)	3 (100%)		
Total	441 (36.6%)	281 (23.3%)	171 (14.2%)	312 (25.9%)	1205 (100%)		

Table 5.42 Fistula classification group by duration of leakage

Classification group	Up to 12 months	13-60 months	61-108 months	Over 108 months	Total	Test results	P		
	N (%)	N (%)	N (%)	N (%)	N (%)				
VVF I	86 (34.4%)	53 (21.2%)	44 (17.6%)	67 (26.8%)	250 (100%)	Fisher's exact	0.514		
VVF II	208 (35.7%)	146 (25.0%)	80 (13.7%)	149 (25.6%)	583 (100%)				
VVF III	29 (38.7%)	17 (22.7%)	7 (9.3%)	22 (29.3%)	75 (100%)				
Combined VVF and RVF	16 (45.7%)	5 (14.3%)	7 (20.0%)	7 (20.0%)	35 (100%)				
RVF I	25 (43.1%)	13 (22.4%)	3 (5.2%)	17 (29.3%)	58 (100%)				
RVF II	74 (36.8%)	47 (23.4%)	30 (14.9%)	50 (24.9%)	201 (100%)				
RVF III	3 (100%)	0 (0%)	0 (0%)	0 (0%)	3 (100%)				
Total	441 (36.6%)	281 (23.3%)	171 (14.2%)	312 (25.9%)	1205 (100%)				

5.4.4: Variables Showing Statistically Significant Associations with Duration of Leakage

Table 5.43 lists the variables that were significantly associated with duration of leakage at a highly conservative significance level of $\alpha=0.25$. In addition, centres were significantly different within Kenya ($p<0.001$) although not within other countries, where the number of centres of referral was limited

Table 5.43 Variables significantly associated with duration of leakage at p<0.250

Block	Variable	Coefficients potentially in model	P	
Sociodemographic	Country of referral	6	<0.001	
	Centre of referral	14	<0.001	
	Age group	6	<0.001	
	Marital status	4	<0.001	
	Woman's education	4	<0.001	
	Woman unemployed	1	<0.001	
	Woman's occupation	8	<0.001	
	Spouse unemployed	1	<0.001	
	Spouse occupation	8	<0.001	
	Whether husband left	1	<0.001	
	Who do you live with now	6	<0.001	
	How did you first know of camp	5	<0.001	
	Menstruating regularly	1	<0.001	
	Religion	1	0.005	
	Birthweight	1	0.015	
	Spouse education	4	0.022	
	HIV status	1	0.154	
	Number of children currently alive	5	0.181	
	Height	1	0.229	
	Childbirth-related	Catheter inserted after birth	1	<0.001
Duration of labour		1	<0.001	
Relative only present at birth		1	<0.001	
Doctor present at birth		1	0.001	
Leakage after birth		1	0.002	
Relative present at birth		1	0.005	
Skilled attendant at birth		3	0.008	
No-one present at birth		1	0.125	
Traditional birth assistant present at birth		1	0.167	
Gender of infant		1	0.142	
Leg weakness after birth		1	0.240	
Fistula-related		Previous repair (vaginal)	1	<0.001
		Previous repair (rectal)	1	<0.001
	Previous repair (vaginal or rectal)	1	<0.001	
	Severity of excoriation	2	<0.001	
	Parity when fistula developed	5	0.002	
	Haemoglobin	1	0.007	
	Pass urine normally	1	0.015	
	Infant still alive	1	0.065	
	Fistula classification	12	0.131	
	Fistula position	3	0.203	
	Fistula size	1	0.206	
	Problem with urine	1	0.216	
	Vaginal stenosis	1	0.225	

5.5: Multivariate Associations with Successfulness of Surgery

5.5.1: Selection of Variables

Table 5.29 listed variables significantly associated with successfulness of surgery at $p < 0.250$. Variables were selected for multivariate analysis to determine their adjusted associations with successfulness of surgery in three blocks, depending on whether they were sociodemographic, childbirth-related or fistula-related. Variables were considered if their bivariate association was significant at a conservative $\alpha = 0.10$ or if they were felt to be theoretically important, the following variables being chosen (Table 5.44).

Table 5.44 Variables selected for fitting multivariate models for successfulness of surgery

Block	Variable	Coefficients in model	P
Sociodemographic	Country of referral	5 [†]	<0.001
	Woman unemployed	1	0.004
	Number of children currently alive	5	0.060
Childbirth-related	Relative present at birth	1	0.014
	Infant still alive	1	0.064
	Skilled attendance at birth	1	0.117
Fistula-related	Vaginal stenosis	1	0.018
	Problem with faeces	1	0.052
	Fistula position	3	0.063
	Parity when fistula developed	5	0.087
	Haemoglobin	1	0.101

[†] excluding Somalia (n=3)

Binary logistic regression models were fitted for each selected variable in turn and for each group of variables. For the group of sociodemographic variables, two approaches were used for country of referral. In the first approach, country was included in the modelling with Kenya as the reference category but with Somalia excluded as there were only three women referred from that country. In the second approach, country was recoded as 0=referred from Kenya, 1=referred from outside Kenya, with the three Somali women included in the modelling.

5.5.2 Associations with sociodemographic variables

Tables 5.45 and 5.46 summarise the results of fitting binary logistic regression models for the selected sociodemographic variables. The first model in Table 5.45 has country of referral included, while the second model in Table 5.46 has whether the woman was referred from outside Kenya instead.

From Table 5.45, only country of referral ($p < 0.001$) and whether the woman was unemployed ($p = 0.018$) were significantly associated with successfulness of surgery. Adjusted odds ratios were significantly less than 1.0 for all countries compared to Kenya, indicating that successfulness of surgery was less likely for women referred from each of the other countries. For women who were unemployed, the adjusted odds of successful surgery were halved (adjusted OR=0.49). The number of children currently alive was not significantly related to successfulness of surgery ($p = 0.119$). These findings were also reflected in Table 5.46, where the odds of successful surgery were reduced to a quarter for women referred from outside Kenya (adjusted OR=0.23, $p < 0.001$).

5.5.2: **Associations with Childbirth-related Variables**

Table 5.47 summarises the results of fitting binary logistic regression models for the selected childbirth-related variables. Having a relative present at birth reduced the odds of a successful surgery by half (adjusted OR=0.48, $p = 0.029$), while the infant still being alive increased the odds significantly (adjusted OR=1.75, $p = 0.044$). Skilled attendance at birth was not associated with successfulness of surgery (adjusted OR=1.10, $p = 0.471$).

5.5.3: **Associations with Fistula-related Variables**

Table 5.48 summarises the results of fitting binary logistic regression models for the selected fistula-related variables. A higher haemoglobin level increased the odds of a successful surgery (adjusted OR=1.16, $p = 0.034$). None of the other variables were significantly associated with successfulness of surgery at $\alpha = 0.05$, although vaginal stenosis showed a significant association at $\alpha = 0.10$: before adjustment, vaginal stenosis significantly reduced the odds of successful surgery (OR=0.46, $p = 0.021$), but after adjustment for other variables, the impact was reduced (adjusted OR=0.52, $p = 0.063$).

**Table 5.45 Associations between sociodemographic variables and successfulness of surgery
Including country of referral (n=1221†)**

Variable		Univariate			Multivariate		
		Unadjusted OR	95% CI	P	Adjusted OR	95% CI	P
Country	Overall			<0.001			<0.001
	Kenya (reference)	1.00			1.00		
	Malawi	0.13	0.04 to 0.40	<0.001	0.13	0.04 to 0.42	0.001
	DR Congo	0.15	0.06 to 0.38	<0.001	0.21	0.08 to 0.53	0.001
	Rwanda	0.20	0.10 to 0.42	<0.001	0.16	0.07 to 0.34	<0.001
	Southern Sudan	0.19	0.09 to 0.40	<0.001	0.25	0.11 to 0.53	<0.001
	Uganda	0.49	0.21 to 1.15	0.101	0.38	0.16 to 0.91	0.030
Woman unemployed	Yes	0.49	0.31 to 0.80	0.004	0.49	0.28 to 0.89	0.018
	No (reference)	1.00			1.00		
Number of children currently alive				0.083			0.121
	0 (reference)	1.00			1.00		
	1	1.21	0.63 to 2.34	0.563	1.06	0.53 to 2.11	0.874
	2	3.64	1.27 to 10.49	0.017	2.98	1.01 to 8.76	0.047
	3	0.73	0.36 to 1.48	0.387	0.57	0.27 to 1.19	0.135
	4	1.25	0.47 to 3.31	0.658	1.05	0.38 to 2.89	0.923
	5 or more	2.09	0.79 to 5.49	0.136	1.58	0.59 to 4.28	0.365

† excluding Somalia (n=3)

Table 5.46 Associations between sociodemographic variables and successfulness of surgery including outside Kenya (n=1224)

Variable		Univariate			Multivariate		
		Unadjusted OR	95% CI	P	Adjusted OR	95% CI	P
Outside Kenya	Yes	0.24	0.15 to 0.39	<0.001	0.23	0.14 to 0.38	<0.001
	No (reference)	1.00			1.00		
Woman unemployed	Yes	0.50	0.31 to 0.80	0.004	0.49	0.29 to 0.81	0.006
	No (reference)	1.00			1.00		
Number of children currently alive				0.087			0.119
	0 (reference)	1.00			1.00		
	1	1.21	0.63 to 2.33	0.574	1.00	0.51 to 1.98	0.993
	2	3.62	1.26 to 10.44	0.017	2.87	0.98 to 8.39	0.054
	3	0.74	0.37 to 1.49	0.393	0.57	0.27 to 1.18	0.130
	4	1.24	0.47 to 3.29	0.666	1.02	0.37 to 2.79	0.972
5 or more	2.08	0.79 to 5.46	0.138	1.66	0.62 to 4.46	0.317	

Table 5.47 Associations between childbirth-related variables and successfulness of surgery (n=1224)

Variable		Univariate			Multivariate		
		Unadjusted OR	95% CI	P	Adjusted OR	95% CI	P
Relative present at birth	Yes	0.46	0.24 to 0.87	0.017	0.48	0.25 to 0.93	0.029
	No (reference)	1.00			1.00		
Infant still alive	Yes	1.69	0.99 to 2.90	0.057	1.75	1.02 to 3.02	0.044
	No (reference)	1.00			1.00		
Skilled attendance at birth	Yes	1.13	0.88 to 1.45	0.328	1.10	0.85 to 1.42	0.471
	No (reference)	1.00			1.00		

Table 5.48 Associations between fistula-related variables and successfulness of surgery (n=1224)

Variable		Univariate			Multivariate		
		Unadjusted OR	95% CI	P	Adjusted OR	95% CI	P
Vaginal stenosis	Yes	0.46	0.24 to 0.89	0.021	0.52	0.26 to 1.04	0.063
	No (reference)	1.00			1.00		
Problem with faeces	Yes	1.90	0.98 to 3.66	0.056	1.72	0.86 to 3.46	0.127
	No (reference)	1.00			1.00		
Fistula position from EUO	Overall			0.070			0.126
	< 1 cm (reference)	1.00			1.00		
	1-2 cm	1.21	0.54 to 2.67	0.646	1.21	0.54 to 2.72	0.652
	2.1-3 cm	0.55	0.23 to 1.29	0.167	0.57	0.24 to 1.36	0.203
	> 3 cm	0.84	0.31 to 2.23	0.719	0.85	0.31 to 2.30	0.749
Haemoglobin		1.11	0.98 to 1.26	0.101	1.16	1.01 to 1.33	0.034
Parity when fistula developed				0.371			0.282
	0, 1 (reference)	1.00			1.00		
	2	0.58	0.30 to 1.11	0.098	0.51	0.26 to 1.01	0.053
	3	0.57	0.28 to 1.17	0.128	0.54	0.26 to 1.12	0.096
	4	1.07	0.36 to 3.17	0.898	0.93	0.31 to 2.78	0.894
	5 or more	0.71	0.34 to 1.48	0.355	0.76	0.35 to 1.64	0.479

EUO=external urethral orifice

5.5.4: Final Models

Variables were selected for the final multivariate models (one model including country of referral, the other including whether the woman was referred from inside or outside Kenya) if they were significant in the multivariate sociodemographic, childbirth-related or fistula-related models at a significance level of $\alpha=0.10$ (Table 5.49).

Table 5.49 Variables selected for fitting final multivariate model for successfulness of surgery

Block	Variable	Coefficients in model	P
Sociodemographic	Country of referral/ Outside Kenya	5 [†] /1	<0.001/<0.001
	Woman unemployed	1	0.018/0.006
Childbirth-related	Relative present at birth	1	0.029
	Infant still alive	1	0.044
Fistula-related	Vaginal stenosis	1	0.063
	Haemoglobin	1	0.034

[†]excluding Somalia (n=3)

In the final models, sociodemographic variables were added in the first block, followed by childbirth-related variables and then fistula-related variables, the significance of the addition of each block being tested. There was no evidence of multicollinearity between variables within each of the three blocks or overall. In the final model including country of referral, tolerance values ranged between 0.879 and 0.991, well above the critical value of 0.1 considered to indicate problems with multicollinearity. In the final model including inside or outside Kenya, tolerance values ranged from 0.966 to 0.990. In the final models, adjusted associations were considered to be significant at $\alpha=0.05$.

Table 5.50 shows the results for the final multivariate model for successfulness of surgery including country of referral. Introducing the two sociodemographic variables (country and whether the woman was unemployed) significantly improved the model ($p<0.001$), but adding the two childbirth-related variables (relative present at birth and infant still alive) did not ($p=0.094$). Adding the two fistula-related variables (vaginal stenosis and haemoglobin) did produce a significant improvement ($p=0.040$). The overall performance of the final model was significant ($p<0.001$) and the goodness-of-fit was acceptable ($p=0.522$), the model explaining 13.2% of the generalised variance in successfulness of surgery. Country of referral showed the most significant adjusted association with successfulness of surgery ($p<0.001$), with Malawi, the DR Congo, Rwanda and Southern Sudan showing significantly lower odds ratios of success (adjusted OR from 0.13 to 0.31) than the reference country Kenya. Each of the woman being employed (adjusted OR=0.50, $p=0.019$), the presence of vaginal stenosis (adjusted OR=0.48, $p=0.041$) and having a

relative present at birth (adjusted OR=0.50, p=0.044) halved the adjusted odds of a successful surgery. After adjustment for other variables, the associations with the infant still being alive and haemoglobin were no longer statistically significant.

Table 5.50 Final multivariate model for successfulness of surgery including country of referral (n=1221[†])

Block	Variable		Adjusted OR	95% CI	P
Sociodemographic	Country	Overall			<0.001
		Kenya (reference)	1.00		
		Malawi	0.13	0.04 to 0.44	0.001
		DR Congo	0.20	0.08 to 0.53	0.001
		Rwanda	0.16	0.07 to 0.36	<0.001
		Southern Sudan	0.31	0.14 to 0.67	0.003
		Uganda	0.43	0.18 to 1.05	0.063
		Woman unemployed	Yes	0.50	0.28 to 0.89
	No (reference)	1.00			
Childbirth-related	Relative present at birth	Yes	0.50	0.25 to 0.98	0.044
		No (reference)			
		Infant still alive	Yes	1.27	0.72 to 2.24
	No (reference)				
Fistula-related	Vaginal stenosis	Yes	0.48	0.24 to 0.97	0.041
		No (reference)			
		Haemoglobin	1.10	0.95 to 1.26	0.208

[†] excluding Somalia (n=3)

Adding sociodemographic block: $\chi^2=46.57$, df=6, p<0.001

Adding childbirth-related block: $\chi^2=4.74$, df=2, p=0.094

Adding fistula-related block: $\chi^2=6.42$, df=2, p=0.040

Final model: likelihood ratio $\chi^2=57.73$, df=10, p<0.001; Hosmer-Lemeshow goodness-of-fit $\chi^2=7.13$, df=8, p=0.522; Nagelkerke $R^2=0.132$

Table 5.51 shows the results for the final multivariate model for successfulness of surgery including whether or not the woman was referred from Kenya. In general, the results were fairly similar to those in Table 5.50. Introducing the two sociodemographic variables significantly improved the model (p<0.001), but adding the two childbirth-related variables did not (p=0.074). Unlike the model including country of referral, adding the two fistula-related variables did not produce a significant improvement (p=0.077). The overall performance of the final model was significant (p<0.001) and the goodness-of-fit was acceptable (p=0.526), the model explaining 11.8% of the generalised variance. Being referred from outside Kenya showed the most

significant adjusted association with successfulness of surgery (adjusted OR=0.25, $p<0.001$), the adjusted odds of a successful surgery being reduced to a quarter for a woman referred from outside Kenya. As in the previous model, the woman being employed (adjusted OR=0.50, $p=0.008$) or having a relative present at birth (adjusted OR=0.47, $p=0.029$) halved the adjusted odds of a successful surgery. Unlike the previous model, the association between successfulness of surgery and the presence of vaginal stenosis was not statistically significant, although the adjusted odds ratio was numerically similar (adjusted OR=0.53, $p=0.067$). As in the previous model, associations with the infant still being alive and haemoglobin were not statistically significant.

Table 5.51 Final multivariate model for successfulness of surgery including outside Kenya (n=1224)

Block	Variable		Adjusted OR	95% CI	P
Sociodemographic	Outside Kenya	Yes	0.25	0.15 to 0.42	<0.001
		No (reference)	1.00		
	Woman unemployed	Yes	0.50	0.30 to 0.83	0.008
		No (reference)	1.00		
Childbirth-related	Relative present at birth	Yes	0.47	0.24 to 0.93	0.029
		No (reference)	1.00		
	Infant still alive	Yes	1.28	0.73 to 2.24	0.394
		No (reference)			
Fistula-related	Vaginal stenosis	Yes	0.53	0.27 to 1.05	0.067
		No (reference)	1.00		
	Haemoglobin		1.08	0.94 to 1.23	0.300

Adding sociodemographic block: $\chi^2=41.42$, $df=2$, $p<0.001$

Adding childbirth-related block: $\chi^2=5.22$, $df=2$, $p=0.074$

Adding fistula-related block: $\chi^2=5.13$, $df=2$, $p=0.077$

Final model: model $\chi^2=51.77$, $df=6$, $p<0.001$; Hosmer-Lemeshow goodness-of-fit $\chi^2=7.10$, $df=8$, $p=0.526$; Nagelkerke $R^2=0.118$

5.6: Multivariate Associations with Duration of Leakage

5.6.1: Selection of Variables

Table 5.43 showed bivariate associations between variables and duration of leakage. Variables were selected for multivariate analysis to determine their adjusted associations with duration of leakage in three blocks, depending on whether they were sociodemographic, childbirth-related or fistula-related. Variables were initially to be considered if their bivariate association was significant at a conservative $\alpha=0.10$ or if they were felt to be theoretically important. Many variables in Table 5.43 had a bivariate association significant at $\alpha=0.10$, so variables were chosen carefully on theoretical grounds avoiding any felt to be overlapping (Table 5.52).

Table 5.52 Variables initially selected for fitting multivariate models for duration of leakage

Block	Variable	Coefficients in model	P
Sociodemographic	Country of referral	5 [†]	<0.001
	Marital status	4	<0.001
	Woman's education	4	<0.001
	Woman unemployed	1	<0.001
	Whether husband left	1	<0.001
	How did you first know of camp	2 [‡]	<0.001
	Menstruating regularly	1	<0.001
Childbirth-related	Duration of labour	1	<0.001
	Catheter inserted after birth	1	<0.001
	Leakage after birth	1	0.002
	Relative present at birth	1	0.005
	Skilled attendant at birth	3	0.008
	Birthweight	1	0.015
	Infant still alive	1	0.065
Fistula-related	Previous repair	1	<0.001
	Severity of excoriation	2	<0.001
	Parity when fistula developed	5	0.002
	Haemoglobin	1	0.007

[†] excluding Somalia (n=3); [‡] to be recoded to radio, hospital referral or other

Logistic regression models were fitted for each selected variable in turn and for each group of variables. As with successfulness of surgery, for the group of sociodemographic variables, two approaches were used for country of referral. In the first approach, country was included in the modelling with Kenya as the reference category but with Somalia excluded as there were only three women referred from that country. In the second approach, country was recoded as 0=referred from Kenya, 1=referred from outside Kenya, with the three Somali women included in the modelling.

Ordinal logistic regression models were fitted first, as duration of leakage had four ordered categories up to 12 months, 13-60 months, 61-108 months and over 108 months. However, the underlying assumption of equal slope coefficients did not hold for country of referral ($\chi^2=27.83$, $df=10$, $p=0.002$), outside Kenya ($\chi^2=9.91$, $df=2$, $p=0.007$) or marital status ($\chi^2=72.02$, $df=8$, $p<0.001$), or subsequent models including these variables. As these were expected to be important risk factors, multinomial logistic regression models were fitted instead.

5.6.2: **Associations with Sociodemographic Variables**

Tables 5.53 and 5.54 summarise the results of fitting multinomial logistic regression models for the selected sociodemographic variables, with country of referral included in Table 5.53 and whether the woman was referred from outside Kenya included in Table 5.54. A detailed interpretation of the odds ratios will be left until the final model, as addition of variables related to childbirth or the fistula may affect the adjusted odds ratios. The overall p-values in the final column show the significance of the adjusted association between each variable and duration of leakage. From Table 5.53, associations with marital status, the woman's education and how she first knew about the fistula camp were significant at $p<0.001$, while menstruating regularly ($p=0.001$), whether the husband left because of the fistula ($p=0.002$) and country ($p=0.007$) were also significant at $\alpha=0.05$. The only variable that was not significant at $\alpha=0.05$ was whether the woman was unemployed ($p=0.091$), but this variable was included in the final model because $p<0.10$. From Table 5.54, where country was dichotomised into referral from inside or outside Kenya, there were similar findings. Whether the woman was unemployed had the highest p-value ($p=0.046$), so all variables were significantly associated with duration of leakage at $\alpha=0.05$.

Table 5.53 Associations between sociodemographic variables and duration of leakage including country of referral (n=1201 excluding Somalia (n=3))

Variable		Univariate	Multivariate						Overall
		Overall	13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		
		P	Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	
Country	Overall	<0.001							0.007
	Kenya (reference)		1.00						
	Malawi		1.07	0.928	3.38	0.063	0.72	0.650	
	DR Congo		1.97	0.117	1.08	0.910	0.55	0.385	
	Rwanda		1.69	0.205	1.82	0.183	1.23	0.606	
	Southern Sudan		2.21	0.019	1.57	0.268	0.60	0.216	
	Uganda		0.58	0.088	0.78	0.473	0.45	0.008	
Marital status	Overall	<0.001							<0.001
	Single		1.20	0.376	0.96	0.847	0.47	0.001	
	Married (reference)		1.00						
	Separated		1.11	0.788	0.90	0.811	1.57	0.212	
	Divorced		3.07	0.005	0.37	0.113	1.48	0.357	
	Widowed		1.92	0.189	1.87	0.249	6.48	<0.001	
Woman's education	Overall	<0.001							<0.001
	None (reference)		1.00						
	Primary		1.02	0.931	0.94	0.838	0.83	0.441	
	Secondary		0.60	0.098	0.69	0.301	0.38	0.002	
	College/university		0.62	0.277	0.89	0.792	0.10	0.001	
Woman unemployed	Overall	<0.001							0.091
	Yes		0.85	0.347	0.63	0.026	0.71	0.059	
	No (reference)		1.00						
Husband left because of fistula	Overall	<0.001							0.002
	Yes		1.41	0.155	2.40	0.001	2.18	0.002	
	No (reference)		1.00						
How did you first know of camp	Overall	<0.001							<0.001
	Radio		3.27	<0.001	3.22	<0.001	7.72	<0.001	
	Other		1.63	0.086	2.82	0.001	3.66	<0.001	
	Hospital referral (reference)		1.00						
Menstruating regularly	Overall	<0.001							0.001
	Yes		1.88	<0.001	1.31	0.158	1.05	0.795	
	No (reference)		1.00						

Table 5.54 Associations between sociodemographic variables and duration of leakage including outside Kenya (n=1204)

Variable		Univariate	Multivariate						Overall
		Overall	13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		
		P	Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	
Outside Kenya	Overall	0.004							0.007
	Yes		1.22	0.308	1.26	0.313	0.65	0.039	
	No (reference)		1.00						
Marital Status	Overall	<0.001							<0.001
	Single		1.15	0.471	0.93	0.740	0.46	0.001	
	Married (reference)		1.00						
	Separated		1.10	0.812	0.90	0.762	1.62	0.179	
	Divorced		2.80	0.008	0.36	0.098	1.45	0.372	
	Widowed		2.05	0.146	1.89	0.241	6.73	<0.001	
Woman's Education	Overall	<0.001							<0.001
	None (reference)		1.00						
	Primary		0.92	0.715	0.94	0.824	0.81	0.370	
	Secondary		0.55	0.043	0.68	0.278	0.36	0.001	
	College/university		0.58	0.209	0.89	0.793	0.10	0.001	
Woman Unemployed	Overall	<0.001							0.046
	Yes		0.97	0.875	0.65	0.034	0.69	0.037	
	No (reference)		1.00						
Husband left because of fistula	Overall	<0.001							0.001
	Yes		1.48	0.104	2.45	0.001	2.21	0.001	
	No (reference)		1.00						
How did you first know of camp	Overall	<0.001							<0.001
	Radio		3.03	<0.001	3.23	<0.001	7.88	<0.001	
	Other		1.66	0.060	2.89	<0.001	3.75	<0.001	
	Hospital referral (reference)		1.00						
Menstruating regularly	Overall	<0.001							<0.001
	Yes		1.93	<0.001	1.30	0.166	1.06	0.717	
	No (reference)		1.00						

5.6.3: **Associations with Childbirth-related Variables**

Table 5.55 summarises the results of fitting a multinomial logistic regression model for the selected childbirth-related variables. Associations with marital status ($p < 0.001$), whether a catheter was inserted after birth ($p = 0.003$), leakage after birth ($p = 0.003$) and birthweight ($p = 0.004$) had the most significant associations with duration of leakage, while having a relative present at the birth ($p = 0.020$) and having a skilled attendant at birth ($p = 0.034$) also had significant associations at $\alpha = 0.05$. The only variable with $p > 0.10$ was whether the infant was still alive ($p = 0.135$). All of the variables except for this one were included in the final model.

5.6.4: **Associations with Fistula-related Variables**

Table 5.56 summarises the results of fitting a multinomial logistic regression model for the selected fistula-related variables. The association with previous fistula repairs ($p < 0.001$) was the most significant, while haemoglobin ($p = 0.004$) and severity of excoriation ($p = 0.005$) also had the associations with duration of leakage. The only variable not having a significant association at $\alpha = 0.05$ was parity when the fistula developed ($p = 0.061$), but this satisfied $p < 0.10$. All of the variables were therefore included in the final model.

Table 5.55 Associations between childbirth-related variables and duration of leakage (n=1106)

Variable		Univariate	Multivariate						
		P	13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		Overall
			Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	P
Duration of labour		0.001	1.01	0.024	1.01	0.040	1.01	<0.001	<0.001
Birthweight		0.012	1.21	0.057	1.38	0.003	1.33	0.002	0.004
Relative present at birth	Overall	0.004							0.020
	Yes		2.32	0.004	1.64	0.174	2.10	0.013	
	No (reference)		1.00		1.00		1.00		
Skilled attendant at birth	Overall	0.007							0.034
	None (reference)		1.00				1.00		
	Midwife		1.34	0.191	1.23	0.437	1.50	0.076	
	Doctor		0.80	0.327	1.03	0.923	1.18	0.461	
	Doctor and midwife		0.47	0.020	0.51	0.089	0.78	0.419	
Catheter inserted after birth	Overall	<0.001							0.003
	Yes		0.69	0.034	0.63	0.023	0.54	<0.001	
	No (reference)		1.00		1.00		1.00		
Leakage after birth	Overall	0.007							0.003
	Yes		1.71	0.074	2.19	0.043	3.16	0.001	
	No (reference)		1.00		1.00		1.00		
Infant still alive	Overall	0.252							0.135
	Yes		0.79	0.179	0.81	0.304	0.67	0.021	
	No (reference)		1.00		1.00		1.00		

Table 5.56 Associations between fistula-related variables and duration of leakage (n=1173)

Variable		Univariate	Multivariate						
		Overall	13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		Overall
		P	Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	P
Haemoglobin		0.006	1.03	0.425	1.11	0.031	1.15	0.001	0.004
Previous repairs	Overall	<0.001							<0.001
	Yes		1.74	0.003	1.83	0.006	3.20	<0.001	
	No (reference)		1.00		1.00		1.00		
Excoriation	Overall	<0.001							0.005
	Mild (reference)		1.00		1.00		1.00		
	Moderate/severe		1.21	0.240	1.01	0.965	1.72	0.001	
Parity when fistula developed	Overall	0.014							0.061
	0/1 (reference)		1.00		1.00		1.00		
	2		0.65	0.044	0.72	0.178	0.54	0.005	
	3		0.56	0.016	0.49	0.017	0.51	0.006	
	4		0.60	0.095	0.49	0.062	0.75	0.309	
	5 or more		0.87	0.527	0.66	0.151	0.82	0.390	

5.6.5: Final Models

As in the modelling for successfulness of surgery, variables were selected for the final model for duration of leakage if they were significant in the multivariate sociodemographic, childbirth-related or fistula-related models at a significance level of $\alpha=0.10$ (Table 5.57). Only whether the infant was still alive was dropped from the final models ($p=0.135$). In the final models, sociodemographic variables were added in the first block, followed by childbirth-related variables and then fistula-related variables. Table 5.58 shows the final model with country included while Table 5.59 shows the final model with country dichotomised into inside or outside Kenya; given the number of independent variables, both tables are in two parts. Although 18 independent variables were included, requiring in 36 and 32 coefficients in each of the three comparisons of a duration group against the reference category of up to 12 months, both models converged to a solution. There was no evidence of multicollinearity between sociodemographic variables, between childbirth-related variables, between fistula-related variables or between all variables included in the final models. In the final model including country of referral, tolerance values ranged between 0.451 and 0.958, well above the value of 0.1 considered to indicate problems with multicollinearity. In the final model including inside or outside Kenya, tolerance values ranged from 0.475 to 0.965. In the final models, adjusted associations were considered to be significant at $\alpha=0.05$.

Table 5.57 Variables selected for fitting final multivariate model duration of leakage

Block	Variable	Coefficients in model	P
Sociodemographic	Country of referral/ Outside Kenya	5 [†] /1	0.007/0.007
	Marital status	4	<0.001/<0.001
	Woman's education	4	<0.001/<0.001
	Woman unemployed	1	0.091/0.046
	Whether husband left	1	0.002/0.001
	How did you first know of camp	2 [‡]	<0.001/<0.001
	Menstruating regularly	1	0.001/<0.001
Childbirth-related	Duration of labour	1	<0.001
	Catheter inserted after birth	1	0.003
	Leakage after birth	1	0.003
	Relative present at birth	1	0.020
	Skilled attendant at birth	3	0.034
	Birthweight	1	0.004
Fistula-related	Previous repair	1	<0.001
	Severity of excoriation	2	0.005
	Parity when fistula developed	5	0.061
	Haemoglobin	1	0.004

[†] excluding Somalia (n=3); [‡] recoded as radio, hospital referral or other

Table 5.58 shows the results for the final multivariate model for successfulness of surgery including country of referral. Introducing the seven sociodemographic variables significantly improved the model ($p < 0.001$), as did adding the six childbirth-related variables ($p < 0.001$) and the four fistula-related variables ($p < 0.001$). The overall performance of the final model was significant ($p < 0.001$) and the goodness-of-fit was acceptable ($p = 0.075$), the model explaining 40.1% of the generalised variance in duration of leakage.

All of the sociodemographic variables included in the final model (Table 5.58 part 1) were significantly associated with duration of leakage after adjustment for other variables (overall $p \leq 0.038$), as were 4/6 childbirth-related variables and 2/4 fistula-related variables (Table 5.58 part 1). Among the sociodemographic variables, marital status and how the woman first heard about the fistula camps were the most significant (both $p < 0.001$), followed by whether the husband left because of the fistula ($p = 0.007$), whether the woman was menstruating regularly ($p = 0.009$) and country of referral ($p = 0.010$). Among the childbirth-related variables, duration of birth ($p < 0.001$) was the most significant, along with catheter inserted after birth ($p = 0.004$) and leakage after birth ($p = 0.006$), and followed by the type of skilled attendant at birth ($p = 0.025$). Among the fistula-related variables, having previous fistula repairs ($p < 0.001$) was the most significant, followed by parity when the fistula developed ($p = 0.002$). Over the three blocks, variables whose adjusted association was not significant included birthweight ($p = 0.279$), relative present at birth (0.225) and haemoglobin (0.160), while excoriation just failed to be significant ($p = 0.052$).

Examining the actual associations to determine why the overall associations are significant was complicated because there were three simultaneous comparisons of duration category against the reference category of up to 12 months. A high adjusted odds ratio indicates that the duration category is more likely than to the reference category; a low adjusted odds ratio indicates that the duration category is less likely than the reference category.

Taking the sociodemographic variables first, relative to a duration of up to 12 months and compared with the reference category of married women, divorced and widowed women were more likely to have a duration of 13-60 months (adjusted OR=3.05 and 2.68 respectively); widowed women were also more likely to have a duration of over 108 months (adjusted OR=12.24) while single women (adjusted OR=0.18) were less likely to have a duration of over 108 months. For single women, the adjusted odds ratio decreased with increasing duration – they were less likely to have a longer duration of leakage, although only the comparison at over 108 months was statistically significant – while for divorced women, the opposite was true: their adjusted odds ratio increased with increasing duration – they were more likely to have a longer

duration, although again, only the final comparison was significant. Separated and divorced women were more likely to have duration of 13-60 or over 108 months; although most adjusted odds ratios were not significant. These observations explain why an ordinal logistic regression model did not fit well.

Compared against a duration of leakage of up to 12 months and being referred from the hospital, women were more likely to have a longer duration if they first heard about the fistula camps from the radio (adjusted OR=2.97, 2.89 and 6.91 for 13-60 months, 61-108 months and over 108 months respectively), and more likely to have a duration longer than 60 months if they heard from other sources (adjusted OR=2.69 for 61-108 months and 2.50 for over 108 months). Women whose husband had left because of the fistula were more likely to have longer durations of leakage (adjusted OR=2.62 for 61-108 months and 2.02 for over 108 months), while women menstruating regularly were more likely to have a duration of 13-60 months (adjusted OR=1.64).

Although country of referral had a significant association overall ($p=0.010$), the adjusted odds ratios were only statistically significant for Southern Sudan and Uganda, durations of over 108 months being less likely (adjusted OR=0.31 and 0.44 respectively). With Kenya as the reference category, adjusted odds ratios were greater than 1.0 for Malawi, the DR Congo, Rwanda and Southern Sudan for 13-60 months compared with up to 12 months. Women referred from these countries were more likely to have a duration of 13-60 months than those from Kenya but not significantly so. Adjusted odds ratios only showed a decreasing trend with duration for the DR Congo and Southern Sudan – women referred from those countries were less likely to have a longer duration of leakage. For Malawi, Rwanda and Uganda, adjusted odds ratios were highest for 61-108 months, further evidence why an ordinal logistic regression model did not perform well.

