Social Re-integration of women undergoing Obstetric Fistula Repairs: A			
Case study of three AMREF Intervention Sites.			
By			
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Dissertation submitted in Partial Fulfillment of the Requirements for Masters of Public Health (MPH) Degree of the University of Nairobi.			
November 2013			

# **DECLARATION**

I Mumbi Wanjiku Kimani do hereby declare that this dissertat	tion is my original work and to the best of			
my knowledge, has not been presented to any institution for the purpose of examination for a degree.				
Signed	Date			

# **APPROVAL**

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# **DEDICATION**

This study is dedicated to the survivors of obstetric fistula in general and specifically the brave women who willingly participated in this study. I share your joy of recovery and the determination to press on with reclaiming your place back in society in all its fullness.

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#### **ACRONYMS**

AIDS Acquired Immunodeficiency Syndrome
AMREF African Medical Research Foundation

ANC Ante-natal Care

BBC British Broadcasting Corporation
CBHC Community Based Health Care

CCBRT Comprehensive Community Based Rehabilitation TZ

CHEWs Community Health Extension Workers
CORPs Community Own Resource Persons

DANIDA Danish International Development Agency

DRC Democratic Republic of Congo DRH Division of Reproductive Health

EmOC Emergency Obstetric Care

FFF Freedom from Fistula Foundation

FDGs Focus Group Discussions FGM Female Genital Mutilation GIT Gastro Intestinal Tract

HIV Human Immune Deficiency Virus IBD Inflammatory Bowel Disease

IDI In Depth Interviews

JOORTH Jaramogi Odinga Oginga Teaching and Referal

Hospital

KDHS Kenya Demographic Health Survey

KII Key Informant Interviews
KNH Kenyatta National Hospital
MDGs Millennium Development Goals

MOH Ministry of Health MMR Maternal Mortality Ratio MSF Medicines sans Frontiers

NGO Non-Governmental Organization

NEP North Eastern Province

OF Obstetric Fistula

OL/PL Obstructed/Prolonged labour

PNC Post-Natal Care

RVF Recto Vaginal Fístula SM Safe Motherhood SSA Sub Saharan Africa

TB Tuberculosis
UN United Nations

UNHCR United Nations High Commission For Refugees

UNICEF United Nations Children's Fund UNFPA United Nations Populations Fund

VVF Vesico Vaginal Fistula
WHO World Health Organization
WWFF World Wide Fistula Foundation

# **ABSTRACT**

According to the American heritage dictionary, a fistula is defined as an abnormal duct or passage resulting from an injury, disease, congenital disorder connecting abscess, cavity or hollow organ to either the body surface or to another hollow organ. Sometimes medical or surgical procedures can result in fistulae. Obstetric fistulae are common in developing countries due to poverty, poor access to maternal health services and absence of EmOC services, in rural health facilities. The African Medical Research Foundation AMREF has an ongoing outreach programme to strengthen safe motherhood services, including OF surgical repairs in Kenya, Uganda and Tanzania. This study was based in three AMREF intervention sites; namely Kenyatta National Hospital, Kisii Level 5 and Jaramogi Odinga Oginga Teaching & Referral Hospital (JOORTH), with the aim of assessing social re-integration of women undergoing OF repairs at the selected sites.

In this study Social re-integration referred to the assimilation of the women back into their communities after they had undergone successful OF repair. While the norm would be to think that evidence of re-integration would be seen in the return of these women to economically productive ways of earning a living, conversations held with these women showed that successful surgery alone was not sufficient to reintegrate them back into their communities as prior to the surgery they had undergone psychological trauma due to stigma and isolation thus counseling of both the women and the community was an integral part of the re-integration process. The study adopted quantitative methods using a prepared questionnaire to collect quantitative data. This was complimented by qualitative data collected through in depth interviews (IDI), case narratives and key informant interviews (KII). The respondents included women booked to undergo OF repairs as new cases and those reporting for follow up, having undergone successful OF surgical repairs. Health care providers were interviewed as key informants.

The major findings reveal that more than three quarters (79.7%) of the participants lived in rural residence. More than half of the participants (58.8%) lived with their spouses. Only (35%) of women living with spouses reported engaging in regular sexual relations (15%) of whom reported experiencing difficulties having sex. Only a small proportion (3.1%) had not had any sex since fistula development.

Some of the spouses were reportedly unable to accommodate sexual denial and resorted to clandestine extra-marital relationships or acquired concubines.