For the women's education, the only significant odds ratio was for those educated to college or university level, who were less likely to have a duration of leakage over 108 months (adjusted OR=0.12). Adjusted odds ratios for those with more than a primary education were all less than 1.0, suggesting that such women were less likely to have a longer duration of leakage. Being unemployed was associated with a shorter duration of leakage (adjusted OR=0.72, 0.54 and 0.65 for 13-60 months, 61-108 months and over 108 months respectively), although only the latter two were significant.

Among the childbirth-related variables, a longer duration of labour was significantly associated with a duration of leakage of over 108 months ($p<0.001$) but the adjusted association just failed

to be significant for 61-108 months ($p=0.054$). Having a catheter inserted after birth was associated with a shorter duration of leakage (adjusted OR=0.72, 0.58 and 0.48 for 13-60 months, 61-108 months and over 108 months respectively), although only the latter two were significant. Women with leakage after birth were more likely to have a longer duration (adjusted OR=1.77, 2.25 and 4.17 for 13-60 months, 61-108 months and over 108 months respectively), although the first two were not significant at $\alpha=0.05$ ($p=0.099$ and 0.062 respectively). For the type of skilled attendant at birth, the adjusted odds ratios were only significant when both a doctor and a midwife were present: when both were present, duration of leakage was more likely to be shorter (adjusted OR=0.35, 0.38 and 0.46 for 13-60 months, 61-108 months and over 108 months respectively), all three adjusted associations being significant. Adjusted odds ratios were consistently higher when there was only a midwife present compared with only a doctor being present, although none were significantly different from 1.0.

Among the fistula-related variables, having previous fistula repairs was associated with a longer duration of leakage (adjusted OR=1.99, 1.99 and 4.17 for 13-60 months, 61-108 months and over 108 months respectively), all three adjusted associations again being significant. For parity when the fistula developed, a parity of 0 or 1 was the reference category. Higher parity was associated with shorter duration of leakage, adjusted odds ratios for parities of 2, 3, 4 and 5 or more all being less than 1.0, although not all were statistically significant. All three adjusted odds ratios for parity 2 and parity 3 were significantly less than 1.0, as were all four odds ratios for a duration of 61-108 months compared with up to 12 months.

Table 5.59 shows the results for the final multivariate model for successfulness of surgery including whether the woman was referred from outside Kenya instead of country of referral. As before, introducing the seven sociodemographic variables significantly improved the model ($p<0.001$), as did adding the six childbirth-related variables ($p<0.001$) and the four fistula-related variables ($p<0.001$). The overall performance of the final model was significant ($p<0.001$) and the goodness-of-fit was acceptable ($p=0.103$), the model explaining 39.2% of the generalised variance in duration of leakage.

The pattern of results for overall associations and odds ratios agreed with that for the previous model with country of referral. The overall adjusted association between referral from outside Kenya and duration of leakage was significant ($p=0.002$), and this was due to the comparison of durations over 108 months compared with the reference of up to 12 months. The adjusted odds of a woman having a duration of over 108 months were halved if she had been referred from outside Kenya (adjusted OR=0.50, $p=0.005$). The similarity between the results for the model

including country of referral and those for the model including referral from outside Kenya indicated that much of the impact of country on duration of leakage lay in whether the woman was referred from inside or outside Kenya.

Table 5.58 Final model for duration of leakage including country of referral (n=1068†) (part 1)

Variable		13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		Overall P
		Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	
Country	Overall							0.010
	Kenya (reference)	1.00						
	Malawi	1.06	0.939	3.72	0.068	0.65	0.592	
	DR Congo	1.79	0.224	0.89	0.867	0.27	0.117	
	Rwanda	1.48	0.372	1.58	0.352	0.91	0.838	
	Southern Sudan	1.64	0.246	0.77	0.634	0.31	0.033	
	Uganda	0.65	0.229	0.76	0.496	0.44	0.021	
Marital status	Overall							<0.001
	Single	0.90	0.643	0.65	0.107	0.18	<0.001	
	Married (reference)	1.00						
	Separated	1.08	0.862	0.75	0.553	1.35	0.475	
	Divorced	3.05	0.012	0.39	0.150	1.36	0.537	
	Widowed	2.68	0.102	3.19	0.072	12.24	<0.001	
Woman's education	Overall							0.035
	None (reference)	1.00						
	Primary	1.29	0.369	1.09	0.799	0.97	0.905	
	Secondary	0.87	0.707	0.80	0.581	0.58	0.147	
	College/university	0.72	0.499	0.80	0.671	0.12	0.003	
Woman unemployed	Overall							0.038
	Yes	0.72	0.096	0.54	0.008	0.65	0.045	
	No (reference)	1.00						
Husband left because of fistula	Overall							0.007
	Yes	1.58	0.086	2.62	0.001	2.02	0.017	
	No (reference)	1.00						
How did you first know of camp	Overall							<0.001
	Radio	2.97	<0.001	2.89	<0.001	6.91	<0.001	
	Other	1.47	0.232	2.69	0.003	2.50	0.010	
	Hospital referral (reference)	1.00						
Menstruating regularly	Overall							0.009
	Yes	1.64	0.007	1.08	0.713	0.88	0.511	
	No (reference)	1.00						

Table 5.58 Final model for duration of leakage including country of referral (n=1068†) (part 2)

Variable		13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		Overall
		Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	P
Duration of labour		1.00	0.189	1.01	0.054	1.01	<0.001	<0.001
Birthweight		1.12	0.303	1.25	0.060	1.16	0.180	0.279
Relative present at birth	Overall							0.225
	Yes	2.32	0.041	1.33	0.467	1.56	0.211	
	No (reference)	1.00		1.00		1.00		
Skilled attendant at birth	Overall							0.025
	None (reference)	1.00				1.00		
	Midwife	1.16	0.543	1.10	0.740	1.33	0.309	
	Doctor	0.74	0.233	1.00	0.992	1.05	0.867	
	Doctor and midwife	0.35	0.004	0.38	0.028	0.46	0.041	
Catheter inserted after birth	Overall							0.004
	Yes	0.72	0.091	0.58	0.015	0.48	<0.001	
	No (reference)	1.00		1.00		1.00		
Leakage after birth	Overall							0.006
	Yes	1.77	0.099	2.25	0.062	4.17	<0.001	
	No (reference)	1.00		1.00		1.00		
Haemoglobin		1.03	0.425	1.09	0.142	1.11	0.043	0.160
Previous repairs	Overall							<0.001
	Yes	1.99	0.002	1.99	0.006	4.17	<0.001	
	No (reference)	1.00		1.00		1.00		
Excoriation	Overall							0.052
	Mild (reference)	1.00		1.00		1.00		
	Moderate/severe	1.14	0.490	1.01	0.982	1.68	0.012	
Parity when fistula developed	Overall							0.002
	0/1 (reference)	1.00		1.00		1.00		
	2	0.54	0.017	0.50	0.016	0.38	0.001	
	3	0.47	0.010	0.37	0.003	0.33	<0.001	
	4	0.63	0.214	0.47	0.072	0.67	0.263	
	5 or more	0.71	0.226	0.37	0.005	0.36	0.001	

† excluding Somalia (n=3): adding sociodemographic block: $\chi^2=334.43$, df=51, p<0.001; Adding childbirth-related block: $\chi^2=70.37$, df=24, p<0.001
Adding fistula-related block: $\chi^2=93.74$, df=21, p<0.001; final model: likelihood ratio $\chi^2=498.54$, df=96, p<0.001; Pearson goodness-of-fit $\chi^2=3158.20$,
df=3045, p=0.075; Nagelkerke R²=0.401

Table 5.59 Final model for duration of leakage including outside Kenya (n=1071) (part 1)

Variable		13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		Overall
		Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	P
Outside Kenya	Overall							0.002
	Yes	1.11	0.628	1.04	0.895	0.50	0.005	
	No (reference)	1.00						
Marital status	Overall							<0.001
	Single	0.86	0.503	0.63	0.085	0.18	0.001	
	Married (reference)	1.00						
	Separated	1.05	0.911	0.76	0.558	1.43	0.388	
	Divorced	2.99	0.012	0.41	0.170	1.43	0.463	
	Widowed	2.80	0.086	3.25	0.167	12.91	<0.001	
Woman's education	Overall							0.033
	None (reference)	1.00						
	Primary	1.22	0.470	1.09	0.784	0.94	0.830	
	Secondary	0.83	0.594	0.79	0.564	0.57	0.122	
	College/university	0.70	0.454	0.78	0.634	0.11	0.002	
Woman unemployed	Overall							0.019
	Yes	0.78	0.198	0.53	0.005	0.61	0.017	
	No (reference)	1.00						
Husband left because of fistula	Overall							0.007
	Yes	1.63	0.062	2.58	0.001	1.97	0.019	
	No (reference)	1.00						
How did you first know of camp	Overall							<0.001
	Radio	2.82	<0.001	2.99	<0.001	7.40	<0.001	
	Other	1.49	0.215	2.68	0.003	2.57	0.008	
	Hospital referral (reference)	1.00						
Menstruating regularly	Overall							0.005
	Yes	1.8	0.004	1.08	0.696	0.89	0.537	
	No (reference)	1.00						

Table 5.59 Final model for duration of leakage including outside Kenya (n=1071) (part 2)

Variable		13-60 v up to 12 months		61-108 v up to 12 months		Over 108 v up to 12 months		Overall
		Adjusted OR	P	Adjusted OR	P	Adjusted OR	P	P
Duration of labour		1.00	0.106	1.00	0.081	1.01	<0.001	0.001
Birthweight		1.10	0.372	1.23	0.081	1.15	0.220	0.351
Relative present at birth	Overall							0.174
	Yes	1.99	0.030	1.35	0.438	1.62	0.171	
	No (reference)	1.00		1.00		1.00		
Skilled attendant at birth	Overall							0.016
	None (reference)	1.00				1.00		
	Midwife	1.15	0.569	1.11	0.718	1.36	0.280	
	Doctor	0.71	0.169	1.00	0.989	1.07	0.801	
	Doctor and midwife	0.34	0.003	0.37	0.024	0.46	0.044	
Catheter inserted after birth	Overall							0.005
	Yes	0.71	0.080	0.58	0.015	0.49	0.001	
	No (reference)	1.00		1.00		1.00		
Leakage after birth	Overall							0.008
	Yes	1.74	0.111	2.16	0.076	3.98	0.001	
	No (reference)	1.00		1.00		1.00		
Haemoglobin		1.02	0.671	1.09	0.133	1.12	0.025	0.104
Previous repairs	Overall							<0.001
	Yes	1.92	0.003	1.98	0.006	4.22	<0.001	
	No (reference)	1.00		1.00		1.00		
Excoriation	Overall							0.054
	Mild (reference)	1.00		1.00		1.00		
	Moderate/severe	1.17	0.420	1.03	0.882	1.69	0.010	
Parity when fistula developed	Overall							0.001
	0/1 (reference)	1.00		1.00		1.00		
	2	0.53	0.013	0.49	0.014	0.38	<0.001	
	3	0.45	0.005	0.36	0.002	0.34	<0.001	
	4	0.61	0.178	0.46	0.066	0.64	0.223	
	5 or more	0.68	0.168	0.36	0.003	0.35	0.001	

Adding sociodemographic block: $\chi^2=319.94$, $df=39$, $p<0.001$: Adding childbirth-related block: $\chi^2=69.45$, $df=24$, $p<0.001$

Adding fistula-related block: $\chi^2=97.03$, $df=21$, $p<0.001$:Final model: likelihood ratio $\chi^2=486.42$, $df=84$, $p<0.001$; Pearson goodness-of-fit $\chi^2=3165.61$, $df=3066$, $p=0.103$; Nagelkerke $R^2=0.392$

5.6.6: Summary of Quantitative Findings

A total of 1224 women took part in the cohort study. Almost three quarters (897, 73.3%) had been referred from Kenya, with smaller numbers referred from Uganda (104), Rwanda (75), Southern Sudan (70), the DR Congo (38), Malawi (19) and Somalia (3). The most common age groups were 18-27 years (36.9%) and 28-37 years (34.8%). Most women were married (60.9%), with 6.5% separated and 6.0% divorced, and almost two thirds (64.7%) had one or more children still alive. Most women had only been educated to primary school level (62.9%) with a further 17.0% having had no education. Only 59 women (4.8%) had been educated to college level or higher and all were from Kenya. Four in ten women (40.1%) were unused: the percentages unused were lower for Rwanda (13.5%) and Uganda (13.2%) where peasant farmer was the most common occupation. Just over half of the women were menstruating regularly (52.0%), although this also varied by country of referral, from 42.1% for Malawi to 84.2% for the DR Congo. Most women (77.9%) were in a good general condition for surgery with 6.0% HIV positive.

There had been a skilled attendant at the childbirth for most women (70.3%), although this percentage varied by country from 54.9% for Southern Sudan to 91.1% for Uganda. A relative had been present at one birth in ten (9.9%). Only a relative had been present at 5.9% of the births while 93 women (7.6%) had given birth on their own. Among all women, the median duration of labour was 48 hours, and the mean birthweight was 3.53 kg. Most babies were male (58.2%) but only 37.5% of the new-borns were still alive. After the birth, just over half of the women had a catheter inserted (55.0%), while 90.2% of women had urine leakage and 32.4% had leg weakness.

The fistula had developed after the first childbirth in almost half of the women (44.6%). Over a fifth of all women (21.9%) had been deserted by their husband because of the fistula. While more than half of all women still lived with their husband (53.1%), 11.9% lived alone and 17.6% lived with their parents. Half of the women (49.6%) had heard about the fistula camps from the radio, with 39.7% referred from a hospital. Women with primary or secondary education were more likely to have heard about the camps from the radio, while college- or university-educated women (who had all been referred from Kenya) were more likely to have been referred from hospital. Slightly more women with no education had been referred from hospital (47.6%) than learned about the camps from the radio (44.2%).

The most common vaginal fistula classifications were VVF 11Aa (25.1% of all women) and VVF1 (20.6%), the most common recto-vaginal fistula being RVF11b (11.0% of all women). The mean fistula diameter was 2.15 cm, with most being 1-2 cm from the external urethral orifice. Among women referred from the DR Congo, the mean size was larger and the fistula was more likely to be at that position. Only 6.3% of women presented with more than one fistula, but 27.5% had had a previous but unsuccessful fistula repair, with repairs being most common in women referred from Rwanda (45.9%) and Uganda (43.4%). Faecal leakage occurred in a quarter of the women (25.2%): most women (80.7%) reported urine leakage, with more than half (60.1%) unable to urinate normally. More than a third (36.4%) had urine leakage for up to 12 months and more than a quarter (26.1%) for over 9 years. Vaginal stenosis was very common (72.4%) while vulvar excoriation was mostly mild (61.2%) or moderate (35.4%).

The high success rate for surgery (94.1%, 95% CI 92.6% to 95.3%) may have limited the ability to find independent predictors of successfulness of surgery. Only being referred from Malawi, the DR Congo, Rwanda or Southern Sudan, being unused, having a relative present at birth and vaginal stenosis were negatively associated with successfulness of surgery. Country of referral was the strongest predictor ($p < 0.003$ for those four countries relative to Kenya).

Many variables were independently associated with duration of leakage. The most significant predictors were marital status, method of knowledge of the fistula camp, duration of labour, having previous repairs, parity when the fistula developed, having a catheter inserted after birth, leakage after birth, husband leaving because of fistula, menstruating regularly and country of referral (all $p < 0.010$ when countries were included separately). Interpretation was complicated by the necessary use of a multinomial logistic regression approach, but a shorter duration of leakage was generally associated with being single, being referred from a hospital, menstruating regularly and having a catheter inserted after birth, while a longer duration of leakage was generally associated with being divorced or widowed, learning about the fistula camp from the radio, a longer duration of labour, having previous fistula repairs, having a lower parity when the fistula developed, leakage after birth and the husband leaving because of the fistula, but there was no consistent pattern for country of referral.

Chapter 6: QUALITATIVE RESULTS

6.1: Introduction

In this chapter, the researcher presents findings of the phenomenology study. A short summary of all respondents in this component of study are described in 6.1. The phenomenological study described herein was conducted in one East African Country, Kenya. Because of logistical challenges, it was not possible to include other East African countries. In Kenya, three counties were selected for study: namely Mombasa, Kisii and Kenyatta Hospital. A total of twenty participants were recruited at month zero when the first interviews were conducted. Second interviews occurred at month six; it is during this visit that four participants failed to turn up. In Kisii, three out of ten respondents failed to attend the second interview while only one failed to turn up at the Coast general hospital as indicated in the narratives below (Gladness, Fatima, Pendo and Patience). Kenyatta Hospital had 100% follow up and interview attendance. All transcriptions were done per verbatim and included in the analysis (Table 6.1). Participants who did not turn up for the second interviews were excluded from the analysis. The table below presents pseudonyms, site codes and number of fistula surgeries attended.

Table 6.1.: Characteristics of Respondents

	Pseudonyms /Codes	1 st Time Repairs	Repeat Repairs
Region 1 Coast General Hospital 6 in-depth interviewees	RC002 Gladness	X	
	RC004 Salma	X	
	RC001 Fatima	X	
	RC003 Malaika		XXXX
	RC006 Taabu		XX
	RC005 Pendo		XX
Region 2 Kisii Level 5 Hospital 7 in-depth interviewees	KR 003 Binti		XX
	KR 006 Sandra		XX
	KR0010 Princess		XX
	KR004 Generous	X	
	KR 008 Flower	X	
	KR007 Patience	X	
Region 3 Kenyatta National Hospital 4 in-depth interviews	KNR001 Fairness	X	
	KNR 003 Clarity	X	
	KNR002 Darling	X	
	KNR004 Starline	X	

X = number of repairs

6.2: Characteristics of Participants

Pseudo names were used to help maintain the confidentiality of respondents as guided by ethical guidelines applied in qualitative research.

1. Gladness

Gladness was aged 28 years with two previous deliveries. Her fistula developed after the second delivery and her baby died at birth. She attended secondary education up to form two (lower secondary school) and had no steady income. She was divorced because of the fistula and had lived with fistula for two years before access to repair services. This was her first repair having been referred by hospital staff. She was operated and the fistula healed well.

2. Salma

Salma was 37 years old with 4 previous deliveries. She had primary level of education with no steady income. She was divorced because of fistula following which her children dropped out of school. She had lived with the fistula for 10 years before repair. There was no history of previous access to fistula services. Her surgery went well; after surgery she presented with stress incontinence which resolved with kegel exercises.

3. Fatima

Fatima was 32 year old, with four deliveries, her last delivery the baby died and it is this delivery time that resulted into her the fistula. She was married and still lived with the partner. She used to supplement family income by farming but now this income generating activity stopped because of fistula. Fatima had lived with fistula for 2years: she had never been repaired before. Her surgery went well and she healed without complications. All through her hospital stay, her husband was by her side until discharge and follow up period.

4. Malaika

Malaika was 25 years old, had four deliveries and on admission she had a two months old baby. She had never attended school, had no steady income and relied on selling charcoal to feed her three children. Her husband had abandoned her approximately 11 months prior to admission. Malaika reported having lived with fistula for 11 years, within this

period she had three pregnancies and had had four previous repairs which broke down due to early engagement in sexual intercourse. Following the repair, she was discharged earlier than planned from hospital after just two days post repair when the staff went on strike. This affected her healing: her repair broke down on the way home and she had to keep the catheter in place for a longer period. She was vulnerable to a failed repair given her history of four previous repairs. This repair failed leading to suicidal tendencies because she had no hope for the future.

5. Taabu

Taabu was a young girl aged 22, with one twin delivery. She recalled that it was a home delivery following which the fistula developed at age 16. She had never attended school and had no income. She had one previous surgery to close the fistula. In 2009 she had an operation where bladder stones were removed. Her first husband divorced her in 2007 because of fistula. At the interview time, Taabu said she was now cohabiting with an abusive partner. However, she reported that he was abusive. The repair went well but during the post-operative period, she was depressed which necessitated psychiatric treatment. Later she healed well and was discharged home.

6. Pendo

Pendo was 53 years old, who had one previous caesarean delivery in a private hospital. Her baby boy died at birth. She attained secondary level of education. Pendo worked as a shop assistant at her uncle's shop in exchange for accommodation and food. She was abandoned in ICU by in-laws. Her partner never turned up at the hospital after fistula developed. Pendo had undergone one previous fistula repair and hysterectomy due to fibroids. After the current surgery, she healed well but on discharge cried a lot because she had no home to go. A friend who had offered to accommodate her declined. The surgeon and the fistula team did rent a small room where she lives now.

7. Fairness

Fairness was an elderly, post-menopausal lady aged 64 years. She was a para eight deliveries, the seven babies were still births. Her only child died at age of 16. The fistula was caused by a 5th delivery where caesarean section was done way back in 1976. She was only 15 years old when fistula developed and her husband packed her things and

ordered her to leave. She had never had VVF repair before. Fairness was a house wife who never attended school. Her post-operative period was uneventful.

8. Darling

Darling was 24 old years. She had one delivery which occurred at home and was divorced six months after fistula developed. She attended school up to primary level and had no income. The surgery went well and the fistula healed completely with no complications.

9. Clarity

Clarity was a young girl, aged only 19 years, was married at age 14, has had two deliveries. She got her first pregnancy at age 16 and delivered at 17 years. The fistula followed delivery by caesarean section during her first delivery, at age 17. She attended primary school up to standard three (lower primary). Clarity lived with fistula for eight months before she conceived her second baby, by the interview time the baby was three months. A house wife lives with the husband and has no income. The fistula was repaired and healed well.

10. Starline

Aged 44 had six deliveries and all the children are alive and well. She had completed secondary education and worked as an office assistant in Nairobi. She developed the fistula in 2005 during a twin delivery in a hospital. Married and lived with the husband. Starline lived with the fistula for 9 years ago before repair. The surgery went well: post operatively she healed well without complications.

11. Binti

Binti was 55 years of age. She had one previous delivery and the child died 9 years later. Her fistula developed in 1993 and she got divorced shortly thereafter. She had never attended school and had a small business next to her house. She had never been repaired before. During surgery, all went well and she healed without complications.

12. Sandra

Sandra was aged 18, had one delivery, dropped out of primary school at age 14 because of pregnancy. She developed fistula during her first delivery, was abandoned in the hospital by her first boyfriend. She had no income and was in a second relationship even

with fistula. She had lived with fistula for three years before repair. She had a successful surgery and fistula healed well

13. Princess

Princess was a young, single, girl aged 17 years, who had delivered once, and was a secondary school student in a day school. Being a student she had no income. She had lived with fistula for two years. She reported a previous surgery done at a different facility which failed to close the VVF. Surgery was done and post operatively fistula healed well without complications.

14. Generous

Generous was a 45 years old lady, with one delivery who had never attended school. At the time of interview she was a housewife with no income. The fistula developed in 1974. She had four surgeries prior to close fistula without success, however, she lived in the same compound with husband with her co-wife who he married a week after fistula developed. Surgery was done and went well. Post operatively she healed but still leaked urine, though the amount had reduced drastically. She was advised to go for physiotherapy. After six months she healed completely.

15. Maua

Maua was aged 28, who had one delivery, was divorced and she was living with her parents. She attained primary school level education, and was a peasant farmer with no steady income. She had lived for 18 years with the fistula having developed the fistula at age 18 just after she had delivered vaginally in hospital. Her husband had complained that she was very wide whenever they had sex and had opted to marry someone else. Her surgery went well and she healed without complications.

16. Patience

Patience was a 13 year girl, single, primary school pupil who lived with her parents. Patience had no income. She was born with the fistula and still a virgin on admission. She had never been operated before. After surgery she healed well with no complications.

6.3: Thematic Analysis

Thematic analysis was used for qualitative data processing (Appendix 6.2). Two main overarching themes emerged from the analysis 1) pathway to social isolation and 2) the pathway to social re-integration. As can be seen from Figure 6.1 the main themes were supported by a number of sub-themes. Many of these themes overlap and contribute to the whole. The overarching phenomenon encompasses the essence of all the themes.

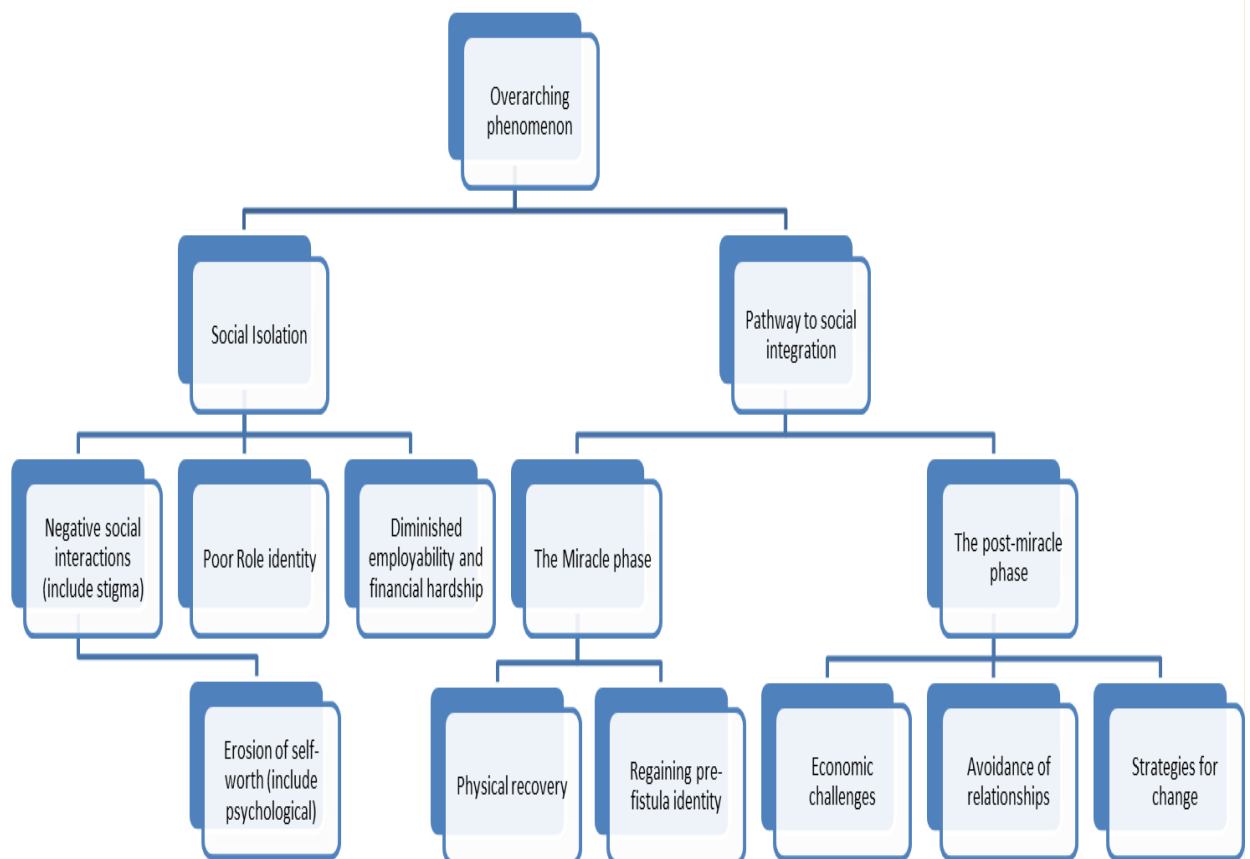


Figure 6.1: Diagramatic Representation of Themes

6.4: Pathway to Social Isolation

Social isolation was a major theme that emerged from the data. As soon as the fistula occurred, irrespective of the cause, women became vulnerable. A major contributor to this **social isolation** was the **negative social interactions** that women had with others. The stigma associated with this condition reinforced this isolation. **Poor role identity**, in terms of loss of social functioning, key roles and personal relationships, was a further consequence of having a fistula. Financial

hardship, through **diminished employability** was also common amongst participants, isolating them further. A combination of the issues mentioned above led to the **erosion of self-worth**: in many cases this led to psychological distress, and in some cases, suicidal tendencies.

6.4.1: **Negative Social Interactions**

Almost immediately following fistula occurrence, women began to experience negative social interactions that initiated feelings of humiliation and distress. Women were stigmatised by members of their local communities: as a consequence they began to withdraw from social interactions.

Due to the constant leakage of urine, and the associated smell, many women were called pejorative names such as *'mama urine'*, *'Mache esosera'* (stagnant rain water) and *'mama mkojo (mother of urine)*. In some cultures, the community compared the fistula women to wild animals like the mongoose (*ekenyaminyonge*). The Abagusii community in Kenya directly compared women to this animal because it is associated with bad odour, self-isolation (many people do not like it) and loneliness (often moves alone). For example, one woman said:

"They call us (fistula patients) ekenyaminyonge (Mongoose)" Sandra.

Another woman elaborated on this, suggesting that it has become a topic that others converse about, using the odour to ridicule the woman:

"Urine stench: others wait for me to pass by then they beckon each other saying 'Hey! Urine is passing!'" Binti.

Disappointingly, this ridicule appears to have become a group activity, in a way that can only be paralleled to school yard bullying:

"They call us (women living with fistula) names that are awful to describe in words. Commonly used word is 'Nyandoso (the stench)" Princess.

Women with fistula clearly felt victimised. However, there was also a misunderstanding of what fistula was, as demonstrated by one woman's narrative. It is unclear, from the following quote, whether community members' own fears influenced their reactions:

"When we (fistula women) pass by, people start to talk. They start pointing fingers at the woman living with fistula saying, that one! She has a terminal illness: she has AIDs that is why she leaks urine nonstop" Salma.

The actions were not limited to name calling alone; sometimes they came with physical desertion and sneering:

“Every time I joined a group of female patients, they would start spitting, saying mkojo huyooooo (urine is here seeeeeeee), and then one by one they would stand up and leave me alone” (Silence.....starts to cry) Gladness.

This constant harassment forced women to withdraw from normal routines and drove them into self-isolation, as though to comply with the community’s mongoose nickname. A respondent from coastal region of Kenya said:

“I resigned to live alone especially in the village because every time I went to where people are, they started to talk so I gave up any social event. Whenever I approached people would say, hey, mama mkojo ndio huyo” (Mother urine is here)’ Taabu.

Women generally had no support network, as indicated by one woman:

“Because of their insults, and hatred, I prefer to walk alone and go on with my chores as if I have no friend” Malaika.

The negative reactions from the community and overt stigmatisation also affected entire families. A woman living with fistula narrated how she was frequently harassed whenever she went to fetch water from the well. Like many mothers in the community she could send her 11 year old son to fetch water and run other errands for her. Surprisingly, when the boy went to fetch water, he was subjected to similar harassment as well:

“One day, a woman in the neighbourhood asked my son, “Hey how old are you now?” The boy replied “I am 11 years old”. To his surprise the woman responded, “At age 11 and you are still fetching water for your mother to go wash her urine hahahaha..... she laughed’ Malaika

Husbands of these women were not spared either. Most of them complied with the societies’ expectations, thereby breaking their marriages and leaving their wives in turmoil:

“Initially, my husband had no problem with my condition. We lived well and even had 2 children while living with fistula. Then, the men in our neighbourhood started teasing him, laughing and saying ‘Are you really a man? They asked: what kind of a man would sleep in urine year in year out till you even produce children? Get real and behave like a Mijikenda

(a tribe in Kenya where he belongs). A real man goes out to work and waits to see if the woman heals, if not, just move on and find a dry and enjoyable bed". Malaika.

For those that could not divorce their wives, because she had other children, the women were abandoned with little or no support. One of the women described the situation:

"The nurses told my husband to give me space since I was now disabled. Shortly my mother in law told the son to leave me. She said 'leave her, she is now disabled". "My husband then left me in hospital without a word, went home and married another woman and sired children with her" Malaika.

6.4.2: **Poor Role Identity**

In most societies women fulfil many roles. The women's accounts reveal that they experienced loss of key roles such as being a wife, mother, sister, daughter, daughter-in-law and being part of a wider family network. Often women were deserted by their husbands and close family soon after developing a fistula and were left feeling shocked and abandoned. The following quote provides some insight into the pain, agony and suffering that women reported when their husbands left them when they had developed a fistula:

"My husband never visited even a single day. I don't know what he was told by his mother. I just can't understand what happened: all I know is that he abandoned me at my hour of need". (Silence...1 minute). Nobody came to take me home or just a visit, I ended up staying in the hospital for 6 months' Gladness.

It is imperative to understand traditional African societies, where women have fairly defined roles; the most important of them is being a wife and having children as these roles give them status and respect within the community. Consequently, women search for confirmation to these roles; when denied, woman felt immensely debilitated. Women's lives changed acutely in a very short period of time, in a way that was out of their control. For example, one woman said:

"I have no shoulder to lean on, no income, no husband and no children. All I had vanished in a flash" Binti

Women who had lost their homes would be offered accommodation by family and others but often this was short-lived and far from ideal. The attitudes of family members would often be very negative and stressful in nature, ultimately contributing to depression and suicidal ideation. One woman described the situation as 'disaster like':

“Life with my sister in-law was difficult, they treated me like an outcast, it is like everything I touched was left with a bad smell. The pain and suffering was immense, I lost a lot of weight and the depression was too much. Many occasions I felt like I could just die and stop bothering people” Pendo.

Another woman was offered accommodation by her sister after her mother abandoned her in hospital, she said:

“I heard my sister telling our other sister that she had a skin rash because I used her washing basin. These were my own sisters remember! They used to talk about me all the time” Sandra.

It was clear that families were not ready to spend any money on fistula women. In one case where a woman lived with her married sister, she overheard her own sister describe her (fistula woman) as ‘a bitch’ to her brother in law (her sister’s husband) when he requested my sister to take me to hospital for treatment. He was heard swearing:

“One day her husband asked my sister to take me to hospital for repair, she replied. “Me! Never! I rather use my money as tissue paper than take that bitch to hospital” Sandra.

A young girl with congenital fistula was not spared either; her role as a pupil was disturbed by the urine leakage and constant odour, thus, raising doubt on the community’s level of understanding of fistula. Politely, she said:

“They (teachers) told my parents it is not possible for me to live in school even when I am in class 7. They had explained that because of hygiene issues brought about by my continuous urine leakage, other children will be uncomfortable sharing the same dormitory” Flower.

For some women, belonging to a church was part of their supportive, social networks before fistula. However, post fistula this was notably disrupted, making it an impossible environment to turn to for support: as one lady clearly articulated:

“Even the church is silent on issues regarding to the fistula problem; there is no help or even counselling in the area. There is nobody who cares for someone like me, not even the church” Gladness.

Therefore, it was not surprising to see church members segregating fistula women. Women questioned where they would go to seek solace, soon realising that this may remain an

unanswered question. Given that the religion and the church are integral parts of the community in the areas of Kenya, it is disappointing to note that only the 'lucky' women would find an understanding pastor who would then offer counselling and pray. In one circumstance, a woman had this to say:

"Even the church members segregated me: I gave up going to church. But one pastor used to encourage me: he would tell me that one day God will find a way, that doctors will come from far and repair the fistula" Sandra.

Some women paid the ultimate price of becoming infertile after fistula development. So expensive this was that, one woman advised her husband to marry another woman to bear children, since she had become infertile for many years. These women would do anything to claim their roles again as described below:

"Since I could not conceive again due to secondary infertility, I allowed my husband to marry another wife, with whom he had two children. We live together as a family, no name calling, no stigma, we are just fine" Fairness.

6.4.3: Diminished Employability and Financial Hardships

As soon as the fistula developed, women's self-esteem was eroded. The constant urine leakage amidst lack of sanitary wear left the women feeling undignified. Many husbands deserted their wives because they could not bear the sight of a woman with urine stains and a constant foul odour. To fill the void left behind by separation and divorce, many men remarried within weeks, eroding the confidence/self-esteem of the woman even further.

Naturally, the women living with fistula tried hard to maintain some level of dignity seeking solutions for their problem and finding different levels of coping. Women began to seek outside help and they adapted their behaviour to cope with the effects of the fistula. Many sought medical services, others used herbal remedies, while others had to contend with unusual behaviours, such as waking up several times at night to change beddings, wash their bodies or change the rags/pampers to hide the smell of urine/faeces. Courageously, some women would say:

"They say this one (woman with fistula) should not come near the visitors. When I hear this, I can't sleep well at night: I keep waking up to clean myself and change my clothing". Binti.

If regular cleaning did not work, the women opted to migrate from their homes to distant places where they were unknown, in order to alleviate their suffering like this woman:

"Finally, I had to move from home to a place far away from who knew me" Binti.

For women who had some income, they used every opportunity to try and improve their situation. Unfortunately their attempts at controlling their symptoms often cost them a great deal of money with no benefit. Women's desperation to improve their condition was clearly being taken advantage of, as outlined by this woman:

"I have visited many public and private hospitals for help but I have not succeeded. In one instance at a private clinic, the doctor gave me 6 pessaries to insert vaginally and 30 tablets to swallow each night after charging me exorbitantly," Fatma.

However, it looks like that the only kind of employment was either a housemaid or subordinate staff. Anyhow, some employers were very sympathetic to the women. In particular, a woman's employer offered counselling and advice to her as she waited for a chance to have an operation. This was of great benefit to the woman rather than dismiss her. She had this to tell:

"My employer told me to keep myself clean all the time, wash myself with Dettol (antiseptic solution) at all times, and keep my clothes /rags clean and dry always," Gladness.

Other women desperately sought new relationships to help finance their needs and expenses of living with fistula.

"Imagine my new boyfriend accepted me with fistula, slept with me in the same bed and bought all the sanitary towels I needed". Sandra.

Women developed a range of coping strategies to adapt and present themselves as leading a 'normal' life. For example, to instil confidence in her children while performing parental roles during school meetings, one woman describes how she adapted to a potentially embarrassing situation:

"Whenever I attend school meetings to support my children, I always carry extra clothes to change. Normally, I put them in a black plastic paper and hide them in a nearby bush. For the sake of privacy, I always make sure I arrive late so that I sit at the back the meeting venue such that it is easier to sneak to the nearby bush and change clothes without being noticed by many people," Malaika.

Because of this kind of desperation, the women could do anything to adapt to their new role which could have been contrary to their initial beliefs and practices. In the case scenario below, the woman started using herbal medicines even when she had never used it before:

“When I was growing up, it never occurred to me that I could use herbal medicine. But, the position changed after the fistula developed, I started using herbal fistula with the hope of healing,”. Salma.

A woman from northern Kenya adjusted to living with fistula by only allowing the public to see the upper part of her body:

“I live behind the shop where I work as a shopkeeper for my uncle. In fact, majority of the people only know how my face looks like because, I am always behind the counter. This shields me from the public eye ensuring that my privacy is safeguarded. Something I yearned for: since I left my home far away”, Pendo.

In order to maintain working some, women would take on work that they would not have normally done, prior to fistula development. Many felt the need to hide the fact that they had a fistula to avoid the reaction from work colleagues, fearing that if they were found out they would be sacked. Women became adept at managing their work environment to avoid being labelled as a ‘woman with fistula’. Notably, this woman described an interesting episode at her place of work:

“I have to wake up at 5am every day so I get to my work place before people arrive so when they get to the office, I have finished my cleaning and made tea so I just sit all day having finished my work. My boss thinks I am hard working but I do so to avoid the embarrassment of having to walk around with urine and faecal smell. If they discover I will certainly lose my job. It is dehumanizing”, Starline.

Many women faced financial hardships and challenges since, principally in these regions: the men are the bread winners while women are mainly housewives. If women were unable to work, either due to the stigma from the fistula or other caring responsibilities they quickly experienced poverty, like this woman who articulated her plight:

“Besides, I have a two month old baby, no food, no income, nothing to hold onto so I am forced to make charcoal to feed my children. I don’t know what to say. Honestly, my life

*has been very difficult. Poverty adds more trouble unto the burden of living with a fistula”
Malaika.*

Poverty is an outcome of fistula, but ironically it is also a contributor. Besides security and intolerable healthcare staff attitudes, as many women stated, poverty prompts women to give birth under unskilled supervision, further increasing the fistula burden.

Lack of the ability to supplement the family income which led to more financial hardship for the whole family indeed plays a significant role in the quality of life these women lead. It could then be understood when one woman explained:

“Before fistula developed I supplemented the family income by working in people’s farms but now the little money my husband makes from casual jobs go to my upkeep. This dependence is not nice: the economy is tough on us all” Fatma.

Sometimes, these women strived to find jobs to raise money for their own treatment like this woman:

“Since I did not have money, I worked in a witch doctors farm for two weeks so that he could treat me”. Salma.

If the jobs were not forthcoming, some women took very drastic measures in order to stop urine leakage. It has been stated before that for these women to heal well without infections and scarring, drinking lots of fluids is of extreme essence as it flushes the bladder/urethra and of course, rehydration prevents further tissue damage thereby, promote tissue healing. Unfortunately, and due to lack of awareness, the women would limit their fluid intake to reduce urine production and reduce her frequency to the toilet so as to maintain work. This made her condition worse as her story further displays:

“Life was very difficult, I stopped drinking any fluids so as to stop urine production but this gave me a very bad urinary tract infection and a bladder stone”, Salma.

6.4.4: Erosion of Self-Worth

The conditions that women were living under (discussed above) eroded their self-worth. Being stigmatised, isolated, and pitied often led to depression. Continuing isolation led to feelings of hopelessness, to the extent that several of them contemplated committing suicide.

Women often felt 'numb' and completely worthless. Furthermore, they believed that they were a burden on others. To relieve such feelings, women considered ending their lives: this was believed to be the only way of ending the suffering for themselves and their families:

"I had no feelings I was like dry wood! My spirit was crushed..... many thoughts crossed my mind, at some point I just wanted to kill myself so my mother and her house could be more habitable especially for those who have no sin, no terrible smell" .Sandra.

At times women became so low that they only saved themselves through their maternal instinct. One woman said:

"In fact, one day I felt like hell had broken loose, I climbed the tree in our home and just as I planned to pull the rope, I looked down to make sure there was no one to resuscitate me, only to see my daughter asking to breastfeed. The maternal instinct worked on me, I came down slowly to breastfeed and go back to accomplish my mission. But as fate would have it, my mother came in only to see the rope around my neck while the baby suckled innocently, unaware of what was happening to her mother" Taabu.

The feeling was so compulsive: she continued to say:

"I wanted to die there and then. I just wanted to commit suicide. In many occasions I had contemplated suicide but on this very day, I went out and bought poison (Rat and Rat) ready to swallow and die". Sandra.

The fruitless attempts to get help further destroyed these women's self-worth. There seemed to be a lack of information exclusively, about the condition (fistula) and its treatment across the divide. The healthcare professionals, family, teachers, church members and wider community failed these women through their ignorance of the condition.

Several women reported leaking urine to health care professionals immediately after an assisted birth: often they were simply ignored or were told that it would eventually go away. Women were and made to feel stupid for asking supposedly unreasonable questions. The following account is from a young fourteen year old girl who had laboured for three days – her baby died during the labour:

"At the time, I did not know I had the fistula and the doctor never informed me about it. The nurses said it is expected and that I will be fine when I go home. So, we came back to the hospital and gave them feedback but none of the health workers seemed to know what next. Nobody even said an encouraging word, instead they said that I am panicking

for no apparent reason, which women go through this (leaking urine) for a while before it stops” Clarity.

In another case scenario, a woman said:

“When I noticed that I was not able to control urine, I informed the hospital staff. The response I got was heart breaking. They said “the person who delivered your baby did not know how to stitch you up”. Apparently, when I gave birth, he (Midwife) cut me on both sides (bilateral episiotomy) and the child made a further tearing” Flower.

The situation can get so desperate that women seek all means to help them get better. Therefore, it was not surprising for some to try all types of alternative remedies like this woman:

“I have tried all herbs, but have not seen any improvement. There are those herbs for chewing, those for boiling, those that I burnt and used the ash; all these concoctions did not yield any relief. The urine still leaks “ Fairness.

In the interviews, many women reported that they had no hope for the future and could not visualise a life without fistula: this made the prospect of having an operation to close the fistula and restore them back to normal life seem nothing short of a miracle.

6.5: Pathway to Social Reintegration

This part formed another major overarching theme from the analysis after women had been repaired. Post repair women’s accounts were exhilarating and very captivating. Social reintegration was shaped by how fast the restoration of both the physical and psychological wellbeing was achieved; these included positive social interactions, recognition of role identity and self-esteem restoration. During the post miracle component, the women were expected to integrate gently back into society with minimal hitches. This process was driven by **physical recovery** which was immediate after fistula closure and boosted by the ability to be continent of urine and/or stool. Additionally, the recovery of these women was aided also by the psychological wellbeing, being able to **regain their pre-fistula identity**.

Full recognition was marked by the ability to overcome **economic challenges** to run her activities of daily living; **renew and /or form new relationships** and positive social interactions. However, because of society expectations of these women, the majority were fearful; if these fears were not allayed in time by her family, friends and the community, the woman would have a tendency

to revert to pre-fistula distress. Some of these fears included future relationships, role identity, employability and future reproduction potential. Furthermore, full recovery and restoration of self-worth was anchored on **physical recovery, regaining of pre-fistula identity** and being able to tackle **economic**, and **relationship** challenges. More importantly, in this theme the women allude to opportunities and strategies for fistula prevention and community change.

Themes generated from women's narratives post fistula repair formed two distinct components a) the 'miracle' component and b) the post 'miracle' component. The road to recovery seemed to start just before surgery, which is described here as the intercomponent, when women expressed high expectations of the surgery. When at the hospital women waiting for fistula repair were both surprised and comforted by the fact that other women also had fistula, as this validated their own experience. A few were also greatly encouraged by those women who had undergone surgery ahead of them.

Notably, for all women, surgery seemed to be their goal. There was a drive towards a solution and the thought of having surgery just evoked happiness in these women. Many prayed and wished that their surgery went well so that they stopped urine leakage, like this woman:

"I just wish my operation is successful and this urine stops leaking", Darling.

Another said:

"My hopes are all in this second operation, I pray that the Lord may grant the doctor the skill to close" fistula. Looks down.....It is in the Lords hands", Sandra.

All the women talked of hope. Based on her previous experience of surgery, this woman described her expectations:

"I am praying that the doctor can close my fistula just like he did for the patients I saw last year: I spoke to my friend from last year's VVF camp at coast general hospital and she is dry: how I wish the same would happen to me. How I wish it closes", Clarity.

Several of the women would go to any lengths to undergo surgery. In one instance, a woman presented herself for surgery when she knew very well she was 6 months pregnant, hoping that she would not be discovered. Surgery is usually deferred for women who have fistula and are pregnant. When her surgery was deferred, she cried a lot and wanted an abortion so that

surgeons would be free to perform surgery on her: she was willing to sacrifice her unborn baby to relieve herself of the life she was leading:

“When I heard that I wait until after delivery before surgery, I was so heart-broken and confused, tears just rolled down my cheeks, I could not hear of it. She said: I really don’t care: all I want is an operation to close the hole where the urine is passing through. In any case I can get pregnant again. I have waited for the VVF team for so long due to poverty: I want an abortion so that I can be operated on”. Clarity.

Then there came the transformation period and the majority of the women underwent surgery, achieved good outcomes and their joy could not be hidden. The account of the women after surgery was unimaginable.

6.5.1: The ‘Miracle’ Component

Following repair of the fistula most women were immediately symptom-free. Full urinary continence was restored and normal pre-fistula behaviour could be resumed. After years of suffering the degradation and humiliation of living with fistula, women were ecstatic and overjoyed with the result. Indeed, many of the women referred to the outcome of the repair as a ‘miracle from God’, a ‘rebirth’ and a ‘time of great celebration’. Elated moods filled the air as this woman jumped up and shouted:

“I am dry, very dry. No urine leakage, not even a drop! Indeed, God works in miraculous ways. In my whole life, I have not witnessed such a miracle, I am completely healed”, Gladness.

While another woman her joy was like an uproar:

“When I was told that I have healed, eh! I hit the roof with shouts of halleluyah, halleluyah” Taabu.

Interestingly, the struggle to regain dignity was so compelling that some women utilised these occasions as new opportunities for social interaction and re-integration:

“When we got home, the following day we made a party for all our friends, it was joy, joy everywhere. All neighbours and my teachers (adult learning instructors) keep coming to witness this miracle” .Fatma.

Several women expressed a sense of disbelief that they felt ‘normal’ again:

"I feel fresh! Very fresh my dear. You can see it from my dressing code (points at her white and red dotted shirt and matching white top). I have healed. I feel so different my sister. Look (pointing at her face) even my general health has improved greatly" Binti.

Another woman said:

"I still cannot believe it, I leak no more... imagine my fistula has healed: I walk around without wearing rags under my pants. This is a miracle....I am healed, I feel like a new human being. No smells, no name calling, all these experiences are overwhelming. It is like a big dream, at times I find myself standing up from where I am seated, look at the chair and touch my clothes just to confirm that there is no leakage", Taabu.

Following successful repair and restoration of continence, women were seen to treat what they went through as history, things of the past; they welcomed in a new horizon:

"All that fear and stigma is now history. I walk with my neck up high and dress the way I want, no worries, no stress. I have healed completely" Binti.

Many of the women's close families had shared in the stigma and shame of the condition. It was apparent that positive effects of the fistula repair were seen to extend to the entire family:

"These days, my children keep asking, mama, are you not washing your clothes today? If you don't wash your clothes early, they will have a bad smell, they say. Even the 3 year old child knows there is a difference in my life: honestly it is now clear to me that my whole family was hurting deeply. Anyway, the most important thing is that all the urine leakage is part of my history, bad history". Fatma.

6.5.2: Effects on Quality of Life: Regaining Pre-fistula Identities

Women reported an instant positive effect on their quality of life in all areas - physical functioning, psychological wellbeing and social interaction. As a consequence women were able to regain their pre-fistula identity and re-connect with their social worlds. Women noted how they felt more confident post-repair. Their sense of womanhood returned and as they engaged in everyday activities that the fistula had affected their self-esteem improved:

"I came by matatus (small vans used for public transport) like anybody, actually I sat in the front seat near the driver without fear of wetting any seat or looking back to see who is talking about me. All that fear and stigma is now history" .Binti.

The regaining of their pre-fistula self was aided by the acceptance of others who had previously shunned them like this woman who wasn't revengeful to her friends:

"The fact that my friends don't make faces or giggle when I pass is overwhelming, indeed dreams do come true....the very friends who used to humiliate me now come to me to teach them mathematics: I do so with pride because the bible says do not revenge" Patience.

The situation was even better when friends and neighbours were warm and welcoming:

"A month after I left hospital, my friends and neighbours started inviting me to help them host visitors or even travel far to visit their children. Remember no one ever wanted me near their homes let alone their visitors! Nevertheless, I accompany them, despite the way they treated me in the past. I do so because the bible says that revenge is left only to the almighty God" Binti.

In particular, women reported that their sleep patterns were able to return to normal as they were not getting up several times a night to wash and change clothes and bedding: Women began to feel immense freedom:

"Now I don't use pads anymore. Although the skin burns are not healed completely it's a small thing compared to the hell (refers to continuous urine leakage) where I have come from. At night I sleep like a baby, no worries no anxieties no shame of washing my beddings every day. It is a whole free world" Darling.

Some described their feelings as beyond excitement and demonstrated what it meant to be continent of urine and faeces:

"It is not just excitement: it is a rebirth, am new and fresh! My flesh and my spirit are in agreement for the very first time. Look (lifts her purple dotted skirt to reveal a white, spotless petticoat)" Sandra.

There was a thin line separating the 'miracle component' and the 'post miracle component'. Gladly, many women had resumed their pre-fistula activities; a few had started small businesses to support themselves and their families, which was extremely gratifying. Unbelievable new lives definitely followed successful fistula repair among many women:

“Everybody around me is full of joy, peace, and love. This has rekindled our lives (herself and the husband) and I feel fully alive”, Starline. Another one said: “I am a human being again”, Gladness.

However, some women expressed fear and desolation which informed the ‘post miracle’ component in the analysis.

6.5.3: The ‘Post-miracle’ Component

Following the initial elation at being ‘cured’ of fistula, and free from urine leakage, some women began to express concerns about the future. They discussed several potential barriers to full integration. These were mainly related to their ability to generate income so that they could retrieve their previous standard of living. For others they were anxious about their personal and sexual relationships with men following repair.

6.5.4: Economic Challenges

Several women in this study had been abandoned by their husbands when they had developed a fistula, which had a detrimental effect on their income. In addition, their ability to work was compromised by the need to take care of children and by the smell of urine that surrounded them. Women expressed fears about reintegration at the pre-fistula stage. Openly, one woman expressed her fears:

“Still if it succeeds where will I go? I have no home or money to start a business of my own. Where will I go? Plus, we were told we will be discharged with the catheter, which man can accommodate a woman with a catheter in his house? Tell me, who?” Pendo.

Post fistula repair these concerns returned. Some women had also lost their homes and families and they expressed that the road back to their pre-fistula living standard was not an easy one:

“I have already talked to some old friends to accommodate me for a while. Once the six months elapse, with a little support I can find a place to bake Mahamri (cookies), sell and take care of my daughter. That is my dream”. Taabu.

This woman did not want to return to her Uncle’s house where she had been unhappy. Securing her own income would give her the choice of where she could live, now that her fistula had been repaired. Many would want to start life afresh and vehemently, they would say:

“Before this surgery my life was hell on earth, no relative wanted me; my uncle picked me from my aunties house where I worked as a house help with no pay. When we got to my uncles house the wife was not happy, she accused him of bringing another wife yet I was so young, sick, orphaned and very thin (she starts to cry and this was followed by a silence for 7 minutes)....I have lived with my uncle for many years but I am not eager to go back...how I wish I could find a job and sustain myself’ Pendo.

6.5.5: Avoidance of Relationships

The trauma of fistula and the experience that some women had received from their male partners led them to reject future relationships. Additionally, self-isolation alone can lead to sexual dysfunction. It is therefore not a surprise for these women to react negatively to suggestions of future marital and sexual involvements. This was worsened by many years of displaced role identity and erosion of self-worth like in this lady:

“Men are creatures I don’t want to embrace, I am done with them. The man whose child I delivered and got a fistula left the minute it developed 30 years ago. He robbed me of my youth, my womanhood, my identity; I want nothing to do with men and their sex appeals, which is a closed chapter in my life. I see men as men, nothing special, if I must say something: I say hi and pass”, Pendo.

Understandably, these women have been through difficult relationships with their husbands, as such they could not contemplate future relationships with men:

“My dear after 32 years of misery I have no slightest taste for men”, Pendo.

Another woman echoes this viewpoint:

“I have no intention of having a relationship with any man, not even the father of my children. Ten years of pain and loneliness have taught me never to trust a man: never. Men are all pretenders I must admit’ Salma.

Following surgery, all women were given written letters to take to their village administrators/elders to deter the husbands from engaging in sexual intercourse with their wives for six months after repair. One lady reported how she shouted for help from neighbours when her husband tried to rape her after she rejected her sexual advance:

“I have not given it a thought (meaning sex with husband). My mind was focused on my healing. However, three days ago he (husband) demanded to have sex with me, when I

declined he became violent and wanted to rape me so I screamed and neighbours came to my rescue. He has not spoken to me yet and for refusing his sexual advances, he refused to give me fare to come for this visit. He is a beast. I thought he will honour the letter that was written by the doctor indicating I abstain from sex for six months, he did not”, Taabu.

6.5.6: Revert to Previous Coping Strategies

An additional sub-theme related solely to those women whose surgery was unsuccessful. For women who were unfortunate not to have healed, their lives were no different from the pre-repair days and they still experienced negative repercussions from their husbands and family. Fortunately, in this study, only one woman failed to heal and her experience was totally varied from the rest of the participants. Like any other surgeries, not every one turns out favourably. Since she was the only one, it is difficult to include her narratives alongside the rest of the women and her case, therefore, is treated differently during this write up. This woman felt truly rejected, her despair being apparent in this quote:

“During Christmas, he did shopping and brought gifts to his children and nothing for me saying, ‘he did not have money’, which was not true. He just did not want to spend money on a woman who was leaking urine all the time. It made me feel rejected, despite the fact that I gave birth to his child in his absence. It killed my desire for him” Malaika.

The woman’s suicidal tendencies were a result of having four failed attempts at surgery. Undoubtedly, she would have built up hope prior to each one of these. However, she was beginning to doubt ever healing:

“Sometimes, I feel like I will die because of this fistula. Imagine this is the fourth time I have been operated and still have not healed. How many times can the doctor operate on me”? She posed! Malaika.

She spoke with lots of bitterness from her heart while sobbing, her despair compounded by her knowledge of the successful repair of others:

“Why me she asked? Imagine all the other patients have healed, I saw them when we came for follow up visit”. Malaika.

This case scenarios bring forth the urgent need for health care professionals and partners in mitigating access to Skilled Birth Attendance and prompt fistula repair services whenever a occurs.

6.5.7: Strategies for Change

As these women repeatedly narrated their experiences, pertinent suggestions came up supporting efforts towards restoration of women's dignity, scaling up skilled birth attendance and women's empowerment initiatives. Of course, counselling and surgical operation are crucial but prevention remains the key to reduction of the burden of VVF worldwide. Undoubtedly, urine leakage was the greatest challenge for most of these women.

A majority of women made recommendations for community engagement in fistula care and prevention services as a way of sensitising the community about the condition and to promote safe childbirth. Some of their suggestions included educating the communities, including the church and schools, on fistula prevention and treatment; initiating small businesses to help generate income for fistula patient's post-surgery; and promoting schooling for young fistula patients. An informed society will be better at treating women and children living with fistula ultimately, by promoting positive social interactions when fistula develops.

Through these narratives, the women made frantic calls to policy makers to mitigate for free, quality maternal health services with the aim of promoting safer childbirth, better infrastructure as narrated by the following respondent:

"In my opinion fistulas should not happen in hospitals: instead, prevention should prevail to avoid fistulas from happening. To do this, management should ensure doctors and nurses are well trained such that they are able to conduct safe surgeries as well as care for those with fistulas instead of just discharging them without a word of advice as they did to me! It is not fair", Taabu.

It was felt that educating the girl child is important because the more trained the women are, the more employable she becomes with a better economic outcome. Conversely, this leads to better decision making power and improved awareness of human rights. In addition, this will provide an opportunity to help women start businesses to generate income and become self-reliant even in adverse events. For example this woman said:

"when I heal, I would like to start a small business, my employer told me she will support me in this venture, it is the only way to get out of poverty and help my family" Gladness.

They also felt that where possible, governments should build shelters as reported by one woman who said:

“Diversification of VVF services should be done quickly to the whole country because the problem is big”, Pendo.

These shelters are waiting places where women can access counselling, HIV and family planning services and life skills training as they wait for repair or are recovering from surgery.

Shelters were seen as an opportunity for the women to become ambassadors for women with fistula and to be able to offer protection against sexual activities prior to wound healing. One woman said:

“respondent stated that, the shelters will allow time for repaired fistula to heal, since women and their husbands cannot wait for healing before resuming sexual intercourse”, Malaika.

All these views were geared towards better health service delivery and better fistula care as a first step towards social integration.

6.6: Phenomenon

The phenomenon of fistula recovery is a complex one, influenced by intrinsic and extrinsic factors. Whilst physical recovery is possible following surgery, psychological wellbeing is not an automatic outcome. For most women, the surgery is the start of their journey to recovery, but their subsequent interactions with family, community and health systems effects their ability to socially reintegrate into their pre-fistula lives. Positive reactions from women’s own children were a restorative factor. However, internalised stigma was a debilitating factor. Women who had been ostracised from their communities found it difficult to return to an environment where they previously had not belonged. Women experience a range of emotions post fistula-surgery which fluctuates from elation (when they realise they are continent) to despair (when they realise that reintegration is not as easy as they thought).

6.7: Conclusion

Fistula surgery alone is insufficient in reclaiming women’s lives. There needs to be a continuum of care for women post-surgical repair which includes assessment of the physical, social and psychological wellbeing of women. The repair is necessary to help the woman achieve continence but it is only the starting point from which women can seek social reintegration. In itself social

integration is a complex phenomenon and it may have different meanings for different women. For some it could mean a return to a stable marriage, for others full integration within the community. The degree to which women can integrate into their communities is dependent on their psycho-social state, available support mechanism and individual self-esteem; health professionals have a key role in recognition of individual needs and initiation of appropriate referral. Further research is needed to explore women's expectations and goals following fistula repair to enable the development of interventions that are suitably tailored. It may also be useful to explore experiences according to the duration of the fistula to identify potential differences to target interventions appropriately.

Health systems need to mainstream fistula care and information provision in existing reproductive health programmes, through training and dedicated fistula teams within the region. Training should include awareness-raising of the impact of their role and communications on women's feeling of isolation and worthlessness. Furthermore, health professionals need to advocate for family and community support for women with fistula. This advocacy could take place through community forums, print and social media.

Fistula teams need to explore the most appropriate ways of socially reintegrating women following a successful fistula repair. However, such interventions are complex and will require a multi-level approach. Careful considerations need to be given to how individual components of such an intervention relate to women's outcomes. To achieve long term goals and program sustainability, such intervention would need to be subjected to a rigorous experimental study.

Chapter 7: SYNTHESIS

7.1: Introduction

This chapter is a synthesis of quantitative and qualitative findings relating to factors affecting the lives of women living with fistula. Some of these factors play a pivotal role in the success of fistula surgery and also in the women's help seeking behaviour. In the quantitative findings, key discussion factors include: women's sociodemographic characteristics, childbirth-related characteristics, fistula-related characteristics, predictors of fistula healing and predictors of duration of leakage. Apart from the success of surgery, quantitative data were collected before and during surgery. Alternatively, qualitative findings focus on factors that negatively impact on women's lives such as physical trauma, stigma and other psychological consequences of living with obstetric fistula. These were evaluated before and 6 months after surgery.

To gain deeper understanding of the factors under study, section 7.2 focuses on the description of the synthesis, while Section 7.3 describes the baseline characteristics of the women, predictors of successfulness of surgery are under (Section 7.4) and factors that influence duration of leakage (Section 7.5). In conclusion, Section 7.6 describes a summary of the synthesis.

7.2: Description of the Synthesis

7.2.1: Obstetric Fistula in Context

Many Researchers agree that fistula is a devastating condition which is largely preventable. Poor access to reproductive health services is attributed to this debilitating condition (WHO, 2014: UNFPA, 2004: Miller *et al.*, 2005: Velez *et al.*, 2007). The prevalence of obstetric fistula globally, as estimated by World Health Organization (WHO, 2014), is more than 2 million women. Each year, it is estimated that between 50,000 to 100,000 new women world wide are affected by obstetric fistula. Fortunately, prevention mechanisms are cheap and available. Preventing and managing obstetric fistula contributes to achievement of the millenium development goal number 5 of improving maternal health (WHO, 2014) and the Sustainable Development Goals 1, 2 and 4 (Sachs, 2012: Bongaarts, 2016).

Researchers have measured several factors that determine fistula healing, such as vaginal scarring tissue, previous repairs, preoperative bladder size, complex fistulas and fistula location (Barone *et al.*, 2013: Kayondo, 2011: Bellows, 2015). Many of these studies were purely quantitative: these were studies of varied quality and small sample sizes (Frajzyngier, 2013). Other researchers have attempted to illustrate the impact of fistula on women's lives using qualitative methods (Drew *et*

al., 2016: Wilson, 2016: Baragaine *et al.*, 2015: Degge, 2017: Yenenesh, 2014), highlighting the devastating effects. It would appear that psychological consequences have the most effect on women's quality of life (Wilson *et al.*, 2015, 2016: Alio *et al.*, 2011: Khisa *et al.*, 2017). Psychological effects seem to be prevalent in many women living with fistula (Wilson *et al.*, 2015). However, these women may also have sexual dysfunction and stigma (Turan, 2007: Bangser, 2006: Baragaine, 2015). Social and economic consequences have also been reported (Ahmed, 2007: Muleta, 2008: Roush, 2009).

The women's quality of life has been shown to sharply diminish once fistula develops (Donnelly, 2015). Many of these studies suggest that intervention programs should target beyond mere surgical closure of the fistula (Wilson *et al.*, 2016: Khisa *et al.*, 2016: Baragaine *et al.*, 2015).

In an attempt to provide a holistic overview of the period around fistula repair, a mixed-methods approach was adopted. Drawing on quantitative and qualitative methods made it possible to explore predictors of success in fistula surgery and duration of leakage, and complementary aspects of women's experiences pre- and post-fistula repair. To this end a pragmatic stance was adopted allowing better understanding of the physical, psychological and social world of women with obstetric fistula.

7.2.2: Synthesis of Quantitative and Qualitative Findings

In this complementary mixed-methods approach, the quantitative part was initially thought to be dominant, the results of which were to be clarified or enhanced by the qualitative part through a sequential explanatory design. However, in the course of data collection and analysis it became evident that the qualitative element was an equally important component. Eventually the studies were at par because of the richness of the qualitative data and the emergence of data on social re-integration.

Whilst the quantitative findings provided insight into reasons why fistula repair may or may not be successful or why duration of leakage may have been extensive, the qualitative component also provided contextual information to aid understanding of why these factors may have occurred. The sequential explanatory design required that the key concepts from significant quantitative results are defined first, e.g. country of referral, presence of a relative at childbirth, unemployment and vaginal stenosis.

By applying the interpretive approach, the qualitative findings are appropriately utilised to elaborate or explain further to gain better understanding of the quantitative findings and eventually how this can inform policy and practice of management of obstetric fistula. The mixed method was adopted to allow robust analysis while taking advantages of the strength of each study in a complementary version. The rationale was grounded in the fact that neither of the methods was sufficient by itself to capture the entire situation in obstetric fistula surgery.

7.2.3: Study Design - the Explanatory Sequential Design

The study design followed three stages, namely prioritisation, implementation and integration. The goal of the quantitative phase was to identify the predictors of success in closure of obstetric fistula and duration of urine leakage. This was originally prioritised over the qualitative phase because of the interest of the investigator, the expected audience of the study, and what the investigator sought to emphasise in this study (Creswell, 2003). This decision was made earlier in data collection and conformed to the sequential explanatory study which prioritises the quantitative component. The predictors were identified from the socio-demographic, childbirth-related and fistula-related variables through data analysis.

The aim of the qualitative component was to seek explanations on the predictors identified and so followed the quantitative component. During this process (the qualitative component), emergent data appeared, shedding light on the complexities of social reintegration in this cohort, articulating contextually the study purpose and research question of this study.

Integration of the phases was grounded in a hybrid approach driven by the quantitative results, the qualitative phase being designed to mainly complement the quantitative component. This partially explained the emergence of new data. Much of the integration of the quantitative and qualitative phases occurred at the discussion of the outcomes. A combination of the results of the two phases gave the opportunity to fully answer and develop a more robust and meaningful picture of the research problem.

7.2.4: Approach Used in the Synthesis.

The purpose of this section is to:

- a) Firstly, interpret the results that help answer the main research question – predictors of fistula closure and duration of urine leakage.
- b) Secondly, interpret qualitative results to answer the qualitative objective – describing the lived experiences of women living with obstetric fistula,

- c) Thirdly, to utilise the qualitative results to clarify and explain the quantitative findings,
- d) Finally, to augment these findings by citing literature and reflecting on both the quantitative and qualitative phases relating to each of the explored factors affecting the success of fistula closure and duration of urine leakage published studies on the topic.

The researcher has made an attempt to illustrate study methods applied and factors affecting the lives of women living with fistula in the region (Figure 7.1).