The study held interactive discussions with women undergoing obstetrical fistula surgical repairs in selected institutions under AMREF fistula repair initiative. The study established the OF survivors' expectations, challenges and levels of successful re-integration back into the community after successful surgical repairs. The study undertook a systematic social analysis of the survivors after successful obstetric fistula repairs, assessing reported impact of the surgical repairs in facilitating re-integration into the family and community social life. The findings show the importance of timely interventions, using community structures for education and social re-integration after successful obstetric repairs.

The study concludes that social re-integration meant different things to different individuals at diverse levels. For some resumption of normal reproductive functions, thriving in socio-economic ventures or being reaccepted in religious and other social activities was full re-integration. The study recommends that OF management should not isolate surgical repairs from overall social and physical environment of beneficiaries. Involvement of male spouses, parents and other close relatives, for instance, recognizes them as final decision makers and impacts on successful OF management. Information education communication on OF prevention and management should be extended to younger women and girls in institutions of learning. Affirmative action should be put in place to ensure women are empowered to seek competent maternal and delivery services to avoid the risk of developing fistula. Medical personnel could team up with professionally trained counselors, specialized in handling fistula clients and their families, to complement social re-integration back into society.

#### CHAPTER 1: INTRODUCTION

#### 1.1. Definition of Obstetric Fistula (OF)

The word *fistula* is of Latin origin and refers to a tube, pipe, reed, cane or ulcer. (The American Dictionary, 2010).

Medically Fistula is defined as a hole or abnormal connection occurring between the vagina and the bladder or the rectum resulting in constant leakage of urine or faeces or both (Wall et al, 2005).

The development of OF is directly linked to obstructed labor which is one of the major causes of maternal mortality. This is labour where the mother's pelvis is too small to enable the baby to be delivered without skilled help. Obstructed labour can last many days and more often than not results in the death of both the mother and the baby. In cases where the mother survives, she will probably develop a fistula and it is likely that her baby will be dead. Access to skilled maternal care can help predict, identify and treat such labour (WHO, 2005)

Each year all over the world more than half a million healthy young women die from complications of pregnancy and childbirth. Virtually all such deaths occur in developing countries (WHO, 2003). The World Health Organization estimates that worldwide, over 300 million women currently suffer from short- or long-term complications arising from pregnancy or childbirth, with around 20 million new cases arising every year (WHO, 2005)

Fistula can be caused by disease, medical treatment or trauma as in case of severe sexual abuse or rape. Disease- related fistulas include inflammatory bowel diseases, such as Cohn's disease which affects the digestive system and may occur in any part of the gastrointestinal tract from the mouth through to the anus. Ulcerative colitis is another inflammatory bowel disease that affects the large intestine and manifests with ulcers or open sores. Complications resulting in medical or surgical operations such as gallbladder surgery may lead to bile leaking from the bile duct, thus causing biliary fistula. Radiation therapy can also lead to vesico-vaginal fistula. Fistulas can also be caused by serious injuries in various parts of the body, for instance, trauma of forceful sex or rape, prolonged obstructed labor can also lead to either (VVF) or (RVF) or a combination of both. Pressure exerted by the foetal head lodged in the birth

canal for a long time and compressing against the bladder or the rectum during obstructed labour, leads to interruption of the blood flow to nearby tissues thus causing tissue damage. The damaged or dead tissue eventually falls off creating holes that leak urine or faecal matter uncontrollably (UNFPA 2005).

According to WHO (2003) ninety percent (90%) of obstetric fistulas in developing countries are caused by obstructed labour. During prolonged/obstructed labour, the soft tissue of the vagina is trapped between the foetal head and the bony pelvis. If the compression is not relieved, the tissue will eventually die. Usually between 3 to 10 days postpartum, this dead tissue falls off and a fistula develops between the bladder and the vagina (vesico-vaginal) or the rectum and the vagina (recto-vaginal) (WHO,2005). Recto-vaginal fistulas occur far less frequently, comprising 10% of fistulas. (Mabeya 2003). Some of the contributing factors include, absence of skilled attendance during delivery; lack of emergency obstetric care and transportation to maternity facilities; young girls whose pelvis are underdeveloped to engage in child bearing activities are predisposed to early sexual debut, thus perpetuating the vicious cycle. This implies that OF development is largely due to the interplay between biological, cultural, social and economic factors of the affected women. This multi-factorial interaction predisposes young women to the vagaries of untimely marriage and early engagement in child bearing in an environment of limited resources including poor access to maternal healthcare. The situation is further compounded by community's lack of correct information about the causes of VVF and the survivors' unawareness or inability to use reconstructive surgery services to get the damages contribute to fistula development repaired. Other factors associated with OF include chronic malnutrition and inadequate or total lack of relevant information. The possibility of socio-cultural interference with the female genitalia, as in case of severe types of female genital cut (popularly known as female genital mutilation (FGM), has yet to be adequately explored to determine its contribution to vulnerability to VVF development.