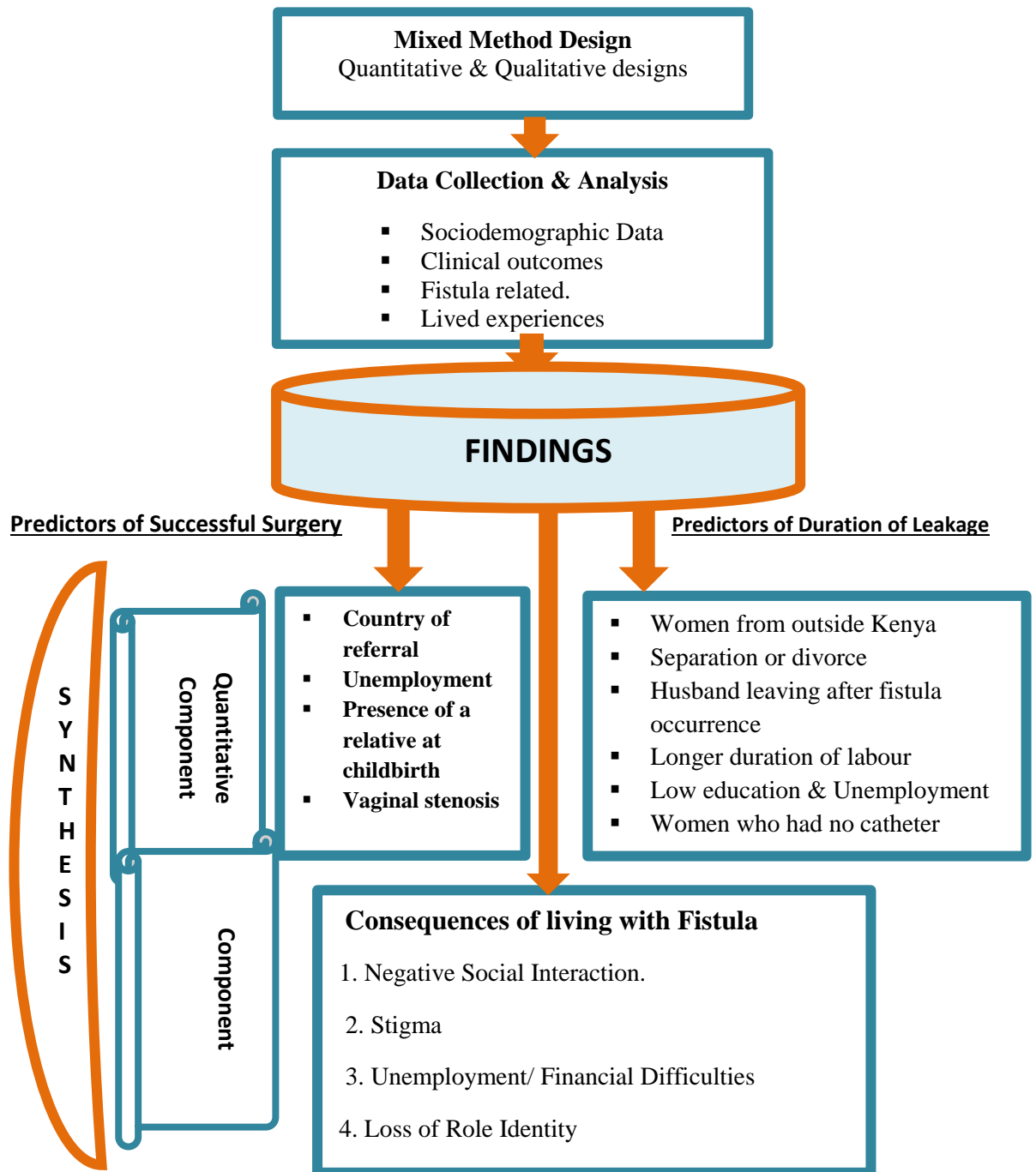


Figure 7.1: Factors Affecting the Lives of Women Living with Fistula Applied Methods

7.3: Baseline Characteristics of Women with Fistula

Empirical evidence on predictors of fistula formation is lacking. What is available suggests an association between socio-demographic factors such as young age in marriage and first pregnancy, the height of the woman, low economic status of the women, illiteracy, culture and social issues and malnutrition as potential risk factors to causation of obstetric fistula (Hilton *et al.*, 1998; Muleta *et al.*, 2010; Murphy *et al.*, 1981). The current study collected baseline data in the quantitative and qualitative components.

The quantitative sample had 1224 participants, which is larger than most observational studies in East Africa. The large sample allows multivariate analysis and enough power to inform practice. The quantitative part of the study shows that a majority of the women were referred from Kenya (73.3%) and the fewest referrals were from Somalia (n=3). Women mostly complained of urine leakage (80.7%) and faecal leakage (25.2%). Many of these were young women in their active reproductive period, i.e. between the ages of 18 and 37 years (71.7%). Age and parity have been associated with obstructed labour, with the young primigravidas being more likely to experience both obstructed labour and subsequent morbidity (Kelly and Kwast 1993b; Neilson *et al.*, 2003; Wall *et al.*, 2004). Most women menstruated regularly (52.0%) and had skilled attendance at childbirth (70.3%). Presence of a relative at childbirth was limited (9.9%). Parity at fistula formation was also considered and indeed many women developed fistula after their first birth (44.6%). Their babies were mainly of male gender (58.2%), with only 37.5% still alive at fistula presentation. The number of infants who died at birth may have been high among this cohort, but estimates of the proportion of cases in which the two co-occur are variable and imprecise (Cowgill *et al.*, 2015) because some fetal and neonatal deaths that occur at home are often not reported (McClure *et al.*, 2006) and some cultural expectations that bar women from deliveries at a facility. Stillbirth may be more common with male babies, perhaps because male fetuses are larger on average (Wall *et al.*, 2004), results that concur with this findings.

Most of the women were in a stable condition before surgery (77.9%). Women in poor general condition tolerate surgery poorly with worse outcomes. In addition, women with co-morbidities such as hypertension, diabetes, sepsis and cardiac abnormalities present a danger to anaesthesia and even surgery (Eagle *et al.*, 1996). The prevalence of HIV was 6.0% among the cohort, which is comparable to the national prevalence of 6.3% in Kenya (KDHS, 2009). A quarter of the women had fistula classification of VVF11Aa (25.1%) and a tenth had RVF11b (11%). These were the commonest lesions witnessed at all country sites. The mean fistula size was 2.15 cm, mostly about

1-2cm from the external urethra orifice. Multiple fistula rates were 6.3% with 27.5% having had previous unsuccessful repair. A third of women had leaked urine for up to 12 months (36.4%) and 26.1% had leaked for over 9 years. Vaginal stenosis was common amongst the women, accounting for 72.4%, while vulvar excoriation was mostly mild (61.2%) to moderate (35.4%).

The qualitative part of the study had 16 participants who were interviewed in depth. They were mainly young in the reproductive age group, reflecting the sample in the quantitative cohort. More than two thirds were below 38 years, which is in agreement with the quantitative data. Another observation was the poor education levels of these women: three quarters had no education or were only educated to low primary school level (reflecting the 79.9% educated to this level in the quantitative part). Half had no formal employment, except being peasant farmers, and the majority (10/16) had been divorced or separated after fistula developed, supporting the risk factors associated with obstetric fistula described above.

7.3.1: Country of Referral

The multi-country setting in this study provided a unique context in which the synthesis occurs. The standardised approach to data collection and surgical procedure made it feasible to analyse the data independently (by country) and in combination, a new feature in this field of surgery. The countries in the study were: Kenya, Uganda, Southern Sudan, Rwanda, Malawi, the Democratic Republic of the Congo and Somalia. Kenya had the highest number of referrals (n=897) compared to any other countries. Uganda closely followed with 104 women having been referred, with the least being Somalia (n=3). The prevalence and incidences of obstetric fistula varies across these countries. However, from epidemiological studies, estimating prevalence of obstetric fistula has been a challenge with many studies being self-reported which tends to underestimate the true prevalence (Ahmed and Tunçalp, 2015). Recently, Maheu-Giroux and his colleagues described lifetime prevalence of vaginal fistula symptoms in sub-Saharan Africa as 3.0 (95% CI 1.3–5.5) per 1000 women of childbearing age and the point prevalence as 1.0 (0.3–2.4) per 1000 women. Ethiopia had the largest number of women who presently have symptoms, followed by Uganda (Maheu-Giroux *et al.*, 2015). There are no recent estimates in East Africa except in 2004 when the incidence of obstetric fistula in East Africa estimated to be 5400 per 100,000 live births (UNFPA, 2004). In this report, the general belief was that more cases were seen than repaired and more cases existed in the regions than presented at the facilities (UNFPA, 2004).

Regardless of the aetiologies, the debilitating nature of the condition and its consequences compound the experience of women with fistula in many African countries. Previous reports conclude that poor health systems, poverty and homelessness make women's lives a very traumatic experience (Siddle, 2013). As a result, women choose to live in isolation not only because of fear but also due to lack of basic needs including access to quality health services (Keyser *et al.*, 2014). Insecurity, poverty and nomadism are known determinants of reproductive health utilisation.

7.3.2: **Women's Characteristics**

This section will be divided into education and literacy, unemployment, living arrangements and source of information sub-sections.

7.3.3: **Education and Literacy**

In all of the countries, literacy levels were low. Illiteracy has been reported as a risk factor in fistula causation in many Nigerian studies (Ampfo *et al.*, 1990; Melah *et al.*, 2007). Primary schooling was the most common level of education for women referred from Kenya (62.9%), Malawi (73.7%), Rwanda (59.5%), Southern Sudan (57.7%) and Uganda (81.8%). Of great concern was the large percentage (71.1%) from DR Congo who had never attended school: in addition, a third of women from Rwanda and Southern Sudan had not received any schooling. This may mean that these women face both information and technological challenges which, if they could be addressed appropriately, may help improve their help seeking behaviour to improve their health. Overall, most women had only been educated to primary school level (62.9%) with a further 17.0% having had no education. Only 59 women (4.8%) had been educated to college level or higher and all were from Kenya.

7.3.4: **Unemployment**

In this cohort, four out of ten women were unemployed, the most common occupations being peasant farmer (35.0%), housewife (31.4%) and small business (13.7%). Unemployment was a problem in many of these countries: the percentage unemployed varied from 92.1% for DR Congo and 76.1% for Southern Sudan 76.1% to only 13.5% for Rwanda and 13.2% for Uganda. The unemployment rates for Kenya and Malawi were 40.3% and 42.1% respectively. The higher rates for women from DR Congo and Southern Somalia may have been due to displacement due to civil unrest while the lower rates for Rwanda and Uganda may have been because employed women

in those countries were more likely to be able to afford to attend fistula camps. As expected, most of their spouses were employed with only (13.5%) being unemployed. The most common occupation for spouses was peasant farming (45.8%), followed by small business owners (14.4%).

Although unemployment was a problem across countries, women from DR Congo, Somalia (2/3) and Southern Sudan were more likely to be unemployed. In the midst of poverty, related stigma, lack of community support, insecurity and daily struggles with the fistula, many women resign themselves to fate, further eroding their self-worth (Lavender *et al.*, 2016; Khisa *et al.*, 2011). Although these qualitative outcomes emanate from Kenya alone, other countries in the region experience similar events, as evidenced by a recent Ugandan study (Baragaine, 2015).

Poverty and parochial family systems, prevalent in Africa, compound women's lives before and after fistula develops. A systematic review found that in non-patriarchal communities, women who have good education with a steady source of income have better access to reproductive health services (Simkhada *et al.*, 2008). In such situations fistula rarely occurs and maternal health issues are not a problem as women make independent decisions as to when and how to access health care (WHO, 2016). Education increases female autonomy decision-making power within the household and builds greater confidence and capability to make decisions regarding their own health (Simkhada *et al.*, 2008).

7.3.5: **Women's Living Arrangements**

Most women in the quantitative component were married (60.9%), with 6.5% separated and 6.0% divorced, and almost two thirds (64.7%) had one or more children still alive. The fistula had developed after the first childbirth in almost half of the women (44.6%). Over a fifth of all women (21.9%) had been deserted by their husband because of the fistula. Marriage dissolution due to obstetric fistula is commonly reported. Many are abandoned or divorced by their husbands especially when it became clear that the fistula persisted (Bangser *et al.*, 2011; Kelly, 1995; Murphy, 1981). While more than half of all women still lived with their husband (53.1%), 11.9% lived alone and 17.6% lived with their parents.

In the quantitative findings, Rwanda (23.0%) and Uganda (17.0%) had the highest percentages of women with fistulas who were living alone. Interestingly, these countries also had the lowest unemployment rates for women with fistula and the two characteristics may be inter-related.

Factors that may have influenced women to live alone are not well understood, but mostly due to constant urine leakage and the accompanying smell.

As previously noted, just over half of women with a fistula still lived with their husbands even after fistula developed. The qualitative findings describe a situation where some women chose to live with their spouses, who in most cases were married to someone else. In a typical African society, a married woman with children is honoured and respected. This culture may be associated with some women and men who chose to persevere with their marriages despite developing fistula. A study in Nigeria reported very high (77%) numbers of women with fistula being divorced/separated following fistula development (Murphy, 1981). Unlike Nigeria, the majority of women (94.5%) in East Africa were Christians. Though the influence of religion on societal level divorce is uncertain and debatable, religion among other socioeconomic determinants plays an important role in the incidence of divorce (Trent and South, 1989; De Graaf and Kalmijn, 2006; Lehrer and Chiswick, 1993).

As noted previously, almost 22% of husbands in the quantitative component of this study left their wives following fistula development and 40.1% of the women were unemployed. Again not all those unemployed were housewives. Women who were separated or divorced experienced unforeseen circumstances of homelessness, while 17.6% of women went back to live with their parents. Women in the qualitative component reported that their partners left home or remarried after the fistula developed: this happened even when women were housewives with no education or employment. The study findings resonate with the findings in Niger which showed that fistula accounted for 63% of all divorces (Lendon, 2001).

The lack of a steady income may be a major contributing factor to low self-esteem witnessed in this cohort. The low self-esteem may diminish women's negotiation skills and subsequent lack of agitation for their rights. This situation was evidenced during the qualitative analysis when it emerged that some women were abandoned at the hospital by their partners who remarried soon after, without dissolving the marriage (Khisa *et al.*, 2017). In the qualitative component, some women (2) choose to live alone, affecting the quality of their lives, while (10/16) of the men remarried. Delan (2008) and Donnelly (2015) in their studies described that such experience diminishes women's quality of lives.

7.3.6: Source of Information

The quantitative data revealed that women relied on different media sources to gain awareness of treatment, the commonest being radio (49.6%). The qualitative data demonstrated that communication was a major issue owing to the continuous urine leakage, bad smell and fear of ridicule from community members (Khisa *et al.*, 2017). In addition, literacy levels were low, limiting access to and utilisation of electronic and print media. Within the increasingly information-centric society, education plays a crucial role in facilitating and enhancing a person's ability to evaluate and harness the power of information (United Nations Educational, Scientific and Cultural Organisation (UNESCO), 2007). Key to harnessing information is the ability to evaluate the information and ascertain its relevance, authenticity and modernity. Utilised properly, this process has been proven to improve health. More importantly, it is how the person utilises the information that contributes to health improvement. The American Library Association defines information literacy as the ability to recognise when information is needed and have the ability to locate, evaluate, and effectively use the needed information (www.cilip.org.uk, 2015). Certainly, this will be useful for women living with fistula who seek advice on treatment and rehabilitation as soon as the fistula develops.

As might be expected, country of referral had an impact on the way women obtained access to fistula information. Radio was the most common source for more than two thirds of the women from Malawi, Rwanda and Uganda, while 37/38 women from DR Congo and all three women from Somalia were referred from hospital. Fourteen (19.7%) women from Southern Sudan learned of the fistula service from friends, relatives or other fistula patients, nearly twice the percentage for any other country (Kenya being the next with 10.2%). This suggests that there may be better sharing of information in this society, mainly because they stay together in refugee camps as a result of the continuous political instability.

Considering these two main sources of fistula information, hospital referral was the most common source of information for women whose education level was above secondary level (57.6% v 32.3%) while radio was more common among women with a primary level of education (53.4% v 36.1%). This implies that women with higher education have access to a health facility/worker compared to the majority who never attended school and heard through the radio. However, delivery in hospital was not synonymous with acquisition of fistula information. This was confirmed in the qualitative study where some women had no knowledge of fistula occurrence or access to care even when the fistula developed in a health facility. It implies that

either the women never received the information or that they did not utilise it appropriately to seek medical intervention.

Studies in Ethiopia demonstrated that lack of access to fistula information was mainly due to low literacy levels and poor communication, especially in rural areas (Wall, 1998 and Muleta, 2008). Situations where women with a fistula lack information on health access were not unique to East Africa. Article 19 is a UK-based organisation that campaigns for freedom of expression across the world and investigates situations where civil liberties may be endangered, such as the case in Senegal. One of their recent reports indicated that 88.3% of 400 fistula patients in Senegal had no knowledge about fistula care. (Article 19, September 2014 Report: accessed at: <https://www.article19.org/data/files/medialibrary/37713/>)

Notwithstanding, in Senegal, only 12% had ever heard about fistula, with 15% of the women saying they knew that fistula care was free, an indication of a widespread disconnect between fistula knowledge and availability of care programs.

7.4: Predictors of Success of Surgery

In multivariate analysis, after adjusting for other variables, four factors emerged as predictors of success of fistula closure. The analysis showed the country of referral ($p < 0.001$) as the strongest predictor of success of fistula closure. This was followed by unemployment, then presence of a relative at childbirth, and finally vaginal stenosis. Interestingly, duration of leakage, which will be considered as an outcome variable in Section 7.5, was not a significant predictor of success of surgery. It was noted that the high success rate for surgery may have limited the ability to find other independent predictors of success of surgery.

These results are unique in the sense that in literature, of all these, only vaginal stenosis has been mentioned as a determinant of successful surgical outcome (Barone *et al.*, 2012; Kayondo *et al.*, 2011). Barone *et al.* (2012) in a multicounty study, found preoperative bladder size, vaginal scarring, previous repair, and urethral involvement as prognostic of genital fistula closure. These results were consistent with the findings of Kayondo *et al.* (2011) who reported fistula size, severe vaginal scarring, and circumferential fistulas as other significant factors. However, that study was limited by the small size ($n=77$) and being a single-centre study. Many of the studies contrastingly did not establish prognostic factors in fistula repair surgery as found in the current study.

Notably, most of the previous studies (Barone *et al.*, 2012; Goh *et al.*, 2008) describe mainly fistula-related factors such as repeat repairs and circumferential fistulas as being strongly prognostic. However, none of the patient characteristics such as age, weight, parity or any of the childbirth level factors (mode of delivery, duration of labour and birth weight) showed any significance as predictors (Goh *et al.*, 2008; Nardos *et al.*, 2009; Raassen *et al.*, 2008; Barone *et al.*, 2012). Despite this, none of these studies looked at contextual factors such as surgeons' experience, whether repairs were conducted during an outreach camp or as part of routine services (Barone *et al.*, 2012).

This section looks at statistically significant independent predictors of fistula surgical closure: country of referral (7.4.1), unemployment (7.4.2), presence of a relative at childbirth (7.4.3) and vaginal stenosis (7.4.4).

7.4.1: Country of Referral

Kenya emerged as the country with the highest percentage of successful surgeries (96.5%) when compared to other countries in East Africa (Table 5.13). This is likely to be a result of availability of surgeons providing routine services as opposed to camps as seen in other countries. Furthermore, women can receive care as soon as they present in Kenya. Early repair of fistula has better outcomes as to healing and reduction of stigma (Waldijk, 2004). This minimises the chances of repeat repairs that may arise from long-term complications of living with fistula such as infections and /or scarring of tissue. Adjusted for other factors, country of referral was a significant predictor of the success of fistula closure ($p < 0.001$) and compared women from with Kenya, the odds of a successful repair were significantly lower for women from each other country except for Uganda, where of 93.2% surgeries were successful (Tables 5.13 and 5.20).

Kenya, Uganda, Rwanda, South Sudan, Malawi, DR Congo and Somalia have a high prevalence of obstetric fistula. A recent systematic review found varied difference and unreliable estimates of obstetric fistula incidences in middle and low income countries of sub-Saharan Africa and south east Asia, but these figures are necessary to guide policy and funding towards alleviating this important public health issue (Cowgill *et al.*, 2015). Additionally, a meta-analysis, in sub Saharan Africa showed that vaginal fistula lifetime prevalence as 3 per 1000 women of reproductive age group and roughly one per 1000 as having symptoms at present (Maheu-Giroux *et al.*, 2015) confirming how common obstetric fistula is in this region. Ethiopia followed by Uganda had the highest prevalence in Maheu-Giroux *et al.* (2015).

These countries of East Africa vary also in social and political determinants of access to health services. For instance, the educational levels across countries were different, with Kenya having the highest number of women who had reached college. Some of the countries experience higher rates of sexual violence as causes of vaginal fistula, like DR Congo (Maheu-Giroux *et al.*, 2015), Southern Sudan and Somalia due political unrest. Countries such as Sudan and DR Congo recorded infrequent fistula outreach services because of civil wars. Such unpredictable nature in the delivery of fistula services seemed to create hurdles for women (Khisa *et al.*, 2017).

Other determinants in access to fistula services vary within developing countries: affluence or class, and living in urban or rural areas, with poor and rural dwellers being less likely to use maternal health-care, cited in Say and Raine (2007). It is important to understand contextually that these factors interact differently in every country, therefore should be considered if designing an intervention (Say and Raine, 2007).

Evidence shows a marked variation in the use of maternal health services within and between countries in developing areas such as those in East Africa. Wealthier and urban women are more likely to utilise maternal health services. Physical distance to the healthy facility and lack of personnel or quality services also vary widely and determine utilisation of health services in developing countries (Say and Raine, 2007).

Looking at the Kenyan health system utilisation, the cost of services and poor access to health facilities were examples of the largest impediments to health seeking behaviour in a country of approximately 37 million people (Turin, 2010). Turin described the health system as lacking political will with disparities or inequities between different regions of Kenya. The stories from the women's experiences summarised these two reasons why they could not get help. Aged 64 and divorced, Fairness (not her real name) developed the fistula at age 15, and it took 49 years before she could access her first surgery to close the fistula. This occurred in Kenya, a country where regular fistula services are provided at no cost to the patient. Such findings point to unknown/unexplored factors that block women from accessing fistula care.

7.4.2: Unemployment

The findings indicate that women who were in employment significantly increased their chance of a successful surgery. Women who were unemployed had lower chances healing with adjusted

odds of successful surgery being halved (adjusted OR=0.50, p=0.019, Table 5.20). This outcome agrees with Browning *et al.* (2004) who report that women without steady income may continue to suffer the pain and shame associated with their fistula because chances of employment remain low.

During the qualitative interviews it emerged that many women believed that they would spontaneously revert back to their pre-fistula roles especially after a successful surgery. However, this was difficult as most women (13/16) had only been educated to primary level which may have limited their opportunity for employment. The low level of education significantly reduced their chances of being financially independent, making the women very vulnerable, even after the fistula healed (Khisa *et al.*, 2017). In almost all East African countries, there is no community programme to support these women after surgery, potentially leaving them miserable and vulnerable even after the fistula heals (Lavender *et al.*, 2016; Khisa *et al.*, 2017; Khisa *et al.*, 2011).

7.4.3: Presence of a Relative at Birth

In the quantitative component of this study, women were asked if a relative had been present at childbirth, although they were not asked which relative it was. In the qualitative component, the woman's mother-in-law was the relative most commonly mentioned as a birth assistant, consistent with local custom. Like in many low income countries, gender plays a pivotal role in access to maternal health services (Simkhada, 2010). Gender roles, norms and expectations attributed to male or females are assigned by culture and various societies where people live. Through these assignments, inequalities emerge in ways that are unfair, unjust and avoidable. These descriptions are commonly seen in Africa and Asia where societies are highly patriarchal in nature. Previous studies in Tanzania have indicated that inequalities between women and their partners exist in terms of age, education and income levels (Simkhada, 2010; WHO, 2010). These differences have been associated with varying partner-controlling behaviours which affect women's access to MNH services (Heise, 1999; Wall, 1998). Ultimately, their autonomy in decision making is eroded and women become overly dependent on their partners for physical and financial accessibility for maternal health services. Reports from Tanzania, Bangladesh and Burkina Faso (Some, 2013; Story, 2012) point to the husband as the main decision maker in cases where wives were younger than their husbands. This situation replicates instances witnessed in the qualitative component where women were abandoned even when in intensive care units (Lavender *et al.*, 2016).

Studies in Nepal, show the mother-in-law was perceived to have negatively influenced ANC uptake and their decisions went largely unchallenged (Simkhada, 2010). Many of their decisions were based on previous birth experiences and expected gender roles of daughters-in-law. Similarly, in Mali, White (2013) found that the mother-in-law influenced the place of delivery, which agrees with both quantitative and qualitative findings in this study. The women told stories of mothers-in-law and other relatives who watched them labour for many days and instead of referring the women to hospital, they ridiculed them, subjecting their lives to fate. This notwithstanding, unskilled birth attendants, including relatives, continue to provide and supervise more than 40% delivery services to many women in Africa (WHO, 2016). Over dependency on partners and lack of economic power contributes to a harsh environment for women with fistulas (Lavender *et al.*, 2016). Subsequently, this limits the decisions on the pathways that any woman would follow when labour ensues. In the qualitative component, the many women were stigmatised as a result of loss of identity and abandonment after the fistula developed. This can be summarised by one of the participants who said:

“The nurses told my husband to give me space since I was now disabled. Shortly my mother-in-law told the son to leave me. She said ‘leave her, she is now disabled’. My husband then left me in hospital without a word, went home and married another woman and sired children with her”- Sandra

Quantitative findings indicate that during childbirth there were instances when women in this study were assisted by a traditional birth attendant (19.2%). Having a relative present at birth reduced the odds of a successful surgery by half ($p=0.044$) (Table 5.20). The current study demonstrated that women whose births were assisted by relatives reported higher fistula failures than those who were attended by skilled birth attendants. In Tanzania, husbands and mothers-in-law continue to determine where and how child birth should occur (Mselle and Kohi, 2016). This brings the realisation that in many low income countries, gender inequity plays a pivotal role in access to maternal health services (Simkhada, 2010). In Nepal, the mother-in-law’s word is final and neither her husband nor her son can overrule it, hence determining the direction of events that can be disastrous to the daughter-in-law in pregnancy and labour (Simkhada, 2010). Reports from Tanzania, Bangladesh and Burkina Faso (Some, 2013; Story, 2012) point to the husband as the main decision maker in cases where wives were younger than their husbands, as is the case in the current study. These differences have been associated with varying partner-controlling behaviour which affects women’s access to MNH services including fistula care (Heise, 1999; Wall,

1998). This behaviour is common in low resource countries as one woman narrated her story where she was denied the fare to go for a scheduled check-up at the hospital because she refused to have sexual intercourse with her partner (Lavender,*et al.*, 2016).

7.4.4: **Vaginal Stenosis**

A fourth predictor of success in anatomic surgical closure of fistula was vaginal stenosis (adjusted OR=0.48, p=0.041) (Table 5.20). The extent of the scarring has been viewed as an important predictor of surgical success and has been incorporated into fistula classification systems (Waaldijk, 1995; Goh, 2004). Vaginal stenosis denotes a narrowing and/or loss of flexibility of the vagina. It follows genital surgery with consequences of vaginal dryness and loss of resilience of scar tissue (Kayondo *et al.*, 2011; Barone *et al.*, 2012; Waaldijk, 1995), shortening and narrowing of the vagina, reduction of vaginal lubrication, and diminishment of the size and number of small blood vessels within the vagina. The result of these is vaginal stenosis and much drier, friable vaginal tissue. This may affect accessibility at fistula repair and subsequently compromising healing of tissues after repair.

In Ethiopia, Muleta *et al.* (2010) reported severe vaginal scarring and obliteration in 14.9% of 14,373 women undergoing obstetrical fistula repair. Other researchers have found vaginal stenosis/scarring as a determinant of surgical failure (Barone *et al.*, 2012; Kayondo *et al.*, 2011). Earlier reports indicated that in the short term post-operative period, repeated/previous repairs and multiple fistulas may influence the outcome (Munoz *et al.*, 2011). However, the quantitative component of the current study indicated that these factors were not significant at predicting anatomical closure of fistula, but that they can predict duration of urine leakage. There were no clear direct observations that were obtained from the qualitative results that would explain this scenario except for self-neglect, repeated repairs, and recurrent infection which could lead to tissue breakdown. Repeated repairs may lead to vaginal stenosis, hence predicting the success of surgery.

Disturbed by the prevailing symptoms and pain associated with vaginal stenosis, women sought treatment from various sources including herbalists. For instance, Salma (not her real name) disappointingly sought treatment from witch doctors and herbalists with the hope of alleviating the symptoms of vaginal stenosis.

7.5: Predictors of Duration of Leakage

This section presents a synthesis of factors predicted duration of leakage in 1224 women who participated in this study. Foremost, country of referral as well as women's Characteristics had a bearing on the time taken before they could access fistula surgery. The women's living arrangements': whether she lived alone or with extended family seems to have influenced the duration of leakage. Lastly, Source of fistula information, Childbirth-related factors (whether women had a living child or not) and fistula-related factors such as vesico vaginal fistula or rectal vaginal fistula or a combination of both (vesico vaginal fistula and rectal vaginal fistula) did influence the duration of leakage.

7.5.1: Country of Referral

Women referred from countries outside Kenya were more likely to have a longer duration of leakage, $p=0.002$ (Table 5.29). Apart from Somalia where all three Somali women had durations of up to 12 months, Kenya (39.0%) and the DR Congo (29.5%) had the highest percentages of women with a duration of up to 12 months (Table 5.13). Even so, the percentage of Kenyan women with a duration over 108 months was 26.1%, with only Rwanda (40.5%) and Uganda (29.5%) showing higher percentages. Such a long period of leakage was not unique to this study: elsewhere in Nigeria and Tanzania, studies report long durations of leakage (Hilton *et. al.*, 1998: Bangser *et al.*, 2011). The researcher agrees with reports by the WHO (2014) which indicate that country-specific factors such as GDP, literacy levels and gender issues are linked to access to health services including fistula care services. Further, UNFPA (2004) reports indicate that low income countries with poor maternal health policies and services seem to be associated with fistula development. This brings to the fore the need for economic and health policies geared towards improved economies. This will serve as a first step towards mitigation for fistula care and prevention.

Unfortunately, women with longer duration of labour also reported longer duration of leakage as was seen in findings from Southern Sudan and DRC (Table 5.8.) Previously, Tahzib (1983) reported that women with longer duration of leakage also had a longer duration of labour. Both reports raise issues around lack of access to maternal health services and timely care, especially during labour. In countries where quality maternity services are available, fistula problem is nonexistent, like seen in developed countries. When a fistula does occur in high resourced settings, timely interventions such as prompt repair are conducted and women do not suffer the pain and shame associated with urine/stool leakage (WHO, 2016).

All these factors hindering access to utilisation of health services fall into the categories that were identified by Thaddeus and Maine as the 3Ds mode: Delay in seeking health care, Delay in arriving at a health facility, and Delay in the provision of care (Thaddeus and Maine, 1994).

Interestingly, it may be the interplay of these factors that are important as neither the 3Ds nor the 3Es (Education, Empowerment and Economic status) considered separately address compressively how maternal health services are utilised and this may be the cause of differences in duration of leakage between and within countries. Separation, divorce or abandonment after fistula occurrence are all interrelated and are linked to delay or poor access to health care. In part, lack of knowledge may have contributed to an increased duration of leakages, even in countries where fistula services are accessible and at no cost to the woman. Limited or poor information about fistula services across countries may explain why many of the women do not access the available routine fistula services that help them. The lack of quality services, in terms of equipment, supplies and medications in resource poor settings make things worse for women with fistula (Tahzib, 1983). If this is sustained it is reasonable to understand why people do not utilise the local services available: this may partly explain a long duration of urine leakage.

7.5.2: **Women's Characteristics**

Education and unemployment were associated with longer duration of leaking urine in the quantitative data. Married/divorced/separated women with a primary level or no education and those who were unemployed were more likely to report a longer duration of leakage than single women with higher education. These findings were similar to other studies where poverty was a major determinant in health seeking behaviour, particularly in obstetric fistula (Jokhio, 2006: Cook, 2004: Marthur, 2010: Bangser, 2007).

Education should improve access to fistula information and care. Unfortunately, for women to access health services, their families may have to spend significant amounts of money and time to access treatment: funds are frequently raised by selling land and livestock (Bangser, 2011). This correlates well with the qualitative findings that showed that in terms of lack of employment, poor education and divorce, financial difficulties played a role in duration of leakage and hence access to fistula services. It was not uncommon to hear women narrate how the church had to raise monies for their transport and how husbands sold family property. These narratives highlight the critical role that employment, education of the girl child and marital status play in duration of leakage.

Drawing from recent work relating to utilisation of maternal health services, findings show that these services are lacking in areas where the need is greatest, especially the disadvantaged populations (Ahmed, 2010). This resonates with Hart who described the “law of inverse care” wherein those least in need of health care, i.e. the healthy and wealthy, are more likely to receive care than the sick and poor (Hart, 1971). Women with a fistula are at a disadvantage: they are often the poorest among the poor and usually least educated (Ahmed *et al.*, 2010; Fotso *et al.*, 2009).

Furthermore, evidence now suggests that women’s Economic, Educational and Empowerment status (3Es) improves the uptake of basic maternal health services (e.g. contraception use, antenatal care, skilled birth attendance). In these East African Countries, available maternal health services may not be woman-friendly (Thaddeus and Maine, 1994). This observation is common in low resource settings where human resources can be scarce (Rahman *et al.*, 2008). The qualitative experiences depicted similar situations where women were despised by members of staff in many health facilities and other women in the wards when leaking of urine started. One woman was advised to either wait for the VVF camp or travel a long distance to Nairobi for care: this was impossible as she had been abandoned in the hospital by her husband.

Parity when fistula developed was seen as a factor which predicted duration of leakage, especially where parity was less than 2 ($p=0.002$). Obstructed labour and fistula occurrence due to cessation of uterine contractions when mechanical obstruction occurs has been hypothesised to be common among primigravidae (Neilson, 2003; Kelly and Kwast, 1993b; Muleta, 2010). Fistula is common in young primigravida who are also likely to experience lack of 3Es, expressing the difficulties experienced in this study where the women resorted to small business or selling sex for survival.

7.5.3: Living Arrangements

Single women who lived alone were associated with a shorter duration of leakage compared to those who were married and lived in the family setup ($p=0.002$). Women who were married before fistula developed but were divorced or separated because of fistula were likely to report a longer duration of leakage. In a way, this reflects the day-to-day tradition of African family life where gender roles assigned to women do not allow married women to leave home without the knowledge of the larger family, especially the mother-in-law (Mselle and Kohi, 2016). Also,

because of the stigma attached to fistula and fear of rejection, women narrated how they lived with the fistula in secrecy for many years (Lavender *et al.*, 2016). It is this secrecy that shielded them from the inhuman experiences narrated by women whose families knew about the fistula (Khisa *et al.*, 2017). Single women are either young and dependant on others for support or running small business or in employment where they can support themselves, as was seen in the qualitative findings (Khisa *et al.*, 2017). In many similar circumstances, decision-making is left to parents, like the youngest participant from the qualitative experiences of this study, who was brought by her able parents for care as soon as they got information of the fistula treatment (Khisa *et al.*, 2015).

7.5.4: **Source of Information**

Findings from the in-depth interviews revealed that women who had no access to fistula information leaked for a longer period of time and they also suffered considerable stigma. Women who had a good education (secondary level and above) were likely to access fistula information from a health worker illustrating the linkage between education and access to information (Table 5.5). Women whose education level was primary or never attended school seemed to have limited access to information and were more likely to hear about the fistula camps from the radio. As a result, women with lower levels of education may have leaked for a longer period than those whose education was higher. Previous work in Ethiopia also highlights lack of access to fistula services, especially for rural women (Wall, 1998; Muleta *et al.*, 2007). Drawing from the literature review and key outcomes in the current study help the author conclude that education and employment are fundamental in facilitating access to fistula services.

The lack of or poor information about fistula services in many communities may explain why many of the women do not access the available routine fistula services that help them. The lack of quality services, in terms of equipment, supplies and medications in resource poor settings make things worse for fistula patients (Tahzib, 1983) and essentially fails to promote useful information transmission, critical for early management of fistula .

Furthermore, more women in Kenya attended higher education and were in employment than seen in other countries (Table 5.2). These factors have been linked to an increase in access to reproductive health services through economic empowerment which is an important factor in women's health seeking behaviour (Liabsuetrakul, 2011). In a related publication, this author

reported that women in this study expressed financial difficulties before and even after fistula closure (Lavender *et al.*, 2016).

7.5.5: **Childbirth-related factors**

Quantitative findings in this study showed a mean duration of labour as 46.7 hours with a mean birth weight of 3.53 kg. Unfortunately, women with longer duration of leakage also reported longer duration of labour, commonly seen in Southern Sudan and DR Congo (Table 5.8). Longer duration of leakage was commonly observed in women who also had no access to skilled birth attendance. Those who had access to skilled birth attendance were more likely to have a catheter inserted after birth ($p=0.004$) compared to those who had had no access but leaked after birth ($p=0.006$) (Table 5.28). This may mean that hospital deliveries are likely to lead to access to fistula information which facilitates early repair/conservative management, both events help reduce duration of leakage (Barone *et al.*, 2015) by promoting early treatment and preventing stigma as this would appear as continuous treatment after childbirth (Frajzyngier, 2012; Raassen *et al.*, 2008). Hospital deliveries were also linked to fistula prevention by Tahzib (1983). In countries where fistula is rare, timely interventions, such as prompt repair, prevents women from suffering the pain and shame associated with urine/stool leakage (WHO, 2016). The social and clinical practice implications of such outcomes are that women with long duration of leakage also endured prolonged and unresolved labour (Wall, 1998). Women with prolonged labour are more likely to be young in age, unemployed and without capability for decision-making.

Prolonged and unrelieved labour may result in fistula formation as a result of compression of the bladder wall and vagina by the foetal head (Wall, 1998). High birth weights are a risk to fistula formation as larger babies are more likely to cause obstructed labour (Gudmundsson *et al.*, 2005).

7.5.6: **Fistula-related factors**

In part, repeat repairs tend to fail because wound healing in previous surgeries may have occurred with fibrosis. In subsequent repairs, the fibrosis reduces blood circulation to the tissues and/or makes access difficult. The experiences of the women in the qualitative part of the study show that when women fail to heal, negative social interactions, including abandonment, continue to haunt them (Lavender *et al.*, 2016; Khisa *et al.*, 2017).

The qualitative component in the current study suggested an association between fistula type and challenges women experienced. Those with RVF alone lived longer and seemed to cope better with the symptoms compared with those whose symptoms were urine leakage. Those with a

diagnosis of RVF alone lived with the leakage for a long period but they experiences less stigma. This is understandable as negative stigma is likely to be less from an RVF than VVF since leakage of stool is easily controllable unlike urine leakage, a finding described earlier on by other researchers (Waalwijk, 2004; Kelly, 1992). Those with a diagnosis of RVF alone seemed to invent coping mechanisms which helped them cope better.

Repeat repairs may lead to despair and further stigma, especially if no improvement in the symptoms is witnessed. Women who had VVF alone or both VVF and RVF were found to seek fistula services earlier than those with RVF alone (Table 5.10) confirming observations by Carpenter *et al.*, (1992).

7.6: Summary

This chapter has discussed the predictors of success in fistula surgery and duration of leakage, interweaving the lived experiences of the women using a mixed method design. The synthesis shows that the country of referral had the strongest predictor of success of fistula closure, with Kenya emerging as the country with highest percentage of successful surgeries. Women who had some education and were employment had a higher chance of healing. The same group also seemed to have shorter duration of leakage compared to those who never attended school and were unemployed. These observations had a direct relationship with women's lived experiences. Women with some degree of empowerment (Education and Employment) reported less stigma and had access to surgery within 12 months of fistula development. Inevitably, unemployed women were less likely to: heal, had long duration of labour, long duration of leakage and fistula related stigma. The analysis showed the country of referral ($p < 0.001$) as the strongest predictor of success of fistula closure. Kenya emerged as the country with the highest percentage of successful surgeries (96.5%) when compared to other countries in East Africa (Table 5.13).

The findings indicate that women who were in employment significantly increased their chance of a successful surgery. Women who were unemployed had lower chances healing with adjusted odds of successful surgery being halved. The many women were stigmatised as a result of loss of identity and abandonment after the fistula developed.

A fourth predictor of success in anatomic surgical closure of fistula was vaginal Stenosis. The extent of the scarring has been viewed as an important predictor of surgical success and has been incorporated into fistula classification systems. Women referred from countries outside Kenya were more likely to have a longer duration of leakage.

Education and unemployment were associated with longer duration of leaking urine in the quantitative data. Married/divorced/separated women with a primary level or no education and those who were unemployed were more likely to report a longer duration of leakage than single women with higher education.

Education should improve access to fistula information and care. Unfortunately, for women to access health services, their families may have to spend significant amounts of money and time to access treatment: Single women who lived alone were associated with a shorter duration of leakage compared to those who were married and lived in the family setup ($p=0.002$).

Findings from the in-depth interviews revealed that women who had no access to fistula information leaked for a longer period of time and they also suffered considerable stigma. Unfortunately, women with longer duration of leakage also reported longer duration of labour.

Chapter 8: DISCUSSION

The tragedy of life is not death, but what we let die inside of us while we live-Norman Cousins (American journalist 1915-1990).

8.1: Introduction

Exploring women's lived experiences using a phenomenological approach gave an insight into their pre- and post-surgery experiences. Importantly, the longitudinal approach enabled observations that captured where individual women were situated on their recovery journeys. It was clear that there was a continuum of recovery stages, with the physical and psychological healing process dependent on multiple factors.

8.2: Importance and Originality of Findings

At the beginning of the study (2013), a review of the literature (Chapter 2) revealed observational studies in similar settings (Barone *et al.*, 2013; Kayondo *et al.*, 2011). In later years, mixed method designs emerged (Wilson, 2016) but these studies were restricted to one or two countries (Barone, 2013) as compared to the current multi-country study settings.

As stated in section 1.4.3 of Chapter One, the researcher set out to achieve five study objectives. The first was to describe demographic characteristics of obstetric fistula patients in East Africa. A total of 1224 women diagnosed with fistula were recruited for study. Literacy levels were low in almost all countries: 62.9% were educated to primary school level and 17.0% had received no education. Only 4.8% of women had college level or higher education and all were from Kenya. Unemployment was highest amongst women in the DR Congo (92.1%), followed by Southern Sudan (76.1%), Rwanda (13.5%) and Uganda (13.2%).

The second objective was to describe the pre- and intra-operative obstetric fistula characteristics: such as type, location and size of the fistula. Other studies (e.g. Kayondo *et al.*, 2011) looking at intra-operative characteristics show that large fistulas have a lesser chance of healing: a huge contrast to the current study findings which show that fistula size or location had no impact on surgical outcomes.

The third objective aimed at establishing predictors of successful fistula closure among obstetric fistula women. Findings indicate that Country of referral was the most important predictor of surgical success followed by and unemployment. The outcomes also indicated that vaginal stenosis and presence of a relative at birth were associated with surgical failure. Previously,

Kayondo *et al.* (2011) identified vaginal stenosis as a predictor for surgical failure: however, none of these previous studies investigated presence of a relative at birth and its influence on fistula healing. Irrespective of fistula size and location, the study recorded a 94.1% mean success rate of surgery.

The fourth objective was to describe predictors of duration of leakage among fistula patients undergoing surgery at selected fistula centres in East Africa. Many factors were significant predictors of duration of leakage in this study, including history of previous repairs, duration of labour, marital status, method of knowledge of the fistula camp, husband leaving because of fistula and regular menstruation ($p < 0.010$). Earlier studies (*Wall et al., 2004; Muleta et al., 2006*) indicated that divorce/separation and unemployment were associated with duration of leakage: these outcomes seem to agree with our findings.

The fifth and last objective was to describe the lived experience of women diagnosed with obstetric fistula, before and after fistula surgery. This qualitative component of study yielded two main overarching themes: Social isolation and Social reintegration. Women reported euphoric feelings following fistula repair, at this point they believed that a 'miracle' had occurred. Overtime, the 'post-miracle phase' showed that even when fistula repair is successful, the social and psychological impact of fistula leaves scars that are not easily healed.

8.3: Meeting the Set Objectives

The uniqueness of this mixed methods and multi country design presents an original approach to fistula research in these settings. In achieving set objectives for this study, the author makes his contribution to the body of knowledge relating to predictors of fistula healing, duration of leakage and lived experiences of women with this debilitating condition. For instance, the author documents the association between country of referral and duration of leakage. From sections 8.4 to 8.5, the author discusses his findings in terms of Maslow's Hierarchy of Needs and Bronfenbrenner's Ecological Systems Theory. The discussion presents a unique approach where two models are applied in a complimentary version: providing the reader with two dimensions in understanding lived experiences of living with fistula. Section 8.3 and 8.4 discusses these two models independently as well as in combination.

8.4: Resonance with Maslow's Hierarchy of Needs

8.4.1: Introduction

Abraham Maslow (1908-1970) was an American psychologist and a leading exponent of humanistic psychology. He developed a five stage model which described the need to satisfy basic human needs as a theory about human motivation for growth and development. The theory focuses on human growth and describes in general, the pathway that human beings follow in life. Maslow utilised the phrases "physiological", "safety", "belonging or love", "esteem" and "self-actualisation or transcendence" as depicted in Figure 8.1. He argued that human beings progress from satisfying their basic physiological needs, such as the need for food, in order to achieve higher needs which he called self-actualisation (fulfillment of one's greatest potential) (Maslow, 1943). In other words, the fulfillment of ones needs frees the human being to endeavor to fulfil another at a higher level in a more or less hierarchical manner.

This model has been applied as a framework for analysing and understanding aspects of human behaviour and growth. A woman living with fistula essentially follows a similar pathway while seeking self-esteem. However, these needs should not be treated in isolation; sometimes there are many interconnections within the needs. Such interconnections of needs were observed in one woman who despite several attempted surgeries did not heal, but still went on to get married to a man who abused her sexually and physically. In such a case, the woman desired higher level goals of love and belonging even when she had not achieved continence, a primary need. Such observations draw similarities with Maslow whereby the hierarchy of needs is not a rigid structure, but rather serves as a framework to evaluate human growth and behaviour (Maslow, 1943) (Figure 8.1).

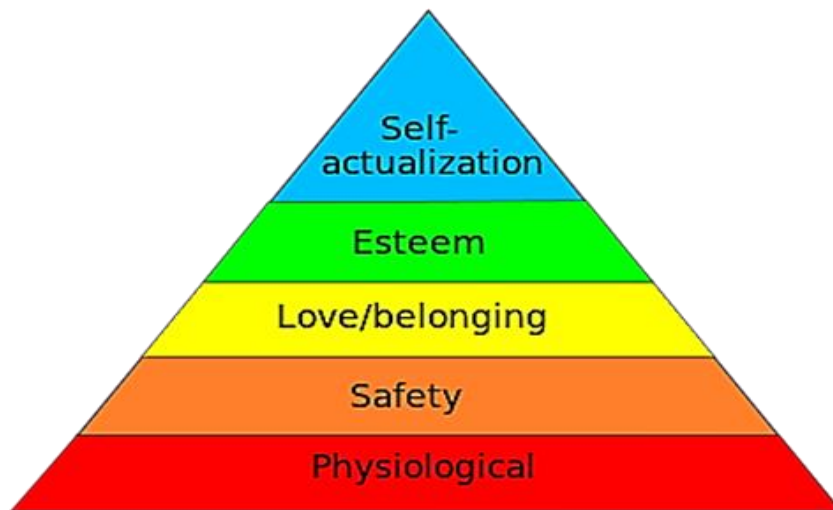


Figure 8.1 Maslow's Hierarchy of Need (Maslow, 1943)

Each level of need is discussed in turn and related to the findings of the study. It should be noted that, in this study, growth was viewed as moving up in the levels of the hierarchy, with the lower needs being physical goals and the higher needs leaning heavily towards psychological goals. It is also assumed that within society, there are local networks such as family, church, women/youth groups that serve these human developmental needs. In many instances, the women narrated instances where these networks were not supportive: whenever this happened, the women in this study felt rejected and unappreciated by their own members.

Individual factors, observed in this study, also resonated with Maslow's model (Maslow 1943), whereby women had to navigate each stage before moving on to the next. It was observed that once women started leaking urine after childbirth, the immediate needs reverted to seeking an explanation and treatment for the urine incontinence. Equally, while the women celebrated becoming continent after surgery, they had a need to regain pre fistula lives and identities as they sought to reintegrate back into the society. The journey for this group of women was challenging as the struggle to restore their pre fistula identities and self-esteem evolved.

8.4.2: Physiological

The obstetric fistula confers such a transcendent experience upon those who develop it. The experience of having a fistula has been described as 'life changed forever' by researchers like Ahmed (2007). In the current study, the women described their experience by saying 'I died inside while alive'; it was seen as being the worst tragedy. Much like Maslow's theory of human needs

(Maslow 1943), the women viewed urine leakage and its consequences as the most basic physiological need and until the need was satisfied the women felt hopeless. It appeared that all the woman's focus and energies were almost entirely driven by the need to be continent of urine again and the rest of the other needs like maternal instinct, unemployment, financial ability, pregnancy, safety, sexual drive quickly drifted into the background. This was captured by one woman who said:

"I am praying that the doctor can close my fistula just like he did for the patients I saw last year; I spoke to my friend from last year's VVF camp at coast general hospital and she is dry; how I wish the same would happen to me. How I wish it closes".Clarity

The women strived to hide urine leakage with the use of rags as continence pads, hiding from people, taking frequent body baths and changing clothing, and reducing the drinking of fluids. Such activities of daily living were carried out to retain both hygiene and esteem needs (Khisa *et al.*, 2011: Wilson, 2016: Pope, 2011: Bangser, 2006: Browning, 2006). It is said that deprivation of basic needs is an important aspect of gratification (Maslow, 1943: Pope *et al.*, 2011) described that familial support is an important aspect in accessing fistula repair and achieving full recovery.

It is the view of the author that the physiological need in the hierarchy corresponds to women's experiences with urine leakage. This view has been documented in the literature by other researchers (Bangser, 2006, Wilson, 2016, Mselle, 2016, Gharoro and Agholor, 2009). Following surgery, most women in the study gained continence, diminishing fear of rejection. In one experience, the woman rode in the front of a bus to the hospital follow-up appointment like everyone else without worrying about leakage of urine or bad smell. Similarly, if surgery was unsuccessful, the scores of 94% would drop once urine leakage occurs again (Pope, 2011). For those women whose surgeries were not successful, women continued to leak urine even after surgery: they narrated a 'stagnated experience'. However, those who gained continence following successful surgery, the physiologic need was satisfied and ceased to be a motivator of their behaviour. Therefore, the women moved to the next hierarchy/level. In their own words, the physiologic level was all "part of history that they did not want to refer to" (Lavender *et al.*, 2016).

8.4.3: **Safety**

Once the physiological needs have been met, the person seeks Safety needs, (Maslow, 1943). At this level the whole "organism" becomes dominated by safety needs turning the person into a

safety seeking mechanism. Safety needs include: secure working environment free of fear and harm; stability; freedom from fear, anxiety, and chaos, need for structure, order, law, and limits. The women in this cohort looked for stable structures in the society, free of uncertainties, but they rarely found support. They wanted to be free and forget about leakage of urine and its consequences; some wanted to go back to school and become doctors like their surgeon.

The journeys of the women before surgery were embroiled in stigma, lack of role identity and employability issues, denying women confidence and safety. This worsens when knowledge and education were suboptimal in the majority of the women (Khisa *et al.*, 2016; Ahmed, 2011). In similar settings, studies attribute low utilisation of health services to abuse of women attending maternal services (Finlayson *et al.*, 2013).

Once the fistula had closed, women's needs changed; many expressed hope and desire to start a business or find employment. A steady source of income was viewed as a foothold to economic independence. Their wish to get employed and relate with people they knew prior to the fistula grew unbelievably high. This may be associated with an inner desire to gain financial security which may help prevent a downward spiral to poverty: experienced during the pre-surgery period. These reports are not new; in their studies Pope (2011) and Wilson (2016) show similar outcomes, where women desired to resume their lives and find work after fistula surgery.

Domestic abuse prevalent before surgery was reduced after surgery and women could freely move whenever and wherever they wanted to go without hindrances or fear of leakage of urine or being sneered at. This need, though seldom mentioned before surgery, became pronounced when it was lost or denied from the women. Domestic abuse was seen commonly if healing had not been achieved and made worse if there were no children in the family, findings that were also described by Pope (2011) in a Tanzanian study. Many husbands abandoned their spouses upon occurrence of fistula, even in hospital, and got married upon advice from mother-in-laws or, on some occasions, from medical staff.

In a few cases domestic abuse was still evident even after fistula closure. This was seen in one woman when the spouse attempted to have sex with her even after a letter had been written by the doctor advising abstinence from sex for a period of six months. The woman had to scream for assistance to avoid being raped. In a Tanzanian study, women would deliberately add more time

for resumption of sex contrary to medical advice, in an attempt to completely heal before resumption of sexual intercourse (Dennis, 2016).

Rachel Pope in her study of social reintegration Pope (2011) found that the majority of the women wanted to start life again, although some expressed fear that they may not be able to conceive again. The fear of developing a fistula again was also documented after repair in the same study. Such reports seem to agree with outcomes in the current study whereby women expressed resentment to resumption of intimacy and sex with partners/husband.

8.4.4: **Love/Belonging**

According to Maslow (1943), once physiological and safety needs have been satisfied, there emerges the need for love, affection and belongingness. As women's journeys continue, loving relationships' became important. Not all women were fortunate to have husbands and children when fistula developed. Women's experiences were varied, for instance, one family held a party to welcome the woman/ wife back: while in another family, the woman was invited to help organise a party for close friends. These gestures gave reassurance and sense of belonging to these women.

Women living with fistula had lost a sense of belonging and role identities as mothers, wives and friends. Living with fistula had eroded the mental faculties (such as memory, will, reason, intuition and perception) of a woman and almost all had lost their ability to reciprocate love. They had been relegated to the periphery of society, described as "physically present but socially absent" (Crocker *et al.*, 2017).

Many studies indicate that women with fistula are divorced, separated or just abandoned (Alio *et al.*, 2011; Wilson *et al.*, 2016; Degge *et al.*, 2016). This trend was also witnessed in this study, that even if they are not divorced or separated, some women are abandoned. They did not have support from their spouses or immediate family members. This made the women feel devalued and stigmatised.

Because of rejection and lack of belonging, women avoided situations which were likely to put a label on them. By socially excluding themselves from society, the women distanced themselves from getting employment and seeking treatment. Obviously, by living in constant state of anxiety, their mental and physical health is undermined (Khisa *et al.*, 2011; Lavender, *et al.*, 2016; Wilson,

2016: Crocker, 2003). Other regional studies also report that fistula surgery is free and accessible to all patients, but for some unknown reasons some women are reluctant in seeking treatment, instead they chose self-isolation (Pope, 2011).

8.4.5: **Esteem, Self-Respect, Self-Worth, Confidence**

For one to achieve esteem, several factors such as a supportive environment must be in place. According to Maslow, most people have a need or desire for a stable, firmly based high evaluation of themselves, for self-respect, or self-esteem. In addition, the inability to mingle and accompany friends or family in social gatherings can elicit doubts in one's ability to live a full life. Ultimately, an inability to control urine, coupled with financial dependency due to employability challenges, can devastate one's self-confidence. Unfortunately, many of these women living with fistula were in their first pregnancy when the fistula occurred and the pregnancy resulted in a stillbirth. Having lost their baby and suffering with a fistula left women with shattered dreams coupled with stigma, loss of self-respect or self-worth. Fortunately, most women in the study regained some confidence as soon as fistula is closed.

Stigma after fistula sets in, is a major social impediment to recovery. Stigma has been known for a long time to affect self-esteem and, by definition, a person who is stigmatised is a person whose social identity or membership in some social category calls into question his or her fully humanity-the person is devalued, spoiled, or flawed in the eyes of others (Crocker *et al.*, 2003). This formed a major part of the pathway to social isolation as a result of negative attitudes towards women with fistula (see results chapter six). From the stories of the women, stigma is an ongoing obstacle to recovery for these women even after fistula has been long closed, as witnessed in the post miracle phase (see results chapter). This is made worse by the loss of value in the society, social rejection, avoidance behaviour, and discrimination which was reported frequently by the women.

There is desperation noted in some women even after surgery as to where they should go or even what they should do even in the face of successful surgery. Some would rather be on their own and running a business to support themselves. If indeed the women can convincingly acknowledge achieving self-esteem and with financial ability, they can advance to the fourth stage of Maslow's hierarchy-self-actualisation, the highest level of human needs. However, this may not always be the case. One unfortunate woman, whose repair had failed, did not feel secure and hence, the unsatisfied lower level needs rendered esteem needs less relevant and lacking priority. Such women obviously need different health promotion strategies. A positive attitude, optimism

and always caring for others should be employed both to the women and the healthcare staff as well.

8.4.6: **Self-actualisation - Gaining Independence, Regaining a Position in Society, Fulfilling**

Goals.

Maslow describes that satisfaction of the esteem need leads to feelings of self-confidence, worth, strength, capability, adequacy of being useful and necessary in the world. 'What a woman can be, she must be'. This is referred as a desire for self-fulfillment, i.e. to become more and more of what one is, or everything that one is capable of becoming. The road to self-actualisation seems to begin as soon as continence and normal micturition sets in. At this point women's upward journey starts.

"Now I don't use pads anymore. Although the skin burns are not healed completely it's a small thing compared to the hell where I have come from. At night I sleep like a baby, no worries no anxieties no shame of washing my beddings every day. It is a whole free world", Darling.

Common among these women is experience of discrimination of performing their social functions like going to church as both Lavender *et al.*, 2016; Wilson, 2016) observed in their studies. Stigma has been observed to lead to unequal distribution of 'life chances' and adds to obstacles of unemployment, poverty and even homelessness to the challenge of recovery (Link, 2006). This scenario makes it difficult for the women to participate fully in community activities and hence compromised support in terms of getting medical help.

However, motivations of self-actualisation behaviours are unique in Maslow's hierarchy from the rest of the other needs since they are not carried out to accomplish another end (Thielke *et al.*, 2012). The women living with fistula are aware of the self, and are concerned with personal growth and are interested in fulfilling their potential (Wilson *et al.*, 2016; Lavender *et al.*, 2016). Furthermore, the expectations from these women by their communities may be too high to meet especially remarrying and relationship challenges that persist way after surgery (Lavender, *et al.*, 2016).

The situation was much improved when friends and neighbours were warm and welcoming. Maslow believed that when one reaches self-actualisation, they move on to *Self-transcendence*, whereby one wants to give something back. Altruism was seen in some of the qualitative findings as women wanted to help others achieve their full recovery.

Women formed friendships whilst in hospital, and they formed groups facilitated by health care workers to support each other. A group of women used social media to facilitate discussion and support such as WhatsApp groups. In this forum they encouraged one another, supported each other to start a business, and acted as ambassadors to help other women with information about fistula treatment. These platforms are now actively being utilised for mobilisation and support for women living with fistula and those who wish to start a business to support themselves and families. It was also noted that in the fistula camps the women recounted stories to encourage new patients as testimonies and help create awareness. They have utilised these forums to encourage each other on fluid intake, when to resume sex and personal hygiene.

There are other factors that deny the women satisfaction, emanating from the woman's environment. Time and social support have been described as important to help women reintegrate back to society with the main emphasis being resuming or starting work (Pope, 2011). These factors will be described in section (8.5) using the Bronfenbrenner's ecological system theory, as they resonate quite closely with it.

8.5: Bronfenbrenner's Ecological Systems Theory

Although Maslow's hierarchy of need provides a suitable framework to explore individual journeys, this study has demonstrated that women's ability to move through each layer of 'needs' was very much dependent on a number of external factors. Bronfenbrenner's Ecological System's Theory provides a suitable framework to reflect on the study findings and highlight areas of influence in hindering or supporting recovery from fistula surgery.

In addition, Urie Bronfenbrenner (1995), an American psychologist, was of the idea that in order to understand human development, one needed to consider the entire ecological system in which growth occurs. The system is composed of five socially organised subsystems that help support and guide human growth. The first was the microsystem which is the most influential and links the relationship between the individual person and the immediate environment. This explains the difference in behaviour when one is with her family compared to when she is at work or school. The second system is the mesosystem, where there are interactions with other microsystems i.e. linkage between family and church, school and family or school and church. The next layer is the exosystem, which defines the larger social system in which the woman does not function directly. The last is the macrosystem in reference to institutional patterns of culture (see Figure 8.2).

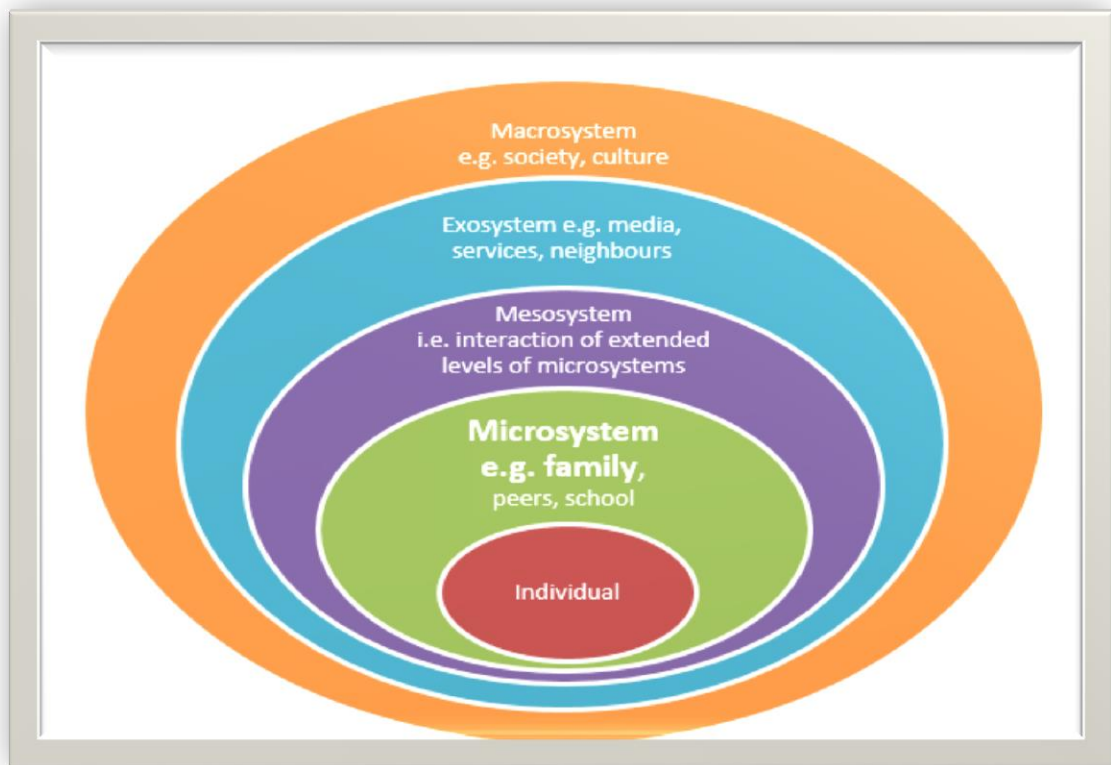


Figure 8.2: Ecological Model by Bronfenbrenner (1995)

In relation to the study findings, each stratum, as identified by Bronfenbrenner, impacts on the women's lives. By studying the internal qualities of the person and the external environmental characteristics (here described as the ecological systems) surrounding that person and how the two interact, one can attempt to understand the person's development. The life of a woman living with a fistula runs through these ecological systems moving from her intimate ecological environment (the home) through outwards to the large external ecological environment (like the school, church or hospital) to the most expansive systems (such as the society and culture). Whilst all these systems are interlinked, each will be discussed in turn to highlight the most influential aspects related to the study findings.

8.5.1: **Microsystem**

This is the smallest and most immediate system in which the woman lives. It may include her home, compound, peer group and community. In a typical situation this describes how the woman relates with her family, friends, neighbours, co-wives, peers and church members. The interactions at this level are bi-directional and affect the woman's behaviour as they interact. Similarly, the woman's reactions and behaviour towards the people determine how they will treat

her. Accommodating, caring and supportive interactions and relationships will positively impact on the woman's healing.

With obstetric fistula, the woman faces untold suffering, negative social interactions, loss of role identities and financial difficulties that makes her socially withdrawn and stigmatised perhaps to the point of thinking of taking her own life. The stories were heart breaking. Being called names like 'the stench', the 'mongoose', the 'stagnant roadside water', 'worse than toilet paper', 'has a terminal illness like AIDS' were dehumanising.

According to Bronfenbrenner it is possible for two or more women found in a similar situation to experience very different experiences due to their inherent personality traits conferred to them through genetic and biological factors. What this means is that there is a group of women who will look at life positively as a challenge with hope and seek assistance. However, there will be others who will be very negative and will view fistula as bewitchment, infidelity or as punishment from God and would rather seek sorcerers, herbalist's assistance and the God's intervention (Wall *et al.*, 2011). Similar observations were made in our study.

8.5.2: **Mesosystem**

This describes the interactions of various microsystems where the woman lives. These linkages include: between the home and school, between family and peer group, or between family and church, between family and neighbours or friends. It is in these relationships that support and a caring attitude can be demonstrated beyond that of the immediate family, friends, and neighbours. Some women are divorced or separated, dismissed from the social gatherings, ridiculed by their peers, or segregated by hospital and church. They experience different emotions which affect their behaviour negatively. Some women in the study were isolated by family/friends; they were not allowed to perform routine family chores. Such inhuman acts contributed to stress and loss of role in this group of women. One best example of women rejection and ridicule was a case in Mombasa where a husband and his children were ridiculed by neighbours and friends as one lady narrated:

"initially, my husband had no problem with my condition. We lived well and even had 2 children while living with fistula. Then, the men in our neighbourhood started teasing him, laughing and saying "Are you really a man"? They asked; "what kind of a man would sleep in urine year in year out till you even produce children"? "Get real and behave like a Mijikenda (a tribe in Kenya where

he belongs). A real man goes out to work and waits to see if the woman heals, if not, just move on and find a dry and enjoyable bed"-Malaika.

Also, in this study, the presence of a relative at childbirth seemed to affect fistula healing. The role of a relative at birth as it relates to fistula healing is not well understood. However, cultural and family pressure for a baby may influence partners to resume sex before the stipulated six months elapse. Unwarranted pressure on the surgical site tends to break the tissues, may introduce infection and eventually the fistula fails to heal. Indeed, previous studies confirm that as soon as fistula develops, women lose their basic rights as women and human beings (Alio *et al.*, 2011). The loss of human rights has been linked to barriers in access to reproductive health (Simkhada *et al.*, 2008).

8.5.3: Exosystem

The Exosystem system relates with the external environment. The interactions may include the media, neighbourhoods, extended family, hospital services or the spouse's working place. Noting that in traditional African societies many women have no status and are dependent on their spouses for financial support. An observation that makes women more vulnerable to stress related illnesses (Lavender *et al.*, 2016). In such circumstances, family level decisions are likely to be weighed against other prevailing circumstances and may not be in the best interest of the women living with fistula (Alio *et al.*, 2011).

The women in the study had very long durations of labour suggesting poor assessment or lack of appropriate decision-making in labour. This was seen to predict duration of leakage in the women. Another unfortunate situation is the unavailability of services and insecurity in some countries which hinder access to health. The institutions are either far away or staff had negative attitudes toward the women further eroding the confidence of patients in the health facilities. This affects both the pre-surgery period and pre-fistula periods.

8.5.4: Macrosystem

According to Bronfenbrenner, this is the largest and most distant collection of people and places to the woman, which still exercises significant influence on the woman. It comprises of the woman's cultural patterns and values, her beliefs and ideas as well as political and economic systems. The study associated country of referral, unemployment and presence of a relative with reduced chances of a successful surgery while the qualitative component described a desperate

situation where these women live with fistula. All the countries are either low or middle income countries which are associated with extreme poverty, unemployment, and strong African traditional and religious cultures factors, which strongly contribute to poor access to health (Namasivayam *et al.*, 2012). The poor socio-economic status, poverty, and ethnicity are all common not only in the women living with fistula but in the general population. These deny the people equal chances or opportunities in education, employment and investment. The situation is worsened if the person is devalued, with low self-esteem and depressed (Khisa *et al.*, 2011, Namasivayam *et al.*, 2012).

Ethnicity is better seen through the mirror of myths and beliefs about fistula in these societies. Historically, these societies have engaged in a fight for survival, with clashes and tribal wars of supremacy. This has resulted in an uneven distribution of wealth with the best medical services being centred in the urban areas while the rest of the rural parts have none or little support. Constant civil strife and nomadism create an insecure environment for these poor women to seek services. Divorce or separation in marriage was common among the women; good communication channels such as media and radio are rare while the media is not well informed on the subject of fistula. Poor infrastructure and inadequate services also hinder access to health care and predicts duration of urine leakage. Secondary prevention of fistula, including access to information and insertion of catheter during and after birth, were seen as wanting in the study. These promote higher chances of repeated repairs, longer duration of leakage and an increased risk of vaginal stenosis together with poorer surgical outcomes for the women as has been reported in previous studies (Kayondo *al.*, 2011: Barone *et al.*, 2012).

Poverty has been linked to access to health care services in many studies (Muleta, 2007: Pope, 2011). Many women in this study were housewives (31.4%), peasant farmers (45.8%) or small businesswomen (14.4%). The majority lived in extreme poverty, a factor that contributed to poor access to health. Furthermore, the majority of women lived in rural areas and where radio was the easiest source of fistula information (48.6%).

8.5.5: Holistic Picture

Clearly both Maslow's Hierarchy of Need and Bronfenbrenner's Ecological Systems Theory have their place in understanding and framing the findings of this study. However, neither captures the complete picture in isolation. This study uniquely suggests that a combination of both theories is required to gain real understanding of the complexities of post-fistula repair recovery. The

chronosystem is made up of the environmental events and transitions that occur throughout a woman's life, including any socio events. Of note is the fact that Bronfenbrenner (1986) added to his model, to include the chronosystem. This added the useful dimension of time, which was particularly pertinent to this study. Change in the woman's environment, such as a change in family structure, address, or employment status of spouse in addition to the changes in the society like economic cycles and wars (Dede *et al.*, 2001), were highly influential. This layer appreciates new technologies such as internet and mobile phone technologies which arose way after the original theory had been published. There are also the sociohistorical circumstances that women living with fistula undergo. These can be external such as timing of a divorce, separation, abandonment, timing of a spouse's death and lack of access to increased job opportunities for women; or internal like aging of the woman over a period of time. The gender rule and affirmative action (Kenya Gazette supplement No.53, 2015) in these countries that aim to improve opportunities and raise the status for women in the society pass unnoticed or are unachievable for many as they cannot achieve self-esteem and self-actualisation as illustrated in Maslow's hierarchy of human need (Maslow, 1979).