According to WHO, obstetric fistula is" the single most dramatic aftermath of neglected childbirth" (WHO 2000). The risk of either or both maternal and neonatal mortality exist. While in many cases the mother survives the ordeal, she suffers extensive tissue damage thereafter that sometimes renders her incontinent, resulting in a double socio-biological tragedy. This includes friction in marital relations, social rejection and loss of self esteem due to feacal matter leaking into the urinary system. Other inconveniencies include persistent urinary infections, poor or absence of intimate marital interactions and quite frequently curtailed consecutive reproductive activities. Despite these devastating consequences

VVF has for many years not received its fair share of resources and attention as a priority maternal health agenda. In the developing world the problem is further compounded by general poverty, poor access to health services, inadequate knowledge of cause, unawareness of repair services and social stigma.

Development of Obstetric fistula is preventable through delivery under health professionals. Surgical repairs have had successful results among many clients. In Kenya the Second National Sector Strategic Plan aims at taking essential package for health to the community, through Community Health Strategy (MOH, June 2006). Gender imbalances among women from poor socio-environmental background must be addressed to ensure women take active roles in improving their obstetric health through preventing obstetric health problems. Improved community based health education and communication would go a long way in this endeavour.

The health provider could learn from untapped wealth of indigenous knowledge found in metaphors, relevant in health education. An elderly Taita woman stated... "The sun should not rise or set twice on a labouring woman." Personal communication (September 2006). This implies community awareness of the dangers of prolonged labour. Similar indigenous knowledge exists in many communities and used well, these could set the stage for information education and communication promotion on OF. In the interactive participation in FGD and KII the investigator probed for such indigenous knowledge and practices.

# **CHAPTER 2: LITERATURE REVIEW**

It is expected that pregnancy and childbirth should be a joyous time in the life of a woman and her family. However, these activities continue to prove tragic for women, a majority of whom live in Sub-Saharan Africa. A report on a meeting held to explore approaches for Safe Motherhood records that of the 135 million women who give birth globally each year, an estimated 5% or close to 7 million will experience prolonged or obstructed labour (UNFPA, 2005). In support WHO states that of the 7 million women experiencing obstructed labour each year, about 50,000 will die (0.7% case fatality rate) and another 50,000–100,000 women will develop fistula. Currently, it is estimated that more than 2 million women in the world live with fistula and its consequences. In the industrialized countries birth related fistula cases were eradicated in the in the mid-20<sup>th</sup> century, yet the ravages of obstructed labour continue unabated in the Sub-Saharan Africa (SSA) and South Asia (WHO 2003). According to Lewis Wall (2006) fistulas found in the industrialized countries are caused by radiation therapy for malignant disease or through accidental surgical injury to the bladder during hysterectomy. (The Lancet, Sep 2006)

#### 2.1 Historical evidence of Obstetric Fistula

The earliest documented evidence of the existence of VVF was recorded in 1909 after an anatomical review of the mummy of Queen Hennit by the Metropolitan Museum of Art in Cairo (Zacharin 1988). The queen lived in Egypt around 250BC. The review revealed severe damage to her bladder and vesicovaginal fistula which may have occurred during childbirth. This could have resulted in her death.

A Persian physician, Avicenna, made the first linking of VVF with obstructed labour in the 11th century. He noted, "In cases where women are married too young, and in patients with weak bladders, the physician should instruct the patient in ways of prevention of pregnancy. In these patients the fetus may cause a tear in the bladder resulting in incontinence of urine. The condition is incurable and remains so until death".

A Dutch physician, Hendricks Van Roonhuyse in the nineteenth century, gave a clear description of the VVF and indicated the possibility of repairs through stitching using swans' quill. However, the first claim of successful closing of a VVF with wire sutures was conducted by Dr. John Peter Mettauer of

Virginia in 1838, via a letter he wrote to the *Boston Medical and Surgical Journal* confirming the relationship between obstructed labor and vesico-vaginal fistulas. Dr. J. Marion Sims recognized as "the father of gynecology" has made significant improvements to the surgical procedures used in the repair of fistula and these are still used as the standard procedures today. Before the mid 19<sup>th</sup> century, many physicians were reluctant to treat female patients, until Dr. Sims recognized the need for specialized medical and surgical attention and opened the first fistula hospital in 1838, this expanded fast and by May 1857 it was moved to Park Avenue where there was bigger space. Currently this is the site hosting the prestigious Waldorf Astoria Hotel in New York City. Dr. Sims and colleagues continued to improve obstetric care thus reducing significantly the problems associated with obstructed labour and VVF in the developed world.