Discussions of Maslow's theory have led to its adaptations. This is in light of the fact that needs are not necessarily hierarchical. Life tends to be more chaotic, than linear, thus needs are an interactive, dynamic system, and are grounded in our ability to make social connections (Rutledge, 2011). In fact, as long as the human brain remains driven by a basic instinct to survive, none of these needs can be achievable without social connection and collaboration (Rutledge, 2011). Social connections acted as barriers and facilitators to women's recoveries, moving them up and down 'needs' layers, dependent on positive or negative experiences. It has been stated that human reliance on each other grows as societies become more complex, interconnected, and specialised, hence, making social connections a requisite for survival emotionally and physically (Rutledge, 2011; Thielke *et al.*, 2012). The women in the study having low esteem show a similar experience when some of their needs are satisfied like urine incontinence (Lavender *et al.*, 2016).

In section 8.5.5, the author proposes a new model based on the current study findings, in the context of his 15 years of experience in fistula work. The new model also combines the two schools of thought as illustrated by Maslow (1943) and Bronfenbrenner (1986).

Figure 8.3 Combined hierarchical needs and ecological systems model for recovery from obstetric fistula

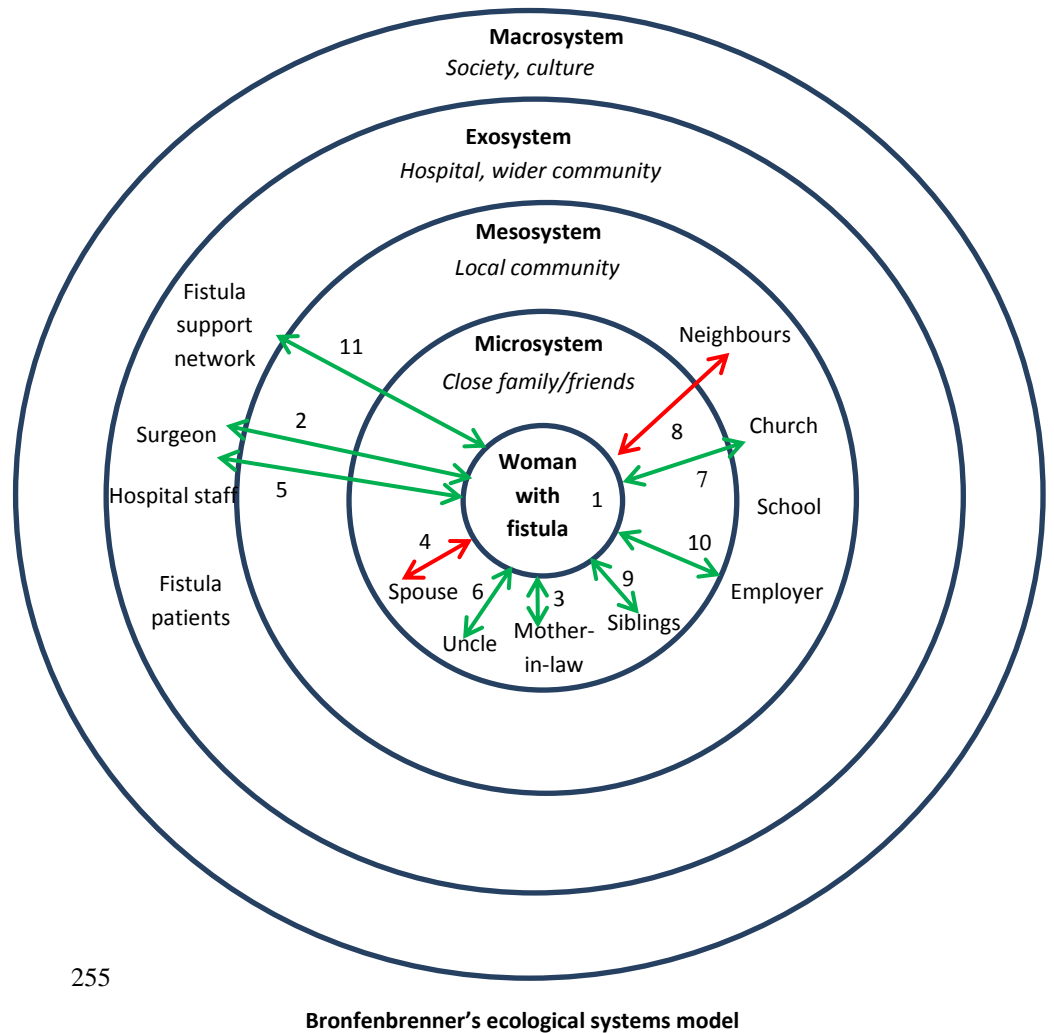
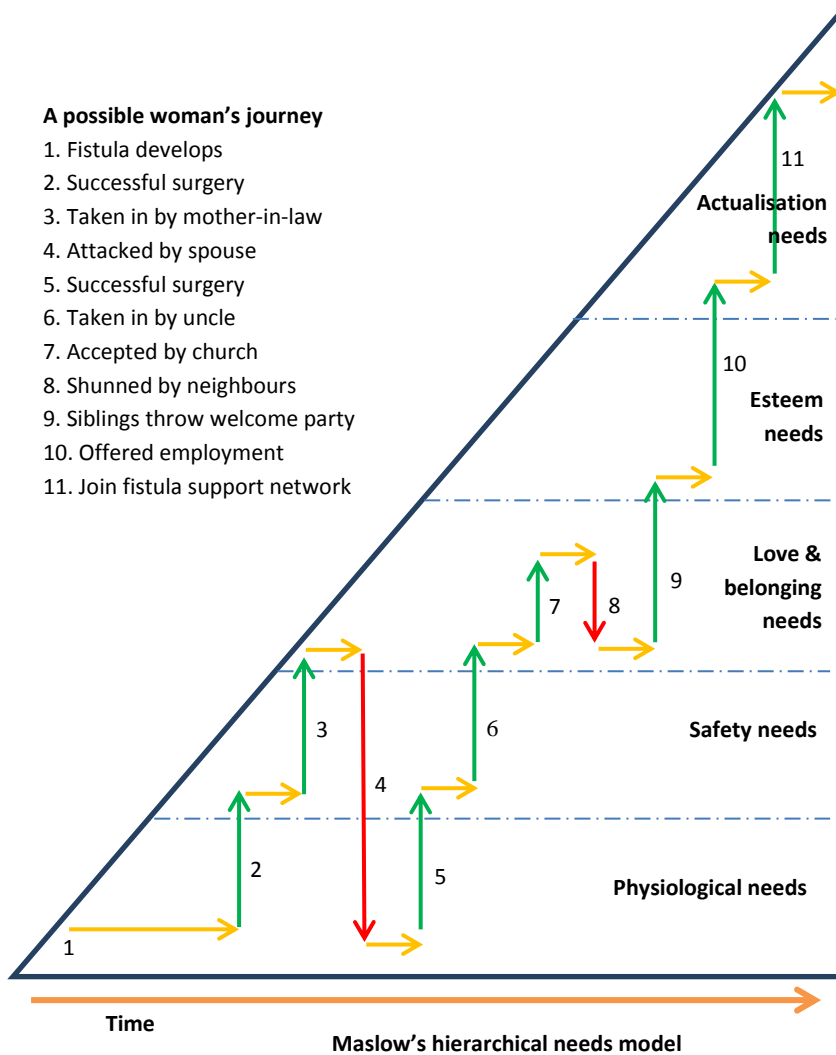


Figure 8.3 presents a pictorial view of a conceptual model based on Maslow's Hierarchy of Needs model and Bronfenbrenner's ecological systems model running in parallel. The woman's journey from developing the fistula to recovery is represented by the steps superimposed over Maslow's hierarchical levels. The hypothetical woman starts her journey at the bottom left, with no needs satisfied when the fistula first develops. This is a simplification of the true picture as some women did have needs such as love and belonging satisfied where the husband was fully supportive and understood her condition.

As time moves from left to right, some steps may be horizontal indicating no change in the satisfaction of needs; some steps are upwards, indicating that a need has been partially or fully satisfied; other steps are downwards, indicating that a need has partially or fully reasserted itself. The upwards or downwards steps occur because of some interaction happening within Bronfenbrenner's ecological systems model. The woman cannot move up or down purely from her own resources; her movement to another of Maslow's levels depends on an external agency. Every woman may have a potentially different journey but the ideal is for her to move from the bottom left to reach the top right of the triangle through appropriate care and support. Some women may not reach the apex depending on their post-surgery journey.

Soon after the fistula develops, the woman finds herself in a position within the first level of Maslow's hierarchy of needs (indicated by the 1 in Figure 8.3). At this point, the woman struggles to maintain personal hygiene and keeping dry due to constant urine leakage that is characteristic of fistula development. This continues until the woman can present for surgery. From the quantitative study the duration ranged from 2 years to more than 10 years, while in the qualitative study it ranged from 2 years to 49 years.

Successful surgery to close the fistula and regain urinary continence (2) will satisfy the woman's physiological needs and moves her up to the next level of the hierarchy. She will need some basic support to satisfying her safety needs, in the example by being taken in by her mother-in-law (3) to get her to the next level of the hierarchy. There may be setbacks. For example, the woman may be sexually attacked by her spouse (4), who may cause the fistula to reopen, and she returns to the lowest level of the hierarchy again. Further surgery to close the fistula (5) and being taken in by another family member (6) will regain the lost ground and satisfy her physiological and safety needs.

She then needs to satisfy her love and belonging needs, which may be an up-and-down experience. She may be accepted back into her church (7) but shunned by neighbours (8) before her siblings throw her a welcoming party to re-establish her back in the family (9), so her love and belonging needs are finally satisfied.

The next need to be satisfied is her esteem. This could be achieved if she was offered employment (10) to give her self-respect and re-establish her self-worth. For some women, this could be the end of the journey to recovery, but some may wish to give something back and join a fistula support group (11) to help other women cope with the problems they had suffered.

8.6: Conclusion

This is an original clinical mixed design study set within a multi country setting in East Africa. This study uniquely suggests that a combination of both theories is required to gain real understanding of the complexities of post-fistula repair. Successful fistula closure and regaining urinary continence is not enough to restore women's dignity because these women have higher needs. Recovery of fistula patients is journey rather than a destination. The need for health and economic policies geared towards mitigating for independency in fistula women is long overdue.

8.7: Importance and Originality of Study Findings

This research work incorporates the first study the author is aware of which examines predictors of fistula surgery in a multi country settings. Five East African countries were simultaneously selected for study. The study documents the association between fistula characteristics, access to care and the lived experiences of women living with fistula problem. The researcher has developed a model that incorporates two theorists: Maslow's hierarchy of needs and Bronfenbrenner model. The new model may later be utilised by fistula teams and policy makers in gaining deeper understanding of the complex nature of fistula problem in target communities. Also, the researcher presents substantial dataset on predictors of successfulness of surgery.

The originality of this study is evidenced by three key attributes: Firstly, the mixed-method design enabled the collection of quantitative and qualitative data simultaneously. The mixed data set allowed for complementarity. Secondly, the multi-country approach enabled comparisons across diverse settings. Lastly, the ability of the researcher to synthesise both quantitative and qualitative data yielded unique study findings: which includes the association between assistance

at birth and successfulness of surgery, and the realisation that surgery alone does not automatically result in full recovery for women.

8.8: Strengths and Limitation of the Design

8.8.1: Introduction

This section presents the strengths and limitations of the mixed method design applicable in this multi country study. The first section (8.8.2) deals with strengths of the design which is then followed by section two (8.8.3), which narrates the design limitations.

8.8.2: Strengths of the Design

The mixed method design and longitudinal approach was unique in that it enabled the researcher to illustrate the temporal changes of the emotional/physical burden of fistula and the longevity of impact on women's lives across the social strata. The mixed method approach enabled the researcher to document fistula characteristics and women's journey's pre- and post-surgery; such events have not been captured simultaneously in the selected East African countries previously. In itself, mixing methods gives opportunities for exploration of the quantitative results in more detail. Morse (1991) describes this method as a useful design when unexpected results arise in the quantitative component, a scenario that was observed in this study. By choosing this design, the author set the stage for data synthesis bringing forth new associations between quantitative and qualitative findings. For instance, the author reports that presence of a relative at birth is directly linked to the duration of leakage.

Having worked in the region, the surgeon had good surgical experience and seemed to know gate keepers very well. This helped him access and retain a large cohort of women in the study. Also, his extensive networking made it easy for him to identify a seasoned research assistant especially for the phenomenology component of study. In this qualitative component, women were interviewed in three sites by a public health nurse who is trained in the conduct of Interviews which may be of a sensitive nature, as was the case in this study. Other strengths include the large cohort size and a longitudinal nature of the qualitative data collection.

8.8.3: Limitations of the Design

The researcher was unable to conduct the interviews himself owing to the fact that he was the surgeon and team lead. This dual role made him miss out on some aspects of qualitative training.

Having worked in the same settings for many years, the patients admired the surgeon who may have influenced their responses: they may have given some desirable responses to please the surgeon, however, we found no evidence of this. The fact that there was limited data from some countries such as Sudan, Somalia and DRC Congo made comparison of findings difficult.

8.9: Transferability of Findings

Throughout the study period, the researcher has demonstrated credibility in protocol implementation as evidenced by patient recruitment processes, surgical techniques/procedures, in-depth interviews and data processing. Such systematic and rigorous process in data collection and analysis ensures rigour. This forms the basis for reliability, validity and transferability of findings in the study (Barbour, 2001). The researcher has provided enough contextual and demographic information to enable others to decide whether the findings are likely to resonate with women in their own settings. He has also clearly presented study associated limitations (8.8.3) and personal reflection on the study (Section 8.10.4), as would be expected of any sound research (Davies and Dodd 2002).

8.10: Recommendations

This section presents some recommendations drawn from the authors research work in East Africa. This section has been presented in three sub-sections; subsection 8.10.1 presents Recommendations for Policy; subsection 8.10.2 presents Recommendations for practice; subsection 8.10.3 presents Recommendations for future Research work; and personal reflections in section 8.10.4.

8.10.1: Recommendations for Policy

- The number of patients seen at each country in East Africa points to increased numbers of women with new fistulas. The duration of leakage was diverse, an indication that there are underlying factors that facilitate/inhibit access to fistula care. The synthesis highlights the intricate factors affecting fistula care; they include individual characteristics, health systems limitations and community issues. These observations require a paradigm shift in policy formulation and an increased health budget towards quality reproductive health and other essential services. There is an overwhelming need for strengthening, proactive and responsive Health systems towards fistula care and prevention especially in countries outside Kenya.

- An increase in skilled birth attendance is important in improving access to fistula care. From an obstetric point of view, advocacy for midwifery stand-alone training policy is long overdue. This is because in these settings, midwives are easily accessible and since they work in hard to reach areas, they will be able to deliver services to most women. Therefore, investing in a highly skilled midwives will increase access to both skilled birth attendance and fistula care in the region.
- Health systems need to mainstream fistula care and information provision in existing reproductive health programs, through training and dedicated fistula teams within the region. Findings also call for curriculum reviews for clinicians, midwives and other health professionals. Such strategies will significantly contribute towards delivery of quality maternal health services, fistula care and prevention in affected countries.

8.10.2: **Recommendations for Practice**

- The need for capacity building initiatives for midwives and clinicians cannot be overemphasised. This study findings point to lack of basic fistula knowledge among providers as reported in the women's narratives: where, after fistula developed, the women are sent home without referral to fistula care services. An indication that staff working in reproductive health units must have operational fistula knowledge. Required knowledge and skills transfer may be delivered during formal trainings, CMEs and /or through e-health.
- Surgical closure of fistula is not enough to restore women's dignity. Ordinarily, the complex socio-cultural and medical/psychological pathway which follows onset of urine leakage is often trivialised during clinical management meetings. The qualitative findings in this study clearly demonstrate the need for clinicians and midwives to work together in mainstreaming social reintegration, counselling and long-term follow up as integral components of a fistula care programme. This approach will ensure that post-operative complications such as: depression, loss of self-worth and loss of income have been adequately addressed, thereby facilitating full recovery of the fistula patient.

8.10.3: **Recommendations for Future Research**

- Future research can take a number of directions: foremost, the associated stigma and erosion of self-worth need further exploration in order to achieve full restoration of

women's dignity. This will yield new information desired by governments, community leaders and health service providers.

- The psychological impact of fistula on women in this study was evident. Further research is required to explore interventions that support women's emotional wellbeing pre and post-fistula repair. Action research may be required to engage different members of local communities, to develop action plans to advocate for improved healthcare and to offer women appropriate support.
- Many women in the study delayed accessing care. Further research is required to gain deeper understanding of the barriers and facilitators to accessing fistula care.
- Future research should explore the secrecy that surround fistula condition, design community based peer support models which promote fistula care.
- Further research is needed to explore women's expectations and goals following fistula repair to enable the development of interventions that are suitably tailored.
- The Fistula Scoring/classification scale by Kees Waaldijk is relatively new and has not previously been tested/validated in an East African Population, therefore further evaluation of the tool is required.

8.10.4: **Personal Reflections**

During my formative years as a fistula surgeon, my mentors told me to follow the principles of fistula surgery if I ever wanted to help the women living with fistula achieve continence. For seven years, I followed the guidelines to the letter, where I used my surgical experience and patient's clinical presentation in making surgical related decisions. Although I did not have a standardised way of documenting all profiles of the patients operated, I began to slowly observe a pattern where almost all patients returned post operatively to appreciate the positive changes in their lives. It then occurred to me that there may be other factors associated with fistula healing other than the documented: fibrosis and fistula type/location (Kayondo *et al.*, 2011; Barone *et al.*, 2013). Besides, I became aware that there was a school of thought that HIV serostatus and duration of urine leakage influences the rate at which the fistula healed.

Considering that the East African region is characterised by a high HIV prevalence and fistula is a common problem, I felt a strong urge to document the observations I was making at the time (Khisa *et al.*, 2011). In the following year, I became aware that a Professor of Midwifery from the University of Manchester who was working with Kenyan Midwives to improve use of partograph as a tool in the management of labour. Since most fistulas in these settings are Obstetric in Origin

(WHO, 2006), I saw an opportunity and jumped on it. I wanted to know the predictors of fistula healing which included: socio-demographics, assistance at birth, fistula type, duration of leakage and lived experiences of women in the region.

Once I received my admission to the Doctorate program at the University, I was assigned mentors who are very dedicated and committed to see me succeed in the program. It is with the support and guidance of my mentors that I have been able to develop and implement an outstanding protocol. This protocol has been replicated in many hospitals, thereby scaling up access to fistula surgery particularly in rural areas. My experience working with Professor Tina Lavender and the team has been tremendous.

Such new developments motivate me to continue working in Reproductive health research as a first step in improving women's lives, especially in Africa. My mentors gave me the opportunity to be the principal investigator in this mixed method study. This opportunity presented itself like a laboratory where I have learnt about things I never heard before like: phenomenological philosophy, new methods of analysing qualitative (Framework analysis) and quantitative data (Univariate and Multivariate methods). Now, I am able to critically appraise literature and design interventional studies without a hitch. It has been a wonderful and interactive learning experience for me.

My data collection was uneventful, but half way through the study, it emerged that we needed to explore the lived experiences of the women we were recruiting for study. This necessitated protocol amendments, which was done and approved by the KNH/ERC. The Ethics board applauded these revisions since such unique dimension had not been explored in Kenya. Following the approval, it was felt that I needed to recruit someone else to help obtain consent and conduct the In-depth Interviews for selected clients. A social scientist with relevant experience was recruited to conduct the qualitative part of study. This was necessary because being the Principal Investigator and the surgeon: it would be contravening the ethics principle of autonomy.

The surgeon conducted the surgeries and collected the required intra-operative/quantitative data. In applying appropriate skills emanating from years of experience, I did manage to close the fistula and help the women gain continence. During the data collection period, the multiple country approach did facilitate capacity building for fistula teams across countries. This was

achieved through on-job training in the course of the surgeries in each country. By so doing, the country teams are at least able to manage simple fistulas as soon as they occur, hence reducing the pain and suffering which the women endure as they await annual camp-based repairs.

The consecutive sampling technique provided a chance for the surgeon to operate on all patients without prejudice or selection of particular fistula types. In a way, the surgical skill of the surgeon was validated as sound and appropriate considering the high success rate (94%). Other reported variables such as low haemoglobin, duration of leakage and HIV seropositivity were not associated with unsuccessfulness of surgery. Such tangible reports make our findings unique and informative: considering that success rate was not dependent on either patients HIV sero positive status or fistula characteristics. Regardless of parity, fistula developed both during home and hospital births. This questions the competencies of the skilled birth attendants, particularly the situations where the fistula developed in a hospital setting. Some women delivered in hospital and were discharged without being informed about the fistula or availability of care services.

The current findings also highlight challenges within the health service providers, especially, the possibility of missed opportunities for education and dissemination of fistula care information. These missed opportunities are undesired; they happen at a time when studies show that early repairs may be beneficial to fistula healing as well as stigma reduction (Semere and Nour, 2008). With these findings in mind, the author desires a future where fistula education and training targets all clinical staff, especially midwives. This is because midwives form the backbone of maternal health services in Africa. Midwives work in hard to reach areas including remote rural areas where factors that predispose to fistula occurrence are prevalent. These predisposing factors include unrelieved obstructed labour, low literacy levels, early marriages and inaccessible health care delivery systems.

The author holds the opinion that investing in midwifery training, supervision and enumeration will be the best thing African Governments can do in the coming years. This will serve as a first step, not only in preventing fistula occurrence, but in initiating early fistula management as well. This will create a friendly and appropriate environment where mothers can safely access skilled birth attendance and/or related services. Finally, my ambition in research is to continue generating new evidence towards fistula prevention, management and social reintegration.

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APPENDIX 2.1: QUANTITATIVE LITERATURE SUMMARY

NO	Paper	Aim	Sample & setting	Design	Findings	Conclusion/ Comments
Quantitative question						
01.	Bodner-Adler <i>et al.</i> (2017) Management of VVFs in women following benign gynaecologic surgery: A systematic review and meta-analysis	To carry out a systematic review and meta-analysis on the effectiveness of operative techniques or conservative treatment for patients with post-surgical VVF	Total-1379 patients treated	Systematic review and meta-analysis of 282 full-text articles to identify 124 for inclusion	Majority 39% treated vaginally.36% transabdominalAA/transversal, laparoscopic/robotic 15%, combined transvaginal/transabdominal-3% Success: conservative - 92.86%, surgical - 97.98%	Transvaginal route is the route of choice for repair of VVF Neither conservative nor early surgery is superior regarding disease management & surgical approach Analysis limited to iatrogenic gynaecological surgical VVFs only.
02.	Moses <i>et al.</i> (2017) State of the art for treatment of VVF	To examine relevant literature on management of VVF	No record of the number of studies reviewed.	Narrative review of literature	Looks at mode & technique of VVF repair and comparing with the trans- abdominal laparoscopy /robotic techniques	Does not enlist any specific prognostic/predictor factors in literature. Researchers seem to promote laparoscopy/robotic repair of VVF, methods that may be too advanced for low-income countries.

03.	Sori <i>et al.</i> (2016) Characteristics and repair outcomes of patients with VVF managed at Jimma university teaching hospital- Ethiopia	To determine obstetric fistula characteristics and surgical repair outcomes among patients with fistula surgical repair	168 patients admitted with VVF Between 2011 & 2014	Cross-section Hospital-based.	93.4% fistula closure, failure rate 6.5%	No predictor or risks of the success of closure looked for. Minimal details on data analysis
04.	Loposso <i>et al.</i> (2016) Predictors of Recurrence and Successful Treatment Following Obstetric Fistula surgery	To determine factors contributing to recurrence and successful treatment of obstetric fistula (OF)	Sample of 166 women with OF in St. Luc hospital in DRC Congo between 2007 & 2013	A retrospective chart review study	Overall success was 71.7% Predictors of recurrence were fibrosis & fistula location Use of Martius flap & size are not predictors	Applied Methods have a challenge with Waaldijk classification anatomically and in size which will compromise data analysis, conclusions and recommendations on f fistula recurrence not agreeable.
05.	Delamou <i>et al.</i> (2016) Factors associated with the failure of Obstetric Fistula repair in Guinea: Implications for practice	To estimate the overall proportions of failure of fistula closure and incontinence among women undergoing repair for obstetric fistula	754 women had been operated	Retrospective cohort study using from hospital medical records in Guinea	Factors identified as predictors were: urethral damage and a preceding vaginal delivery	It proposes a mixed method in realist evaluation design for further insights into factors associated failure of repair The study is elaborate on background and results. Less so on analysis

<p>06.</p>	<p>Bengtson <i>et al.</i> (2016)</p> <p>Identifying patients with VVF at high risk of urinary incontinence after surgery</p>	<p>To develop a risk score to identify women with VVF at high risk of residual urinary incontinence after surgical repair</p>	<p>401 women recruited at Bwaila Fistula Centre in Lilongwe, Malawi</p>	<p>Prospective cohort study for first time VVF repairs.</p> <p>September 2011 December 2014.</p>	<p>3% of women had unsuccessful fistula closure, 23% had residual incontinence after fistula closure.</p> <p>Factors considered included: duration of leakage, HIV status, BMI, previous repair vaginal scarring, bladder size, urethral length, & fistula size, circumferential fistula)</p>	<p>A well-detailed paper with a risk scores for identifying women likely to have residual incontinence after repair.</p> <p>Positive Predictive value of 43 %</p> <p>Negative predictive value was 91 %</p>
<p>07.</p>	<p>Wahab <i>et al.</i> (2016)</p> <p>Outcome of VVF repair without omental interposition</p>	<p>To find out the outcome cases of Vesicovaginal repair</p>	<p>Sample of 28 women operated on in Timergar a District Pakistan</p>	<p>Descriptive cohort study</p>	<p>Paper has minimal details on results</p>	<p>A tiny sample to make conclusions</p> <p>Discussion not based on their findings</p> <p>Not related to either lived experience or predictors of surgical closure.</p>

08.	<p>Delamou <i>et al.</i> (2015)</p> <p>Good clinical outcomes from a 7-year holistic programme of fistula repair in Guinea</p>	<p>To prevent and discuss clinical outcomes of a 7- year work involving 2116 women repaired in three hospitals across the country.</p>	<p>2116 women repaired</p> <p>Hospital-based</p> <p>Study data received In August 2014</p>	<p>Retrospective cohort study</p> <p>Data abstracted from hospital medical records (2007-2013)</p>	<p>85% fistula closure rate.</p> <p>The loss to follow-up a limitation.</p>	<p>Well written with details in almost all sections. Attempts to remove bias in data entry explained.</p> <p>Identifies risks to failed fistula closure as: previous repair, multiple fistulae, severity of lesion, surgeon's experience & short duration of fistula</p>
09.	<p>Gedik <i>et al.</i> (2015)</p> <p>Which surgical technique should be preferred to repair benign primary Vesicovaginal fistulas?</p>	<p>To evaluate and compare outcomes of good primary VVF treated using the transabdominal, Trans vesical technique and the transvaginal techniques without tissue interposition.</p>	<p>53 women with VVF</p>	<p>Appears a retrospective comparative cohort design</p>	<p>A mix-up of results with sampling & selection of patients.</p> <p>Neither mode of treatment is superior.</p>	<p>Poorly designed to answer the research question. A randomised clinical trial is superior.</p> <p>Conservative management/ technique of repair of patients raises questions</p> <p>Lack details across the methods, results, ethics, and results</p> <p>No new knowledge</p>

10.	<p>Javed <i>et al.</i> (2015)</p> <p>Doctor! Will I be dry? Factors determining recurrence after VVF repair.</p>	<p>To evaluate various prognostic factors which determine outcome after surgical repair of VVF?</p>	<p>640 women records analysed between January 2007 to June 2012</p> <p>Hospital-based.</p>	<p>Retrospective cohort study on Hospital data</p> <p>Checked patient 296characteristic, fistula & surgical procedures</p>	<p>87.2% success rate</p> <p>VVF recurrence related to the multiplicity of fistula, pre-operative size, secondary repairs and duration of fistula.</p>	<p>No ethical clearance sought. Only permission from the hospital.</p> <p>Age, parity, aetiology, route of repair fistula location not significant prognostic factors. Lack of standardized fistula terminologies making comparison difficult.</p>
11.	<p>Cowgill <i>et al.</i> (2015)</p> <p>Obstetric fistula in low-resource countries: An under-valued & under-studied problem-systematic review of its incidence, prevalence</p>	<p>To review literature reporting original population-based estimates OF incidence, & prevalence rates in low resource countries</p>	<p>PubMed/ Medline, CAB Global Health Database</p> <p>Ancestry search of references & Grey literature</p> <p>Total number of s-62 included</p>	<p>A systematic review of literature from 1 January 1995 – 16 November 2014</p> <p>Explicit criteria, search strategy clear, inclusion and exclusion criteria.</p>	<p>The incidence of VVF varies considerably from Asia & Africa. Highest incidence estimated to range from 0-4.09% per 1000 deliveries.</p> <p>SB associated with OF range from 32.3% - 1005</p>	<p>Methods and quality of primary articles were inconsistent hence difficulties making conclusions that would guide policy and funding responses.</p>
12.	<p>Loposso <i>et al.</i> (2015)</p> <p>Obstetric fistula in a District Hospital in DR Congo. Fistula still occur despite access to caesarean section</p>	<p>To study the profile of classification, aetiology, and the relation between initial classification & the results of VVF surgery in a district hospital</p>	<p>Sample of 117 women with VVF at Kisantu between November 2006 & November 2012</p>	<p>Retrospective study on hospital data</p>	<p>Reasons for not accessing emergency C/section on were: distance to health care facility, poverty, care of local midwife, mistrust in the staff, traditional beliefs</p>	<p>Waldijk classification misrepresented hence implication on analysis and conclusions leading to bias acknowledged.</p>

13	Wright (2015) Circumferential urethral fistulae in Sub-Saharan Africa, current outcomes and prospects.	To quantify circumferential urethral fistulae and their prognosis after repair	A sample of 106 women operated at Hamlin fistula hospital Addis Ababa in Ethiopia January 2011 to December 2013.	Retrospective cohort study	Success – 25% continent at discharge. 19 % improved. The distance of fistula from the external urethral orifice did not influence prognosis.	This was a three-year audit The use of buccal mucosa as a graft during surgery is useful knowledge for practice Paper has given a good view of management of circumferential fistula
14	Mellano <i>et al.</i> (2014) Management of genitourinary fistula	To review current literature on the management of genitourinary fistula: techniques for diagnosis, timing to repair, surgical approach and recent advances	Not Reported	Narrative review of literature	Introduction to epidemiology, cancer/radiation, Vesicouterine fistula. Reviews on patient presentation & diagnosis, classification systems, fistula management & post-operative care.	No discussion on predictors of fistula closure or any risks. It lacks structured research question, explicit methods, and search strategy and quality assessment of reviewed articles.

15	<p>Takayanagi <i>et al.</i> (2014)</p> <p>The outcomes of surgical repair of VVF in 16 patients</p>	To report the outcomes of surgical repair of VVF	Sample size 16 operated between 1995 - 2012 at Sapporo Medical University Hospital	Retrospective study design, hospital based	14 of the 16 patients successfully healed required a re-operation.	<p>All the VVFs were iatrogenic and in a different setting from Africa.</p> <p>No prediction factors assessed.</p> <p>Sample too small to make logical conclusions</p>
16	<p>Taylor-Smith <i>et al.</i> (2013)</p> <p>Obstetric Fistula in Burundi: A comprehensive approach to managing women with this neglected disease</p>	To describe the model of care, patient outcomes and the operational outcomes.	458 women treated between July 2010 and December 2011 at Gitega Fistula Centre in Burundi	A retrospective study of routine programme data	Conservative treatment success was 11%, surgical, 87% fistula closed at discharge & 76% was continent.	<p>Results are encouraging and applicable in other East African countries.</p> <p>The paper is well-written giving details of the setting, population, case finding and challenges of the programmes.</p>
17	<p>Tenggardjaja <i>et al.</i> (2013)</p> <p>Advances in Minimally Invasive Repair of VVFs</p>	Not recorded however addresses advances in minimally invasive repair approaches in VVF	Not recorded	Narrative literature review	The paper outlines new technologies utilised in fistula repair amenable to developed countries, never the less useful in the future in developing countries.	<p>Presents detailed methods used in fistula repair.</p> <p>Conclusions are subjective.</p>

18	<p>Wang <i>et al.</i> (2012)</p> <p>Laparoscopic transabdominal transvesical repair of supratrigonal VVF</p>	<p>To investigate the clinical efficacy of early laparoscopic repair of supratrigonal Vesicovaginal fistula</p>	<p>Sample of 18 women with iatrogenic fistula at Wenzhou Medical College China</p>	<p>A retrospective cohort study</p>	<p>Successful closure was 100% with no complications like reduced bladder capacity or bladder dysfunction</p>	<p>The tiny sample to make a strong conclusion.</p> <p>The results section has methods/procedures in it.</p> <p>A clinical trial would be better for assessing its efficacy.</p>
19	<p>Barone <i>et al.</i> (2013)</p> <p>Determinants of postoperative outcomes of female genital fistula repair surgery</p>	<p>To determine predictors of fistula repair outcomes three months post- surgery</p>	<p>Multicounty Prospective cohort study conducted between 2007 and 2010.</p>	<p>109 women were recruited for study</p>	<p>Overall, 109 women out of 754 (14.5 %) were unsuccessful at discharge.</p> <p>Prognosis related to bladder size, previous repair, vaginal scarring and urethral involvement</p>	<p>Outcomes are from many countries and many surgeons.</p> <p>The experience of the surgeon was not considered as a factor for fistula healing.</p> <p>Follow-up period was only three months post-op.</p>

20	<p><u>Frajzyngier et al. (2013)</u></p> <p>Factors influencing the choice of surgical route of repair of a genitourinary fistula, and the influence of route of repair on surgical outcomes:</p>	<p>Factors influencing route of repair</p> <p>The influence of route of repair on fistula closure three months after surgery</p>	<p>The descriptive study design was used in the study.</p>	<p>Participants</p> <p>1,274 women</p> <p>11 HFCS in Africa and Asia</p>	<p>A vaginal route of repair was associated with increased risk of failed closure -(ARR, 1.41: 95% CI, 1.05–1.88): stratified analyses suggested elevated risk among women meeting indications for the abdominal route.</p>	<p>Interesting to note that vaginal route is associated with failure, reports cut across two continents, elevated risk for women qualifying for the abdominal surgical route.</p> <p>Additional studies powered to test effect modification hypothesis are warranted to confirm that abdominal route of repair is beneficial for certain women</p>
21	<p><u>Rafique et al. (2013)</u></p> <p>Repair of Vesico vaginal fistula: Single –centre experience and analysis of outcome predictors.</p> <p>(2013)</p>	<p>Analysis of Vesico vaginal fistula surgical outcomes</p>	<p>A total 27 patients with vaginal fistulae were included in the study in Pakistan.</p>	<p>Prospective descriptive study</p> <p>Mahar Medical College Hospital, Sukkur, Pakistan</p>	<p>The most common cause of fistulae was total abdominal hysterectomy in 59.25% and 33.33% due to obstructed labour</p> <p>Duration of VVF and surgical approach, position of VVF were listed as significant factors without specifics</p>	<p>Supra-trigonal and vault fistulae are best treated by the trans-abdominal approach.</p> <p>The results were not concrete enough to make conclusions.</p> <p>Sample size was small</p>

22	Kayondo <i>et al.</i> (2012) Predictors of surgical repairs of Obstetric Fistula at a regional referral hospital	Determine factors that predict outcomes of surgical repairs of Obstetric Fistula in Mbarara, Uganda	Prospective observational study February 2010 to June 2010	77 women were recruited for study	Vaginal scarring was the only factor independently associated with unsuccessful fistula repair, (Odds ratio 1.12-100.57) 95% confidence interval 1.12-100.57).	They concluded that large fistulae, circumferential fistula and marked vaginal scarring are predictors for unsuccessful fistula closure. Participants were small. Follow-up period was short
23	Hategekimana (2005) Results and predictors of success of Vesico Vaginal Fistula repair at a national Reference in Rwanda,	Determine predictors of surgical results	Participants-112, Kigali Hospital, Rwanda	Prospective design. Conducted between 1997 to 2001	Bladder neck and urethral involvement were associated with failure p=0.048	Failure was linked to level of destruction of bladder necks well as magnitude of scarring

List of Appendices

APPENDIX 2.2: QUANTITATIVE PAPER SCORING USING HAWKER'S TOOL

Authors	Abstract & Title	Introduction & Aims	Method & Data	Sam-ling	Data Analysis	Ethics & Bias	Results	Transferabilit	Implication	Total
1. Bodner-Adler et al. (2017)	4	3	4	4	4	2	4	3	3	31
2. Moses et al. (2017)	3	4	2	2	2	1	3	2	3	22
3. Sori et al. (2016)	4	3	4	3	3	3	4	3	2	29
4. Lopusso et al. (2016)	4	3	4	3	3	2	4	4	3	30
5. Delamou et al. (2016)	3	4	4	4	4	3	4	3	3	32
6. Bengtson et al. (2016)	4	4	4	3	4	4	4	4	4	35
7. Wahab et al. (2016)	4	3	3	3	1	3	1	3	1	18
8. Delamou et al. (2015)	3	4	4	4	4	3	4	4	3	33
9. Gedik et al. (2015)	2	2	2	2	3	2	3	3	2	21
10. Javed et al. (2015)	3	2	2	2	3	2	3	3	2	22
11. Cowgill et al. (2015)	4	4	4	4	4	1	4	4	3	32
12. Lopusso et al. (2015)	4	3	4	3	3	4	3	4	3	31
13. Wright et al. (2015)	3	3	3	2	2	3	3	3	3	25
14. Mellano et al. (2014)	4	4	2	2	2	2	4	3	3	26
15. Takayanagi et al. (2014)	3	3	4	3	3	3	4	3	2	28
16. Tayler-Smith et al. (2013)	4	4	4	3	4	3	4	4	3	33
17. Tenggardjaja et al. (2013)	3	4	2	2	2	2	2	3	3	23
18. Wang et al. (2012)	4	4	4	3	3	4	3	3	4	32

19. Barone, et al. (2013)	3	4	4	4	4	3	4	4	3	33
20. Frajzyngier, et al. (2013)	4	4	4	3	4	4	4	4	3	34
21. Rafique et al. (2013)	3	4	2	2	2	2	2	3	2	22
22. Kayondo et al. (2012)	4	4	4	2	4	3	4	4	3	32
23. Hategekimana, (2001)	4	4	4	3	4	4	4	4	3	33

APPENDIX 2.3: QUALITATIVE LITERATURE SUMMARY

Paper	Aim	Sample & setting	Design	Findings	Conclusion/ Comments	Score
Qualitative question						
1. Siddle et al. (2017) Psychosocial impact of obstetric fistula in women presenting for surgical care in Tanzania	An evaluation of the impact of surgery on psychosocial aspects of obstetric fistula.	A total of 100 fistula patients were studied. At the Comprehensive Community-Based Rehabilitation in Tanzania (CCBRT)	Descriptive study design. A screening assessment tool' was used on admission, at CCBRT's fistula ward.	Fistula patients were reported with high rates of physical and psychosocial morbidity. Over half of the patients said they would not have been able to access treatment without the transport facilitation.	Study tools need to be validated in these settings. Need to link effects of still birth in women with fistula.	30
2. Lavender <i>et al.</i> (2016) Secrecy inhibits support: A grounded theory of community perspectives of women suffering from obstetric fistula, in Kenya	To gain understanding of the views of community members in relation to obstetric fistula.	16 participants. Two hospitals in Kenya: Kisii and Kenyatta. Interviews took place either in the home, place of work, or hospital.	A qualitative, grounded theory approach Was used in data collection.	Keeping fistula secret reinforces uncertainties around fistula, which in itself fuels myths and ignorance regarding causes and treatments. Lack of openness, at an individual level, prevents support being sought or offered.	A multi-layered strategy is required to support women with fistula. Study was limited to one country. Long-term follow up may explore positive coping strategies.	34

<p>3. Khisa <i>et al.</i> (2016) Understanding the Lived Experience of Women Before and After Fistula Repair: A Qualitative Study in Kenya</p>	<p>To gain understanding of the first-hand experience of women prior to and following repair of a vaginal fistula, to determine the most effective support mechanisms.</p>	<p>16 fistula women selected in three fistula clinics in Kenya.</p>	<p>Qualitative phenomenological study using a series of in-depth semi-structured interviews at two time points: prior to fistula repair and 6 months post-surgery. Data were analysed thematically.</p>	<p>The two main themes emerged: social isolation and social reintegration. The social and psychological impact of fistula leaves scars that are not easily healed, even when fistula repair is successful.</p>	<p>Women's experiences of living with fistula have an impact beyond that which can be repaired solely by surgery.</p> <p>A regional scope may yield other new findings.</p> <p>Health care providers need to link up with communities for better fistula care outcomes.</p>	<p>34</p>
<p>4. Baragein <i>et al.</i> (2015) "I am alone and isolated": a qualitative study of experiences of women living with genital fistula in Uganda</p>	<p>explore the experiences women living with genital fistulas to understand how their lives were affected and how they coped with the condition</p>	<p>56 purposively selected women Mulago Hospital, Uganda.</p>	<p>Qualitative, used 8 focus group discussions (FGDs)</p>	<p>Women were alone and isolated, either by themselves or were isolated by society. Their sex lives were no longer enjoyable, and generally, women felt a loss of their marital and sexual rights.</p>	<p>Women use both problem- and emotion-focused coping to minimise their sense of isolation.</p> <p>In-depth interviews would have been best design in such a sensitive study area.</p>	<p>32</p>

<p>5.Donnelly et al. (2015) The quality of life of Ethiopian women after fistula repair: Implications for rehabilitation and social reintegration policy and programming.</p>	<p>To link obstetric fistula prevention and treatment to recovery and social reintegration programmes.</p>	<p>51 women in the qualitative arm</p>	<p>Mixed method study of equal dominance. Grounded theory and facility survey on perspectives</p>	<p>Themes captured factors that: impair full QOL in the cohort such as: persistent physical & mental, fear of fistula recurrence, marital disharmony, The study identified Fistula advocacy as a useful role.</p>	<p>-Lack of: counselling services, follow-up at community level, support for income generating activities, -The study underscored the need to scale up the continuum of care beyond surgery.</p>	<p>30</p>
<p>6.Wilson et al. (2015) Reintegration to the community</p>	<p>To compare the severity of depression and PTSD in women admitted for obstetric fistula repair compared with gynaecology patients</p>	<p>140 women, Tanzania</p>	<p>A Qualitative study design using exploratory approach in data collection.</p>	<p>54 obstetric fistula participants and 90 Were recruited</p>	<p>Study population did not have similar inclusion criterion. It is not possible to compare group fistula patients with those presenting with gynaecology conditions in outpatient</p>	<p>26</p>

<p>7.Lombard (2015) Rehabilitation experiences after obstetric fistula repair: systematic review of qualitative studies*</p>	<p>To synthesise evidence on women’s experiences surrounding rehabilitation and Reintegration after obstetric fistula patients.</p>	<p>Ten studies were included in the review.</p>	<p>A systematic review of qualitative research surrounding rehabilitation experiences of women in sub-Saharan Africa</p>	<p>Search yielded 426 studies but ten were reviewed. The most important rehabilitating factor for women was fulfilment of social roles.</p>	<p>Counselling services and community health education are priorities. Study could have expanded the review work done In Asia and other regions.</p>	<p>34</p>
<p>8. Ojengbede (2014) Group Psychological Therapy in Obstetric Fistula Care: A Complementary Recipe for the Accompanying Mental Ill Health Morbidities?</p>	<p>To determine the impact of group psychological therapy (GPT) on the mental health of obstetric fistula patients. Design.</p>	<p>Nigeria</p>	<p>A comparative pre and post intervention</p>	<p>There was a significant reduction in those with very low self-esteem from 65.0% to 18.3%. Suicidal ideation reduced generally: severe (15.0 to 0%), moderate (16.7 to 5.0%) and mild (25.0 to 21.7%)</p>	<p>Group Psychotherapy is a useful adjunct to OF care: it improves their overall mental health status.</p>	<p>26</p>
<p>9.Gebresilase (2014) A qualitative study of the experience of obstetric fistula survivors in Addis Ababa, Ethiopia</p>	<p>Exploration of the evolution of survivors’ perceptions of their social relationships and health sin</p>	<p>Eight participants, Addis Ababa, Ethiopia</p>	<p>In-depth interviews conducted with eight survivors Thematic and content analysis for data analysis</p>	<p>Coping mechanism used: Self-isolation, having suicidal thoughts, their family support, sold their properties</p>	<p>Fistula has significant physical, psychosocial, and emotional consequences. Sample size was small to generate the amount of data presented</p>	<p>28</p>

<p>10. Mselle et al. (2012) Hoping for a Normal Life Again”: Reintegration After Fistula Repair in Rural Tanzania</p>	<p>To explore women’s expectations, worries, and hopes related to returning to their family and community after fistula Repair</p>	<p>One hundred fifty-one women completed a questionnaire, eight were interviewed using a qualitative tool</p>	<p>Mixed methods design with a Hospital survey and qualitative interviews.</p>	<p>-Women were concerned about where they could live after discharge. - They had concerns about not being accepted by their husbands and in-laws. -All women wished to live with their parents -All women hoped to have children in the future</p>	<p>Women’s expectations of going home after fistula Repairs are linked to their history of living with obstetric fistula. Qualitative Sample size was small</p>	<p>34</p>
<p>11. Khisa and Nyamongo. (2012) Still living with fistula: an exploratory study of the experience of women with obstetric fistula following corrective surgery in West Pokot, Kenya</p>	<p>Document challenges women faced following corrective Surgery and their needs within the broader context of women’s health.</p>	<p>Eight women were recruited for study in West Pokot, Kenya</p>	<p>Qualitative study design</p>	<p>Women experienced separation/ divorce, infertility, stigma, isolation, shame, reduced sense of worth, psychological trauma, and unemployment. Even after fistula healed</p>	<p>Small sample size, Focus group discussions may not be the best approach for gathering data in this cohort.</p>	<p>28</p>

<p>12. Alio et al. (2011) The psychosocial impact of vesico-vaginal fistula in Niger</p>	<p>explore the psycho-social impact of VVF on women in Niger</p>	<p>21 Women in convalescence Health Center in Niamey, Niger, in 2008 and 2009</p>	<p>Qualitative study on at the DIMOL Reproductive</p>	<p>Women reported: psychological consequences of VVF i.e. depression, shame, Social rejection isolation, rejection by husband and/or divorce. Women reported having lost their Social network and support</p>	<p>Fistula is a direct result of lack of access to skilled birth attendants and emergency obstetric care in Niger. Recommendations are not linked to study findings</p>	<p>30</p>
<p>13. Khisa <i>et al.</i> (2011) Depression among women with obstetric fistula in Kenya</p>	<p>Establish the prevalence of depression and describe associated factors among fistula patients attending an obstetric fistula surgical camp in Kenya.</p>	<p>Nairobi, Kenya. A structured questionnaire</p>	<p>A cross-sectional In patients attending a national fistula camp held in August 2008 at Kenyatta National Hospital</p>	<p>Depression was present in 51 (72.9%) patients, Depression was significantly associated with women older than 20 years of age (P=0.01), unemployment (P=0.03), lack of social support following fistula (P=0.04), and living with fistula for over 3 months (P=0.01)</p>	<p>Women with obstetric fistula are predisposed to high levels of depression. The study design was limited to descriptive data, a mixed method would have linked the observed variables with life events</p>	<p>26</p>

<p>14. Pope (2011). Restoring dignity: Social reintegration after obstetric fistula repair in Ukerewe, Tanzania</p>	<p>Explored barriers and facilitating factors women experience reintegrating into society after treatment of an obstetric fistula in</p>	<p>A total of 71 women were interviewed in the Mwanza region of Tanzania, Including a community control group</p>	<p>Qualitative study design</p>	<p>Women were able to resume many of the social and economic activities they engaged in prior to the development of a fistula. Familial support facilitated both accessing repair and recovery</p>	<p>Attention is needed for women who are not completely healed. A well designed study with practical recommendations A well</p>	<p>34</p>
<p>15. Turan <i>et al.</i> (2011) Experiences of women seeking medical care for obstetric fistula in Eritrea: Implications for prevention, treatment, and social reintegration</p>	<p>The interviews were designed to inform programme Design for the prevention and treatment of obstetric fistula</p>	<p>11 new fistula repair patients, 15 women returning for follow-up five accompanying family members were all interviewed. In Eritrea</p>	<p>Qualitative interviews with women seeking medical care for obstetric fistula</p>	<p>Lack of transportation from remote villages. Marked improvements patient's conditions. Many continued to have problems with incontinence and sexual health. They patients lacked specific information about fistula</p>	<p>There is need for community mobilization, education and counselling. Eligibility a criterion was not standardized raising concerns about reliability of outcomes</p>	<p>23</p>

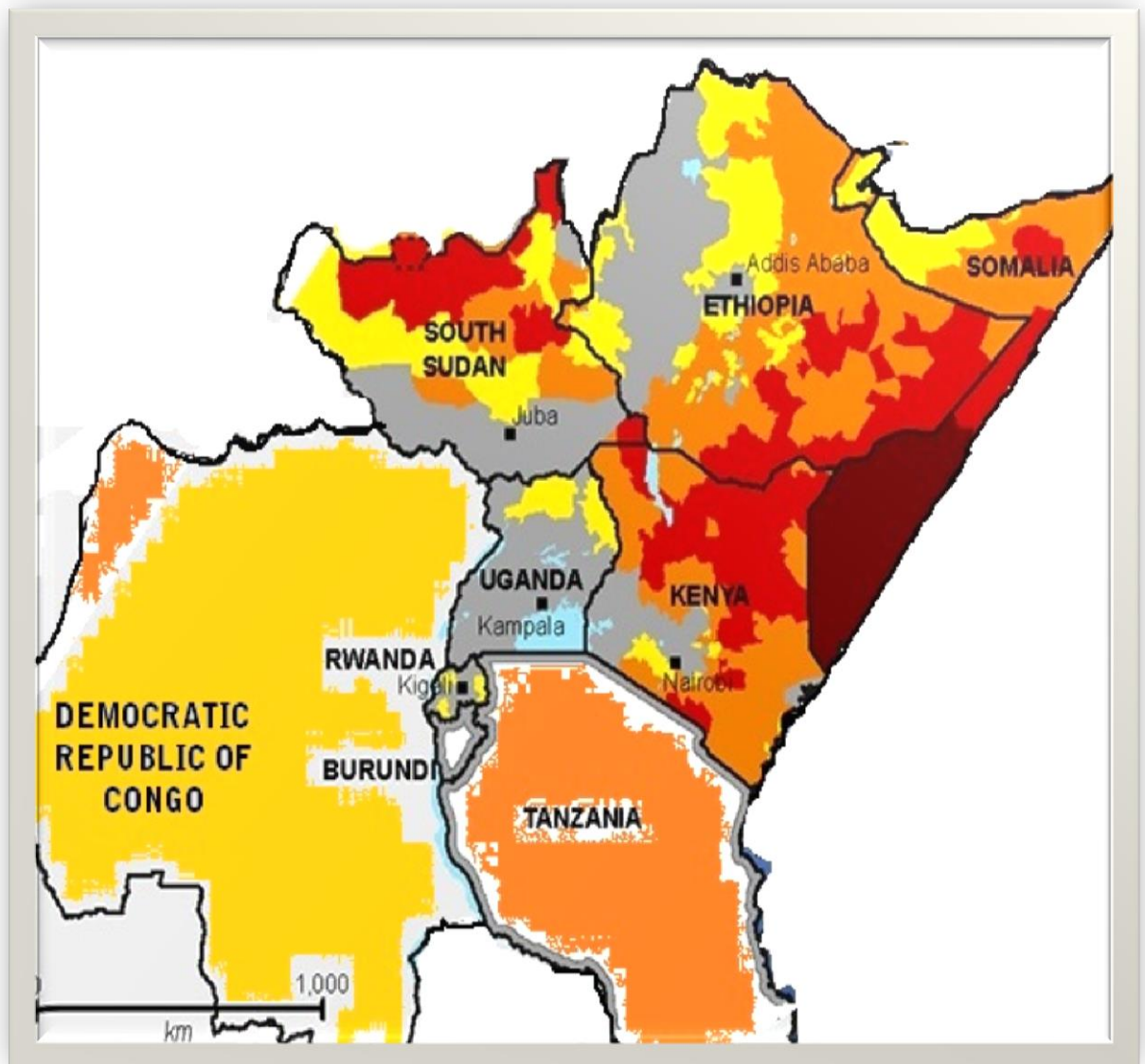
<p>16.Umoyyoho (2011) Quality of life following successful repair of Vesicovaginal fistula in Nigeria</p>	<p>To discover the effect of successful VVF repair on affected women's quality of life</p>	<p>150 women studied, quality of life was assessed using WHO Quality of Life (WHOQOL)-BREF Questionnaire</p>	<p>Descriptive study design in Nigeria</p>	<p>20% felt satisfied with their general state of health and quality of life before the repair, while this increased to 90% following successful repair</p>	<p>Successful repair of VVF is associated with significant improvement in the quality of life. The study design fell short of narratives to qualify level of satisfaction</p>	<p>28</p>
<p>17. Nielsen (2009). A community-based long-term follow up of women undergoing obstetric fistula repair in rural Ethiopia</p>	<p>To assess urinary and reproductive health and quality of life following surgical repair of obstetric fistula</p>	<p>Prospective study. In Rural Ethiopia</p>	<p>38 women (86%) of 44 who had undergone Fistula repair were identified in their community</p>	<p>Surgery improved quality of life and facilitated social reintegration to a level comparable to that Experienced before fistula development</p>	<p>Community-based, long-term follow up after fistula Repair was successful The pre-fistula period was not well documented to justify the conclusion</p>	<p>33</p>
<p>18. Browning (2007) The impact of surgical treatment on the mental health of women with obstetric fistula</p>	<p>Determine the impact of surgical treatment on the mental health of women with obstetric fistula</p>	<p>51 obstetric fistula admitted to the Barhirdar Hamlin Fistula Centre, Ethiopia.</p>	<p>Prospective study, Questionnaire (GHQ-28) for potential mental health disorder before and 2 weeks after fistula surgery</p>	<p>By 2 weeks after, this had dropped to 36% (P = 0.005). 27% of the 45 women who were cured of their incontinence screened positive, while all 6 of those with severe Residual incontinence continued to screen positive</p>	<p>Surgical treatment of obstetric fistula results in marked Improvements in mental health</p>	<p>28</p>

<p>19. Muleta (2007). Health and Social Problems Encountered by Treated and Untreated Obstetric Fistula Patients</p>	<p>To assess health, social, and psychological problems encountered by women with obstetric Fistula (OF)</p>	<p>27-women participated in in-depth interviews In Rural Ethiopia</p>	<p>A cross-sectional study</p>	<p>24 women attributed their development of a Fistula to evil spirits, to a curse, or to sin. -treatment improved family and social life.</p>	<p>Women have health, psychological, and social consequences that are not completely resolved by repairing fistula. Outcomes point to cultural practices that impeach on women health</p>	<p>30</p>
<p>20. Velez (2007) The Campaign to End Fistula: What have we learned? Findings of facility and community needs assessments</p>	<p>To expand knowledge on causes, impact, capacity to manage fistula, see Clinical and programmatic gaps</p>	<p>25 countries in Africa and Asia</p>	<p>Mixed method study design. 40 countries were involved i.e. Africa, Asia and Arab countries</p>	<p>Most women reported home births with TBA. Women had limited decision making regarding their own health at delivery. About 3000 new fistula cases each year, with 7.5% currently treated</p>	<p>key assessment tools to guide national programs to eliminate VVF Unstandardised tools for data analysis affected uniformity of results</p>	<p>22</p>
<p>21. Mohammad (2007). A community program for women's health & development: Implications for the long-term care of women with fistulas</p>	<p>To improve the social, economic, and health status of women affected with vesico-vaginal fistulas</p>	<p>Sub Saharan Africa, 7 year program</p>	<p>Descriptive design, an assessment of community based program using a holistic approach in providing surgical repair and rehabilitation</p>	<p>Women returned to their communities with skills to generate income for economic independence The project succeeded in helping women live normal lives and bear Children.</p>	<p>Promote integration of women's health, education, income, productivity, and community participation Country specific OF contexts are not well outlined</p>	<p>26</p>

APPENDIX 2.4: QUALITATIVE PAPER SCORING USING HAWKER'S TOOL

Authors	Abstract & Title	Introduction & Aims	Method & Data	Sampling	Data Analysis	Ethics & Bias	Results	Transferability	Implication	Total
1.Siddle et al. (2017)	4	3	4	4	4	2	4	4	3	30
2. Lavender <i>et al.</i> , (2016)	4	3	4	3	4	3	4	3	4	34
3.Khisa <i>et al.</i> (2016)	4	3	4	4	4	3	4	3	3	34
4.Baragein (2015)	4	3	4	3	3	2	4	4	3	32
5.Donnely et al. (2015)	3	4	4	4	4	3	4	3	3	30
6.Wilson et al. (2015)	2	2	3	3	3	3	4	4	2	26
7.Lombard (2015)	4	4	4	3	4	4	4	4	4	26
8. Ojengbede (2014)	3	4	4	4	4	3	4	4	3	28
9.Gebresilase (2014)	2	2	3	3	3	3	4	4	2	26
10. Mselle et al. (2012)	4	4	4	4	4	3	4	4	3	34
11. Khisa &Nyamongo (2012)	2	2	3	3	3	3	4	4	2	28
12. Alio, et al. (2011)	4	3	3	3	3	3	3	4	3	30
13. Khisa <i>et al.</i> (2011)	3	3	3	3	2	3	4	4	3	26
14. Pope (2011)	4	4	4	4	4	3	4	4	3	34
15. Turan <i>et al.</i> (2011)	3	3	2	2	2	2	3	3	3	23
14.Umoyoho(2011)	4	3	3	3	3	3	3	3	3	31
15. Nielsen. (2009).	4	4	4	4	4	2	4	4	3	33
16. Browning (2007)	3	3	3	3	2	3	4	4	3	28
17 Mohammad (2007).	4	4	2	2	2	2	4	3	3	26
19. Muleta (2007).	3	4	4	4	3	3	4	3	3	30
20. Velez (2007)	3	4	2	2	2	2	2	3	2	22
21. Mohammad (2007)	3	4	2	2	2	2	2	3	2	22

APPENDIX 4.1: EAST AFRICA STUDY MAP



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Access to fistula care during rainy season is difficult.

APPENDIX 4.3: PARTICIPANT INFORMATION SHEET

PREDICTIVE VALUES IN SURGICAL REPAIRS AMONG VESICO VAGINAL FISTULA PATIENTS IN EAST AFRICA

Background Information

You are being invited to take part in a study looking at Vesico Vaginal Fistula (VVF), a condition whereby you continually leak urine from your body. This condition usually arises following an obstructed labour during childbirth. Occasionally, the condition may occur following abdominal surgery. Owing to the continuous urine leakage, routine activities are affected largely because the offensive odour created by the urine mixing with the air makes it difficult for you to work or socialize hence you may have become ostracized (shunned or avoided by others). Therefore, I am interested in speaking to women such as you, who has urine leakage and has either never been operated on or whose operation has not helped regain continence.

Please feel free to discuss this information with others (e.g. your family, your midwife or your doctor) before deciding whether to take part. You can also contact the research team directly (details outlined on page three of this document), if something is unclear. If you would like to take part, please complete the enclosed contact form, and consent form, and then return them to the research team in the hospital. If you agree to take part in the study, we will contact you upon admission.

What is the purpose of the study?

This study will investigate the burden of having a VVF among women presenting with a fistula and who have a desire to regain continence. It is hoped that information gained from the research may help to improve fistula care for other women who have the same problem in the future.

Why have I been chosen?

You have been chosen because you have been leaking urine either following the birth of your child or following your abdominal surgery.

Do I have to take part?

No, it is up to you to decide whether to take part or not. The decision to take part is voluntary. If you decide to take part you will be asked to sign a consent form, a copy of which you can keep together with a copy of this information sheet. If you do consent to take part: you are still free to withdraw from the study at any time, without giving a reason. A decision to withdraw, or a decision not to take part will not affect the standard of care you receive now or in the future.

What will happen to me if I take part?

If you agree to participate, you will be required to complete the first questionnaire that collects information about your personal such as age, number of children, last delivery and when fistula developed.. As part of preparations for the operation, we shall draw about 5ml of blood from you for preliminary tests (Full haemoglobin). You may also undergo Voluntary Counselling and Testing which is part of routine preparations for surgery, this is optional.

During the operation that surgeons will perform on you to close the fistula, more information will be collected using the part II of questionnaire, this will collect information about the location and size of the fistula. This will occur while you are undergoing surgery, so you will be asked to give consent before the operation. After the surgery is done, a dye test will be done by the surgeon to check whether the fistula has closed or not. After surgery, you will be taken to the wards where you will stay for at least two weeks before you are discharged home. Once you have been discharged, you will be asked to come to the fistula centre for three follow up visits which are 2 weeks apart. During each of these visits, you may spend 30 minutes to 1 hour, depending on your progress. At the follow up visit, you will be interviewed using a part III of the questionnaire which will collect information about complications that may have occurred after you were discharged, you will also be examined to see whether you have healed and a dye test will be done to assess continence. In cases where continence has not been achieved, the patient will be rescheduled for repeat repair.

What do I have to do?

You will be required to complete a contact information form discuss your care with the research team and sign consent form. The questionnaire will be completed by a research team member. You will be expected to comply with fistula care plans which include 5 litres of oral fluids and perineal hygiene before and after surgery.

What are the possible disadvantages and risks of taking part?

There are minimal risks to you for participating in this study. There is a possibility that some of the questions we ask may make you uncomfortable. If you do become upset, you do not have to answer these questions if you do not want to. If you are particularly upset by taking part in this study you can be referred to a counsellor for additional support should the need arise.

What are the possible benefits of taking part?

Although we cannot guarantee that policy makers will make use of information from this study, the research team will use the information in the training of health professionals in the future to help improve VVF services in the region.

Will I be paid for taking part?

No. You will not be paid for taking part in this study, although transport arrangements can be made through the social worker for individuals who need support to return home upon discharge. The initial interview and follow up visits will take place at hospital in a private room.

How long will the study last?

This study will last for about 24 months, although your involvement will only take six months from the time you enrol into the study until the time you make your last visit at six months.

Is this study part of an educational qualification?

Yes, the study is going to form part of Dr Weston's thesis, his supervisors are as follows
Name: Prof. Tina Lavender, University of Manchester.

What if something goes wrong?

This study does not involve you taking new medications and so we do not expect that taking part in the study will cause you problems. However, if there is anything about the research study that you are not happy with then you need to you contact the lead researcher, Dr Weston, is responsible for the day-to-day conduct of the study. He can be contacted at the address above, or by email weston.khisa@amref.org or by telephone on +254 0721 242 347. You can also contact the Chairperson, Kenyatta National Hospital Ethics and Research committee. If you are still not happy then you need to contact one of the research supervisors named above. Any complaint you make will be taken very seriously.

Will my taking part in this study be kept confidential?

All data obtained during the study will be kept strictly confidentially, stored in encrypted, fire-wall protected and password protected computers in the lead researcher's office which will be under lock and key always. The information obtained will not have any identifiers on it so that it will remain anonymous so that participants cannot be identified. We will not identify you or use any information that would make it possible for anyone to identify you in any presentations or written reports about this study. We will not tell healthcare professionals responsible for your care if you have taken part, unless it is felt that you or others are at serious risk of harm.

What will happen to the results of the research study?

Information generated from this study will be used to write a PhD thesis for Dr. Weston. So that others can learn from our study, we will write s for peer reviewed journals and give presentations at health-related conferences. We will be careful to ensure that it is not possible to identify you

individually in any reports, articles or presentations. We will also present the information gathered at community forums to help reduce stigma and help others access VVF treatment.

Thank you very much for taking the time to read this information sheet.

Lead Researcher: Weston Khisa, Kenyatta National Hospital and University of Manchester, University Place, Oxford Road, Manchester, M13 9PL, Tel: +254 721 242 347

APPENDIX 4.4: CONSENT FORM

CONSENT FORM FOR INVOLVEMENT IN THE STUDY

The University of Manchester



VERSION 2.1 – Jan 2012: (To be kept in a locked cupboard by the research team)

Fistula Diagnosis and Management

Please put your initials next to the statements below and then sign the bottom of the form where it says ‘name of participant’.

PLEASE RESPOND TO ALL OF THESE QUESTIONS

Please initial box

1. I confirm that I have read and understand the information sheet dated February 2012 (version 1.0) for the above mentioned study and have had the opportunity to ask the research team questions about the study.	<input type="checkbox"/>
2. I understand that I am free to withdraw from the study at any time, without giving any reason and that such withdrawal will not affect my care or legal rights in any way.	<input type="checkbox"/>
3. I am aware that the researcher will require that I complete a questionnaire regarding my Condition, will document my intra-operative proceedings that such data will be stored by the researcher in a secure place and will be destroyed once the study report has been completed to which I agree to give consent to take part in this study.	<input type="checkbox"/>
4. I agree to the use of my direct quotes in any reports or publications, only if they are used as anonymous responses without any identifiers. I agree to give consent to take part in this study.	<input type="checkbox"/>

Full Name of Participant Signature Date

Lead Researcher Signature Date

Where applicable witnesses by

WitnessSignature Date

You will have a copy of this form to keep. A further copy will be stored in the researcher’s site file.

Lead Researcher: Weston Khisa, School of Nursing, Midwifery and Social Work, University of Manchester, University Place, Oxford Road, Manchester, M13 9PL, Tel: +254 721 242 347

APPENDIX 4.5: QUANTITATIVE DATA COLLECTION FORM

PREDICTIVE VALUES IN SURGICAL REPAIRS AMONG VESICO VAGINAL FISTULA PATIENTS IN EAST AFRICA

Study SITE.....**DATE**..... **SURGEON**.....

Section 1.0: Social demographics.

1.1: **Study ID**..... IP: No.....

1.2: Age.....Date of Birth.....Place of birth.....County...

1.3: Educational background of patient.....

Education of spouse

Patient Occupation.....Spouse Occupation.....

1.4: Current residence.....Religion.....Marital status.....

1.5: Did husband leave because of fistula? **1.** Yes **2.**

1.6: Who do you live with now.....

1.6.1 How did you first know about this VVF programme.....

Section 2. Fistula characteristics

2.0: Problem with urine? **1.** Yes No.

2.1 Problem with faeces? **1.** Yes

2.2: Can patient pass urine normally? **1.** Yes **2.**No

2.2.1 When did the leakage start?.....

2.3: After delivery? **1.** Yes No

2.3.1 Age at which fistula developed.....

2.4: Duration of leakage.....

Parity when fistula developed.....

2.5: Date of delivery.....If not obstetric, what is the other cause.....

2.6: Sex of infantBirth Weight.....Is Infant AliveDied.....

Duration of labour..... **26.1** Assistance in labour-Midwife, doctor, relative, TBA.....

2.7: What was the interval between delivery and leakage?.....

2.8: Did you have a catheter inserted to help drain the urine **1.**Yes **2** No Duration with catheter.....

2.9: Other deliveries: Year.....Type.....Place.....M/F.....Outcome.....

Year.....Type.....Place.....M/F.....Outcome.....

Year.....Type.....Place.....M/F.....Outcome.....

2.10: Number of children alive currently.....

2.11: Leg weakness after delivery (Yes/No).....Left/Right.....Resolved now (Yes/No).....

2.12: Menstruating regularly (Yes/No).....LMP.....

2.13: Number of previous unsuccessful repairs.....

VVF Repairs.....YearRVF repairs.....Year

Hospital.....Surgeon.....

Section 3.0: Past medical history

3.1: Other operations.....

3.2: Significant past medical History

Section 4.0: Intra operative Characteristics

4.1: General Condition-(Poor/Fair/Good).....

4.2: Fistula classification.....

4.3: Dye test outcome.....

4.4: Current lesions: RVF.....

- 4.5 Paralysis peroneal nerve R.....L.....
 4.6 Vaginal stenosis.....Excoriation-
 (Mild/Moderate/Severe).....
 4.7:
 HB.....Creatine.....HIV.....PDT.....
 4.8: Other investigation results.....
 4.8: Plan of action.....
 4.9 Intra-operative complications.....
 5.0 Immediate Post-operative complications.....

Section 5.0: Family planning practices.

- 5.1: Have you ever heard of family planning options/methods? 1. Yes 2. No
 (Yes/No).....If yes, please mention all that you know (Cycle all that applies)
 1. Pill 2. Injection 3. Norplant 4. IUD 5. Tubal ligation.
 6. Others (Specify).....
 5.2: Do you know any benefit of family planning?
 1. Yes 2. No
 If yes mention at least three
 5.3: Do you know any disadvantages of family planning? 1. Yes 2. No
 If yes mention at least three
 5.4: In your opinion when should women use family planning?
 1. Before marriage 2. In marriage 3. Never 4. Other
 Specify.....
 5.5: Have you ever used a family planning method?
 1. Yes 2. No If yes which onewhen.....if no, please
 explain why not.....
 5.6: Since the VVF, have you ever used a family planning method?
 1. Yes 2. No If yes which onewhen.....if no, please
 explain why not.....
 5.7: Where do you or other women get family planning supplies? 1. Clinic 2. Pharmacy
 3. CHW 4. Don't know 5. Others
 If Other, Specify.....
 5.8: Are these family planning services free in your community?
 1. Yes 2. No If not how much do they cost. Specify.....
 5.9: Do you have any intention of using family planning after VVF repair?
 1. Yes 2. No
 If yes which method and if not why.....
 5.10: In your opinion, do VVF patients need family planning?
 1. Yes 2. No 3. Don't know, If yes why and if not why
 not.....

Section: 6.0 Follow Up

- 6.0: Is this your first visit? 1. Yes 2. No
 6.1: How long has it been since you were operated?
 1. Two Weeks 2. Four weeks 3. Six weeks 4. Eight weeks 5. Six months
 6.2: Have you gained continence? 1. Yes 2. No
 6.3: Dye test outcome 1. Positive 2. Negative
 6.4: Do you have any post-operative complications? 1. Yes 2. No
 If Yes, please specify.....
 6.5: Have you had menses after surgery? 1. Yes 2. No

6.6 Currently who do you live with?

1. On my own 2. Spouse 3. Parents 4. Family member 5. Other
specify.....

6.7 Is the above living arrangement same as what you had before fistula developed? If Not why not? -----

6.8 How long did you take before resuming sexual contact?

1. Two Weeks 2. Four weeks Six weeks 4. ht weeks
5. Other pecify

6.7 Currently are you on any family planning method? 1. Yes 2. o

6.8 Do you plan to get pregnancy? 1. Yes No

Thank you for making this visit, to help us improve service delivery we would like to have your comments. *The End*

APPENDIX 4.6: QUALITATIVE INTERVIEW GUIDE

INDEPTH INTERVIEW GUIDE

LIVED EXPERIENCES FOR WOMEN WITH FISTULA PROBLEM IN EAST AFRICA

Instructions for in-depth interview facilitator: Here the facilitator will describe the purpose of the interview, reiterate the confidentiality of the material, remind the patient that they will be asked to talk about their personal experiences before and after fistula developed and emphasize how important it is that they discuss these issues openly, so that we will be able to better understand the problems of women living with the fistula problem in East Africa.

Instructions to the facilitator: Use the prompts in each question only if the issues don't come up spontaneously.

Q1: What are the attitudes toward Vesico Vaginal Fistula (VVF) in the community?

- What words or terms are most commonly used to describe VVF in your community?
- Do you think that VVF is a problem in your community?
- In your opinion, who is most affected by the VVF problem in your community?
- Do you feel at risk of developing a fistula again?
- Do the people in your community openly talk about VVF? Why or why not?
- Do women with VVF use herbal medicines? Which ones?
- How easy or difficult is it to find a woman with VVF in your community? Please explain.
- What support exists in the community for VVF patients and their families?
- In your opinion what can be done to improve the lives of fistula patients?
- How can VVF be eliminated from our midst?

Q2. How would you describe your life before you received fistula surgery?

- Instructions to the facilitator: Use the following prompts only if the issues don't come up spontaneously.
- What was the greatest challenge for you, your spouse and family? How did you handle these challenges
- While living with the fistula, did you ever receive alternative treatment.
- While living with the fistula, did you ever receive VVF treatment/surgery in a hospital setting. How would you describe this experience?
- In general, how did living with the fistula affect your life?

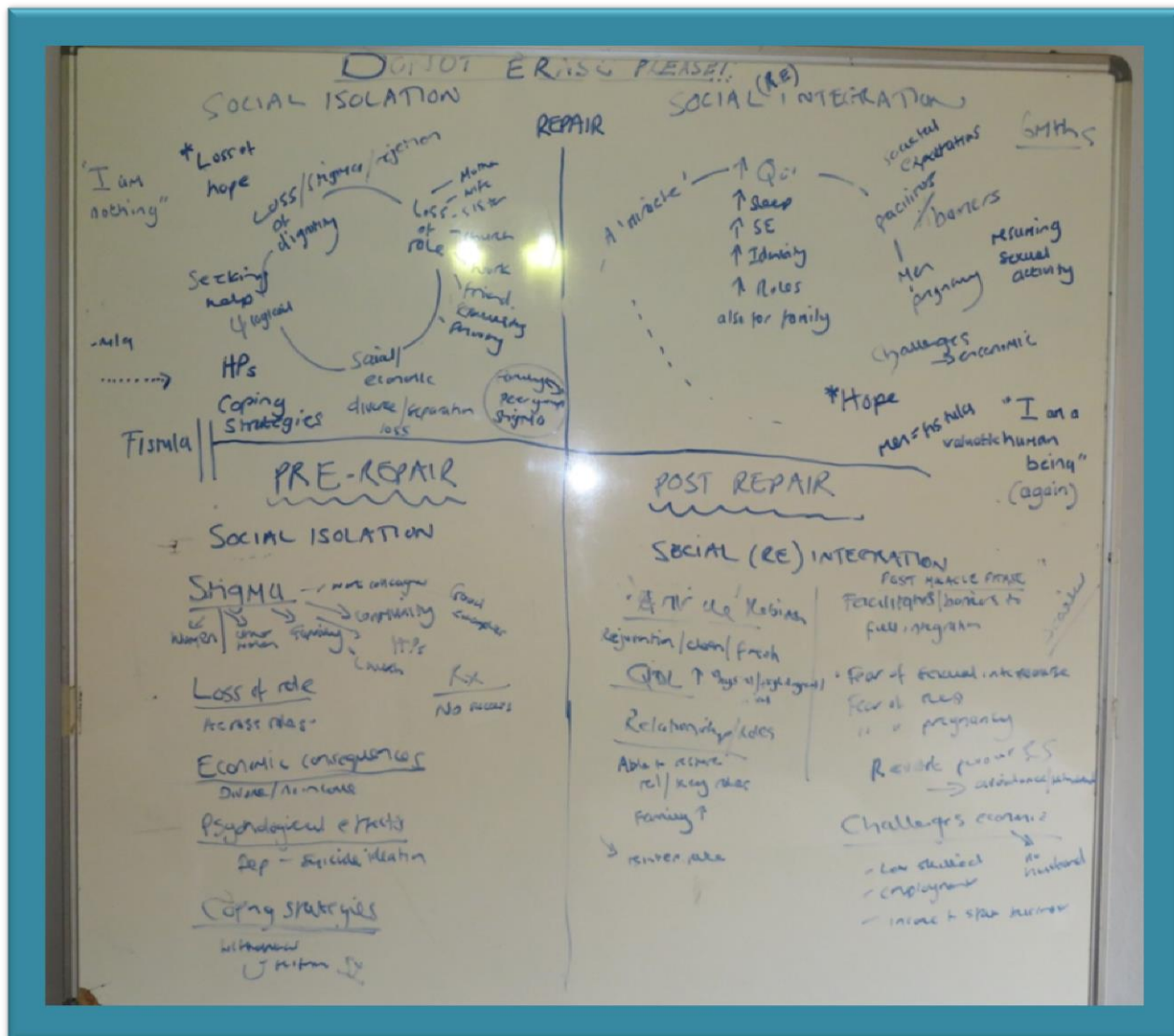
Q3. What has been your experience since the operation?

- What did you like most about the way you were received and admitted to the hospital for VVF treatment?

- What did you like least about the way you were received and admitted to the hospital for VVF treatment?
- In your opinion, has your fistula healed? Explain your Yes or No answer.
- If your answer is yes, how can you describe your experience after fistula healed?
- If your answer is No, how can you describe your experience after fistula failed to heal?
- How has your sexuality changed since the fistula developed?
- What other issues should we take into consideration in order to improve VVF programme.
- In closing, are there any questions that you have for us?

Facilitator: Thank you for taking time to participate in this research study

APPENDIX 6.1: QUALITATIVE THEMATIC ANALYSIS SAMPLE-I



APPENDIX 6.2: SAMPLE OF IN-DEPTH NARRATIVE- 01

LIVED EXPERIENCES FOR WOMEN WITH FISTULA PROBLEM IN EAST AFRICA

ENGLISH TRANSLATION- KC-006-TAABU

Facilitator: My name is Sabina, your interviewer today. I thank you for your participation in this study. I assure you that all discussions will be confidential. This interview will last about 20-30 minutes and will be recorded. Please feel free to tell us about your personal experiences before and after fistula developed. It is important that you discuss these issues openly without fear. The information gathered here will help us better understand the problems of women living with the fistula problem in East Africa.

Facilitator: What are the attitudes toward Vesico Vaginal Fistula (VVF) in the community?

NB: Even before the interview commenced, the respondent apologized for the continuous urine leakage, true to her words by the end of the interview, the bench and her clothes were all wet.

RC006: I have not heard of a special name referring to fistula or even bothered to ask. What I know is that my former classmate had the fistula but was repaired and healed well. About the larger community I don't know, many times I resigned to live alone especially in the village because every time I went to where people are, they started to talk so I gave up any social event.

Facilitator: When you say they started to talk what do you mean?

RC006: Whenever I approached people would say, hey, mama mkojo ndio huyo (Mother urine is here). Even the church members segregated me: I gave up going to church. But one pastor used to encourage me: he would tell me that one day God will find a way, that doctors will come from far and repair the fistula. Back then, I did not believe him, but now I know he was right, very right. Although I did not attend church, I used to fast and pray a lot. One day after the fasting, I had a dream, saying, you are a small girl, you have deserted me, will you manage what is ahead of you. Somehow, my mother had three similar dreams: little did we know what lay ahead of me. What this fistula has put me through is unspeakable.

Facilitator: Kindly explain what you mean by saying it is unspeakable, help me understand you better.

RC006: Early into my marriage, I was traumatized by my mother-in-law. She could make demands such that if my husband buys me a dress or a particular shoe she could have it so my husband bought things in doubles. Imagine, I loved her despite all that. But one day I said enough is enough. I was about 26 weeks pregnant: she knocked at our door at 6 o'clock in the morning while we were making love. She pushed the door open since the makuti houses don't have

permanent doors. She found us having sex, instead of leaving slowly she yelled: *“Looooo! You are busy fucking each other at this time? Stop it right now and go to the farm! I never used to be fucked all the time”*. After this drama, I did not cry, but my husband cried a lot. Later in the day, we agreed that I should leave. My husband gave me 1,600 Kenya shillings (\$20) for my upkeep but my mother-in-law took it along with my other personal belongings. Despite this episode, I left for my parents’ house that evening empty handed. I lived with my parents till labour started, they took me to the hospital for delivery. I delivered twins at age 18 through caesarean section, the first born was a boy who died two days after birth, the second was a girl and she lived, now aged 6.

Facilitator: Ok, go on.

RC006: According to our culture, the baby boy was to be buried at my husband’s place, he (husband) had no issues but my mother-in-law refused till the elders went to court. Finally the baby was laid to rest. All this time, I did not know I had a fistula because of the indwelling catheter: they discharged me home with it, without an explanation as to what I should expect. Upon catheter removal I started to leak nonstop. It has been a challenge: it is not easy living with the leakage, in this poverty, no pampers and coupled with hot climate. Remember there is no help in the villages for people like me (women with fistula). I have tried everything from prayers to herbal medicine, nothing worked. I even had a repair in Machakos in 2009, nothing worked. So for me, it is man for himself and God for us all. What can I do?

Facilitator: Do you feel at risk of developing a fistula again?

RC006: Well I can’t really tell, I am still young and if I heal, I may find someone to marry me. When that happens and I become pregnant there is a possibility because I got the fistula at the hospital during Caesarean section. Since the first birth was through caesarean section, other births will follow suit with all the risks. In my view, fistulas should not happen in hospitals: instead, prevention should prevail to avert fistulas from happening. To do this, management should ensure that doctors and nurses are well trained such that they are able to conduct safe surgeries as well as care for those with fistulas instead of just discharging them without a word as they did to me. It is not fair.

Facilitator: How would you describe your life before you received fistula surgery?

RC006: It is a long story. After I was divorced because of the fistula, lived with my parents for two years. Then out of the blues, my mother-in-law came begging me to return to my matrimonial

home, she went on her knees and for some reason my father agreed. I could not believe it given that this is the very woman who laughed so loudly in court when the judge passed the divorce sentence. Back then she had said, *"Who wants a urine clogged woman for a wife, go to away"*. Anyway, since I still loved her son (husband) I accompanied my mother in-law back to Kaloleni, *(The village where she was married)* with my fistula not repaired. When we reached there, what I saw left me in shock. My husband had married an elderly woman who had beaten him senseless. Essentially, my mother in-law had come for me help her throw the other woman out. I stood there, perplexed: I cried a lot and just turned back, without a word I left.

Facilitator: Did your husband say anything to you? Like apologize.

RC006: Nothing, in any case he was in a bad state and to say the truth I did not care.

Facilitator: What happened when you went back home?

RC006: My brother gave me some herbal medicine for three months, it did not work. Later that year he took me to Machakos hospital for fistula repair. Unfortunately, the doctors could not repair my fistula because I had big bladder stone. They said the bladder stones were as a result of dehydration. It is true: I was not taking enough water. But what could I have done, I had no pampers, the clothes (Rugs) were getting torn quickly because of the frequent washing. Really drinking 5-6 litres of water daily was out of the question in my case. I stayed at the hospital for three months because I could not raise the bus fare back home since my brother had already left for upcountry. The doctor and his wife offered to accommodate me as I awaited another for a second operation. Although the doctors family were very kind to me after three months, I gave up and decided to go back home. During this time, the leakage had reduced.

Facilitator: What happened when you got home?

RC006: I lived well with my parents fairly well. Then one day my father brought a man home to marry me, can you imagine? He had not even talked to me, just because the man had a car, my dad felt he was rich, he will take care of me and send me for fistula repair at Kenyatta National Hospital. I was so upset. The following morning, I left home to live in Kilifi with a former classmate.). It is through this friend that I met the man I live with now. Even as I live with this pokot man *(the man is from far Northern Kenya, a nomadic community while she is from the coast)*. I do have a small business selling mahamri *(homemade bread)*, but the proceeds cannot sustain me or anyone else in town.

Facilitator: So, are you now married to the pokot man?

RC006: I cannot call it a marriage: it is a union of convenience in a way. I had run away from home, had no money, no education: no job so what could I do than find someone to support my daily living as I meet his other needs. Unlike other men who cannot have sex with a woman leaking urine, he does not care whether I leak or not. So I live day by day, as much as I hate having sex especially when I have periods, plus the leakage and he still must have sex, I hate it.

Facilitator: How is this new relationship?

RC006: At first, all seemed well, he asked me to bring my daughter to live with us since he too has a son from a previous relationship. But six months into the relationship, the man just changed. He is very manner less when it comes to his sexual desires. Imagine he can come from work at any time during the day and find me seated outside the house with the other women, then he calls me into the house and tell me to have sex with him. It is like: I am a sex object, no preparation, no feelings attached, no respect or regard to my position. It does not matter to him, whether I like it or not, whether I have menses or not, he will fuck me and just go, it is like a goat cutting leaves from a tree. No emotions are involved, yet I have to bear it all for I have no income. What can I do, I have a daughter who needs shelter, food, school and I needed a place near town so when the VVF camp is announced I can come quickly to be helped.

Facilitator: Is this the only reason why you live with this man?

RC006: Basically that is the reason. Although, he also supports my people, he has no respect for them. One day I was unwell and my mother came to see me and help with the children for just one week. Belief me, what the man did was unprintable. One evening, he came from work: out of the blues he started telling my mother how her presence is affecting his sex life. That since she came to stay with us, I had rationed my vagina so he was sexually starved. Remember we live in the quarters where houses are very close and one can hear the conversation in the other house. My mother cried all night, the following day she left very early in the morning. The man had no apologies, nothing: all he wanted was space to satisfy his sexual desires. It stresses me up that he does not even care for privacy even when the children are around he will have what he wants. Sex is everything to him.

Facilitator: How did you feel?

RC006: Miserable. Hopeless. Bitter. Since that day, I vowed to leave him. But since this VVF camp was approaching, I decided to hang on till this time. I plan to go to my mother's place after discharge.

Facilitator: Since admission had he been to visit you?

RC006: Who? No, not yet. To be honest, I don't think he will come. All he is waiting for is my return. If I make such a mistake again, he will do just as he did last year.

Facilitator: What did he do?

RC006: I had an operation to repair the fistula repair in 2012 here in Coast general. When I discharged home, he demanded to have sex with me the same day the catheter was removed, which is why the fistula did not heal.

Facilitator: What? Why did you agree to have sex before you heal?

RC006: My dear, I can't argue with the beast, remember he is a prison warder: he has a gun, he can do anything so I live in fear.

Facilitator: What are you doing to cope and help yourself out of this situation?

RC006: My mother already took my daughter with her. This time round, when I am discharged I will cheat him that I have gone to Nairobi for further treatment. This way, he will not bother my family with telephone calls that mean nothing. Because of what he did to my mother he cannot come to our home, my brothers will not spare him. This way, I will have peace: take time to heal before I map out a new way of life.

Facilitator: In general, how did living with the fistula affect your life?

RC006: Talking of life with fistula is not easy. To be honest, I can't tell you about my childhood, my youth and my adulthood: it is all but a bad dream. As a teenager, I grew up in the village and before I realized it, I had dropped out of school, became pregnant at 17, lost the baby, developed the fistula and my misery started. I have nothing to talk about other than pain, suffering and rejection. In fact, one day I felt like hell had broken loose, I climbed the tree in our home and just as I planned to pull the rope, I looked down to make sure there was no one to resuscitate me, only to see my daughter asking to breastfeed. The maternal instinct worked on me, I came down

slowly to breast feed and go back to accomplish my mission. But as fate would have it, my mother came in only to see the rope around my neck while the baby suckled innocently, unaware of what was happening to her mother. My mother was heartbroken, have never seen her cry that way, I felt her pain, we talked and I resolved to live for the sake of my baby. It is the well-being of my daughter that motivates me till today.

Q3. What has been your experience since the operation?

RC006: Fantastic! My hospital stay was most memorable because whatever I wanted I got without delays. The admission, surgery and hospitalization were free of charge. The hospital was like my homes, my family, remember no one came to see me not even that pokot man (Husband). This particular admission was very different: we had someone dedicated to talk to the VVF patients, it made us feel better and appreciated for the very first time. The interview questions were very personal, nobody had ever asked such questions and this was a reflection of how deeply the VVF team cared for me. It (Interview) also served as a platform to share and pour out my heart like I have never done before. As they say, a problem shared is half solved.

Facilitator: In your opinion, has your fistula healed? Explain your Yes or No answer.

RC006: I still cannot believe it, I leak no more imagine my fistula has healed: I walk around without wearing rugs under my pants. This is a miracle. I had actually given up going by the number of operations I have undergone. But has it was planned, I am healed, I feel like a new human being. No smells, no name calling, all these experiences are overwhelming. It is like a big dream, at times I find myself standing up from where I am seated, look at the chair and touch my clothes just to confirm that there is no leakage. What else can I ask from God? The lord has been merciful, he has kept his faith, and he sent you (interviewer) and my Doctor (Dr. Khisa) to save our lives, to restore our dignity. I have no words, no gift befitting the noble work you (VVF team) do. All I can do is pray that the good lord may grant you peace and good health so you can continue to do this noble mission.

Facilitator: It is great to know that you have healed. But did you have any challenges or complications.

RC006: My greatest challenge was when I was discharged before the catheter was removed. This happened because of Doctors and nurses strike which occurred in December 2014. Reaching home that day was a nightmare, I was in pain, the road was bad and the matatus (public transport) kept stopping at every stop. When I got home, the catheter had blocked, it was tough that night. The following day, I went to the nearest health facility only to be turned away. The

health care providers said that they will not touch the catheter because they don't understand why and for how long I was to have it. I stayed like that for one more week then I travelled back to Mombasa where I had it removed. Immediately it was removed I was asked to take a lot of water, this happened for about an hour, each time I felt the urge to pass urine I went to the toilet and voided normally. Then it hit me that I had actually healed, eh! , I hit the roof with shouts of joy, singing halleluiah and praising the lord. The people around the clinic were in shock but I did not care.

Facilitator: How has your sexuality changed since the fistula developed?

RC006: I have not even given it a thought. My mind is focused on my healing. However, three days ago he (Husband) demanded to have sex with me, when I declined he became violent and wanted to rape me so I screamed and neighbours came to my rescue. He has not spoken to me since and for refusing to accept sexual advances he refused to give me fare to come for this visit.

Facilitator: But the last time we spoke on phone you lived with your parents. What really happened?

RC006: True after discharge, I lived with my parents but in January my daughter and his needed to report back to school. I did not want to keep the children at home and for some reason, I thought he could honour the letter the doctor wrote for me indicating that I must abstain from sex for at least six months. I was wrong. The man is a beast! Now that I do not have sex with him, he treats me with a lot of contempt, I think he buys food because of the children, otherwise he cannot.

Facilitator: For how long do you intend to live in this arrangement?

RC006: I have already talked to some old friends to accommodate me for a while. Once the six months elapse, with a little support I can find a place to bake Mahamri (cookies), sell and take care of my daughter. That is my dream.

Facilitator: In closing, are there any questions that you have for us?

RC006: Can I ask you a personal question.

Facilitator: Yes.

RC006: Last week I talked to an old friend, a male friend. He wants me to go and live with him. He is very kind but I am afraid he might turn out to be like the pokot man. What are your thought on this.

Facilitator: As you said earlier, this is a personal issue. You weigh the options but remember you must abstain from sex for six months. I suggest that you take care of yourself, heal first before you can get sexually active again. Otherwise the fistula will break down as it did previously.

RC006: I hear you. Trust me, will never let you down, ever after all it is me who knows what I have been through. It been a tough life, I can't forget the rough road that I have travelled. Facing Dr. Khisa again with urine stench is my worst fear dream: never again will I degrade myself for a man, black or white, men are all the same anyway.

Facilitator: As we come to the close of this interview, allow me to go make a summary of the points you have discussed, regarding your experiences while living with fistula, your hospitalization, surgery and after discharge. These include, a feeling of dejection, cohabiting with a man you have no feelings or respect for, rejection, poor, stigmatized, stressed, Continuous urine leakage, lack of pampers, suicidal tendencies, gender violence and homelessness for yourself and your daughter. On the other hand, you have a caring brother who has been checking on you. Your hospitalization and surgical experience was good experiences. In your words, the fistula has healed since you don't leak anymore. The challenge remains on your accommodation since you have no place to call home. Anything I have omitted?

RC006: No, thank you. But I want to see Dr. Khisa and tell him how I feel. If he is too busy I will fund raise fare and come to Kenyatta Hospital, I feel he must see the new Eunice. That is my new year's wish, to see him, to talk to him, to give him a big hug without worrying about the characteristic fistula smell.

Facilitator: From the rest of the fistula team, we thank you for taking time to participate in this study. We wish you the very best in your future undertakings.

The end

APPENDIX 6.3: SAMPLE OF IN-DEPTH NARRATIVE- 02

LIVED EXPERIENCES FOR WOMEN WITH FISTULA PROBLEM IN EAST AFRICA

INDEPTH INTERVIEW GUIDE

Facilitator: My name is Sabina, your interviewer today. I thank you for your participation in this study. I assure you that all discussions will be confidential. This interview will last about 20-30 minutes and will be recorded. Please feel free to tell us about your personal experiences before and after fistula developed. It is important that you discuss these issues openly without fear. The information gathered here will help us better understand the problems of women living with the fistula problem in East Africa.

Instructions to the facilitator: Use the prompts in each question only if the issues don't come up spontaneously.

Facilitator: What are the attitudes toward Vesico Vaginal Fistula (VVF) in the community?

RC005: I really don't know if there are words used to describe fistula or even women living with the fistula. The community is nomadic with temporary structures. This is because where I live in Marsabit, fistula is a very secretive thing; nobody dares to talk about it (*she was born in another county, Meru*). Plus, there is no community movement or organization that supports women with the fistula so it is pointless telling people who can't help, won't help. In my case, only my uncle knows. Since I don't get to interact with the indigenous people I find it difficult to start disclosing my condition to people whose culture and practices are divergent with mine.

Facilitator: Do you mean to say you don't socialize?

RC005: With whom can that happen? I live behind the shop where I work as a shop keeper, for my uncle. In fact, majority of the people only know how my face looks like, because I am always behind the counter. This way, nobody really gets to know me very well. It shields me from the public eye, therefore, safeguarding my privacy which I yearned for when I left Meru, my home town.

Facilitator: Do you think that VVF is a problem in your community?

RC005: Although I have not visited the Marsabit hospital, I know there is a problem in the community. You know, in Marsabit, women dress up only in Kanga (*a piece of cloth measuring about 1¹/₂ meters, usually wrapped around the waist, fits up to the feet and use lots of perfume*) so you really cannot tell who is affected and who is not. It is taken for granted that the women

like dressing in Kangas but the truth is, there is much more than meets the eye. If ever you people (*VVF team*) do half of the mobilization you do here in Mombasa, the turn up will be shock you all. They know there is a problem but how to start addressing it or where to seek help is the challenge.

Facilitator: In your opinion, who is most affected by the VVF problem in your community?

RC005: Women of reproductive age are most affected. It really does not matter whether it is their first time giving birth or not because child birth is conducted in a cultural manner. Instead of going to hospital for deliveries, special huts build within manyata serve the purpose. Traditional birth attendants perform functions of midwives. These traditional birth attendants have no education or midwifery training; the skill is dependent on previous experiences, hence when complications develop the woman is left at the mercy of God. If the woman survives, she is likely to get a fistula which is highly stigmatized and treatment is unheard of.

Facilitator: Do you feel at risk of developing a fistula again?

RC005: Ha! Who? Me? that is a bad dream. Men are creatures I don't want to embrace, I am done with them. The man whose child I delivered and got a fistula left the minute it developed 30 years ago. He robbed me of my youth, my womanhood, my identity; I want nothing to do with men and their sex appeals, which is a closed chapter in my life. I see men as men, nothing special, if I must say something, I say hi and pass. Deep down I know all men want one thing in women, sex, the minute they realize you cannot service them they dump you, me? not again.

Facilitator: Do women with VVF use herbal medicines? Which ones?

RC005: I don't know, but in my case I have not taken any herbal medicine to treat fistula or any other condition.

Facilitator: In your opinion what can be done to improve the lives of fistula patients?

RC005: Seriously, the women in Marsabit need help. Try doing there (*Marsabit*) what you are doing here in the Mombasa, help them. Many people don't know a solution exists for the fistula problem. The hospital may not be well equipped as the one here but you will have helped thousands of women come out of their hiding and get help. Family planning is also unheard of; the women in Northern Kenya truly need access and support to plan their families. This is one way through which new fistulas can be prevented, boosting women's health and self-esteem.

Facilitator: How would you describe your life before you received fistula surgery?

RC004: I was in a very steady relationship with an Indian guy, so I thought. He had taken me to deliver in a private hospital where I had a cesarean section done to deliver the baby. I have no recollection what happened, all I recall was that after two weeks, I was still in Intensive care Unit with tubes in every open space of my body. I did not see my fiancée, instead his mother used to come in the evening as though to check if I am still alive or dead. When the condition improved, I was transferred to Nyeri Provincial Hospital for more surgery, can't tell what surgery but I recall getting into theater at eight in the morning and left at six in the evening. Two days later, I was transferred to Kenyatta National Hospital where we found the doctor's strike was running into the second week. I was asked to go back and return when the hospital situation resolved. I refused to be taken back to Nyeri; instead I requested to be taken to my auntie's place in Meru.

Facilitator: All this time where was your fiancée?

RC004: I never saw him. All I was told was that when I left theatre, he saw me once at the ICU then left to bury his son never to return. Many months later, his brother told me he had relocated to the United Kingdom. Back then I made up my mind never to give him a second thought, he is not worthy it. I have since moved on despite the challenges of having to leak urine for thirty years in a hot and hardship environment.

Facilitator: What was your experience in Meru?

RC004: After just a week, my aunt made it clear that she has no money to waste taking me to Kenyatta yet she has school going children. Despite this, I worked for her for quite some time before I decided to move to my brother's house. Life with my sister in-law was difficult, they treated me like an outcast, it is like everything I touched was left with a bad smell. The pain and suffering was immense, I lost a lot of weight and the depression was too much. Many occasions I felt like I could just die and stop bothering people. Fortunately, my maternal uncle heard about my life situation and decided to come for me. I moved to Marsabit with him, which is the place I have lived for the last ten years.

Facilitator: While living with the fistula, did you ever receive VVF treatment/surgery in a hospital setting. How would you describe this experience?

RC004: I was operated in this very hospital in 2010. They removed my uterus due to fibroids but the fistula was untouched. Back then, it was a nasty experience, I was returned from theatre twice because the doctor needed some special x-ray which I could not afford. One day, another doctor

decided to help me, he operated me from six in the morning till three in the afternoon. Anyway I thank God it went well and I am alive to tell the story. After discharge, a friend offered to accommodate me for a while. But after two weeks, I noticed things were changing in the house. So, as soon as I attended the clinic for review I left for Marsabit with my urine leakage problems.

Facilitator: In general, how did living with the fistula affect your life?

RC004: To be honest, I have no life to talk about. Look, now I am 50, I got this fistula 30 years ago. My youthful life is gone, in a flush! My adulthood is a bad dream, what is there to talk about. As we speak, I have no penny on me, I ask what life is? At night I can't find sleep, my head spins, all I do is take paracetamol which gives me 15 minutes relief, when I wake up the realities hit me like thunder.

Facilitator: What do you mean when you say realities hit like thunder?

RC004: My dear, tell me what if this surgery does not succeed? Where will I go? Still if it succeeds where will I go? I have no home or money to start a business of my own. Where will I go? Plus we were told we will be discharged with the catheter, who can accommodate a woman with a catheter in her house? Tell me, who? However hard I try, I can't find answers to these questions. Imagine, even the transport I used to this place was borrowed from mshwari (*A loan facility in safaricom, this service is available for subscribers*).

Facilitator: How does this make you feel?

RC004: Lost, very lost. Many times I ask God, what did I do to deserve this in life? Why did my mother have to die leaving me very desolate? If she was a live today, could my brothers and their wives treat me like trash? What I know is that if mama was a live I could have a place to call home, a place to hide away from the world's beatings, now I am alone and lonely.....*she spoke these words with tears running down her cheeks, she asked for paracetamol which was provided, interview was paused for a while then resumed.*

Facilitator: We are coming to the end of part one of this interview, please feel free to ask any questions you may have?

RC005: Now tell me what will happen when I am sent home after 14 days with a catheter? Who can accommodate me in that state?

Facilitator: Do not worry about the time of discharge; we shall cross that bridge when we get there. For now, adhere to the fluid intake and hygiene instructions as given by the fistula team.

Facilitator: What has been your experience since the operation?

RC005: Foremost, I want to thank you all for everything, for giving me a reason to see tomorrow. You know I had been attending the clinic here in anticipation for fistula repair. But the first contact was nasty; the doctor referred me to his clinic in town and ordered for an x-ray. I had no cent on me so I could not pay; I left with tears on my cheeks. As God planned it, a friend offered to accommodate me for a while. Then, one day I met a nurse who works here in the hospital, she informed me about the upcoming fistula camp by doctors from Kenyatta Hospital. That was my lucky day. One day, a nurse called me and asked me to report to the hospital on 30TH November, 2014. When I came to the hospital, the clinic nurse admitting VVF patients looked at me and said: Hey, this is not the place for you please give up the seat for women leaking urine. I did not say a word; I stood up and gave way for the other VVF patients. Afterwards I moved close and told the nurse I too had a fistula problem; she looked at me and smiled. From then all, my hospital stay went very smooth.

Facilitator: What did you like least about the way you were received and admitted to the hospital for VVF treatment?

RC001: I remember the day I went to theater, the injection that I received on the theater table was very painful. I told Dr. Khisa if there will be a next time, I will run away from him. After that injection, we just chatted all through the operation and the surgeon made things looks so easy yet deep down I knew it was a tough job.

Facilitator: How can you describe your experience after fistula healed?

RC005: It is a miracle. Imagine today I have worn white underpants, white, and I mean white. It is still a miracle to me. Usually, I sleep on a small mattress on the floor, which is the way it has been for the last 32 years. After the catheter was removed, I sat down for an hour, I had no leakage and then I went home still thinking it will happen again (*urine will leak again*). When I got to the house, I shared the good news, the family that accommodates me shared in my joy, unbelievable joy. Then the night came, Mmmm, I slept, half the night I woke up to change as usual then the reality strike... silence..... I was dry; truly I had healed. For what you (VVF team) and Dr. Khisa have done for me. I ask God to reward you that your goodness may pass down to your children and children's children for I am lost for words.

Facilitator: How has your sexuality changed since the fistula developed?

RC005: My dear after 32 years of misery I have no slightest taste for men. After all I had a total hysterectomy four years ago, so that chapter is closed, don't even mention it. Before this surgery my life was hell on earth, no relative wanted me, my uncle picked me from my aunties house where I worked as a house help with no pay. When we got to my uncles house the wife was not happy, she accused him of bringing another wife yet I was so young, sick, orphaned and very thin. She starts to cry sobbing a lot.....silence (7min). I have lived with my uncle for many years but I am not eager to go back. How I wish I could find a job and sustain myself.

Facilitator: In closing, are there any questions that you have for us?

RC005: Questions? No, none at all. All I do is pray and pray for you. Pass my greetings to Dr. Khisa; tell him I will be here in December 2014, to help destigmatize VVF, educate the patients before and after surgery. Only God can pay him (*Dr. Khisa*) for his goodness, his humility, I have no words, be blessed.


Facilitator: As we come to the close of this interview, allow me to go make a summary of the points you have discussed, regarding your experiences while living with fistula, your hospitalization, surgery and after discharge. These include, abandonment, orphaned, homelessness, rejection, penniless, stigmatized, stressed, the burden of urine leakage; On the other hand, you have a caring maternal uncle who has been taking care of you for the last ten years. Your hospitalization and surgical experience was uneventful. In your words, the fistula has healed since you don't leak anymore. The challenge remains on your accommodation since you have no place to call home. Anything I have omitted?

RC005: No, thank you. There are many women out there suffering, we pray that God gives you strength day by day so you can continue helping us. I also pray for Dr. Khisa's eyes so that he can have a good eye sight even when he is 100 years old, so he can continue repairing fistulas.

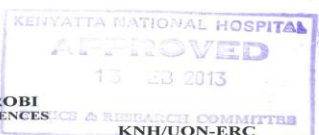
Facilitator: From the rest of the fistula team, we thank you for taking time to participate in this study. We wish you the very best in your future undertakings.

The end

APPENDIX 6.4 ETHICS APPROVAL




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13th February 2013

Dr. Weston W. Khisa
Dept. of Obs/Gynae
KNH

Dear Dr. Khisa

**RESEARCH PROPOSAL: PREDICTIVE VALUES IN SURGICAL REPAIR OUTCOMES
AMONG VESICO VAGINAL FISTULA PATIENTS IN KENYA (P529/10/2012)**

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above revised proposal. The approval periods are 13th February 2013 to 12th February 2014.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal.*)
- f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- g) Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website www.uonbi.ac.ke/activities/KNHUoN

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