The situation is totally different in the developing world, specifically SSA in the 21<sup>st</sup> century, where the ravages of obstructed labour continue to cause perpetual misery to thousands of women. An Australian gynecologist specialist's couple, Catherine and Reginald Hamlin, traveled to Ethiopia to start a midwifery training school in Addis Ababa in 1959. They came face to face with the tragedy facing mothers during childbirth and shifted their focus from training to the treatment of women with obstructed labour and obstetric fistulas and they summarized their experiences as follows: ... "The high Ethiopian mountains make it one of the most spectacularly beautiful country in the world; but mothers who live in such remote areas, cut off from access to medical help, must, when childbirth becomes difficult, endure the torture of unrelieved obstructed labor. Those who survive find themselves afflicted with the most appalling damage and mourning the still-birth of their only child ...ashamed of a tragic injury suffered in their first, only experience of childbirth."

The exposure of the Hamlin's to the plight of women made it possible to open a second fistula hospital in Ethiopia in May, 1975. To date the hospital operates about 700 -1200 patients per year and it is estimated that the Hamlin's have treated more than 15,000 women since first opening the fistula hospital. This implies the journey is still long before VVF is eradicated in SSA.

### 2.2 Types and major causes of Obstetric Fistula

Fistulas are defined according to where they occur. There are five types of obstetric fistula namely: Vesicovaginal (VVF) fistula which is a fistula that occurs between the bladder and vagina, Rectovaginal fistula (RVF): which occurs between the rectum and vagina, Urethrovaginal fistula occurs between the urethra and the vagina, Ureterovaginal fistula occurs between the distal ureter and vagina and Vesicouterine fistula which occurs between the uterus and the bladder (ECSA-HC, 2012).

According to Worldwide Fistula Fund, obstructed and prolonged labour during childbirth is rated among the most common cause of fistula. In a small portion of births difficult labour might cause the perineum to tear or an episiotomy might tear more than was intended, thus causing holes in the pelvic area. (Worldwide Fistula Fund, 2006). Some surgical procedures can unintentionally create a fistula between the vagina and the rectum, the bladder. Other injuries can occur to arteries and veins and even the stomach and the skin. Cohn's Disease, which is a chronic disorder that causes inflammation of the digestive or gastrointestinal (GI) tract, can also be a potential cause of fistulas. This inflammation can occur in any area of the GIT from the mouth to the anus, it most commonly affects the small intestine and/or colon.

Cohn's disease causes inflammation of the bowel and can lead to a weak spot in the wall which could result in fistulas between the rectum and the vagina or within the intestines themselves, requiring surgical repair. However, any inflammatory disease has the potential to cause a fistula in numerous parts of the body. Cohn's disease is sometimes confused with ulcerative colitis because the symptoms of the two diseases are very similar. Both diseases are an indication of an abnormal response by the body's immune system. The immune system is meant to protect the body against infection but in this case it mistakes microbes, such as bacteria that is normally found in the intestines, for foreign or invading substances, and launches an attack resulting in the body sending white blood cells into the lining of the intestines, where they produce chronic inflammation resulting in ulcerations and bowel injury. These two diseases belong to a larger group of illnesses called inflammatory bowel disease (IBD) (Cohn's and Colitis Foundation of America, 2009). Some form of infections can lead to tissue death when left untreated. It is plausible that the presence of bacteria or fungi can wear away tissue, leaving one organ exposed to another organ. Areas that are especially susceptible to fistulas caused by infection include the rectum, vagina, intestines, neck and sinuses.

Obstetric fistula is predominantly caused by long or obstructed labour lasting several days, before the woman receives obstetric care. Under efficient obstetric care a caesarean section would safe both the mother and baby. Sexual abuse and rape causing injury could also causes fistula. Several complications of unsafe abortions, surgical trauma such as the type that causes injury to the bladder, may also result in fistula.

Malignant diseases such cervical cancers, in situations of low socio-economic status and poor access to basic medical care, such as screening for cervical cancer, are increasingly becoming common. Women have little or no access to screening for cervical and as the cervical cancer grows, it may spread into the vagina and bladder, causing a fistula. Tumors can lead to a breakdown of the tissue between organs and other structures.

Radiation treatment can weaken the tissue between the two areas, causing a fistula to develop later. Usually, a fistula caused by radiation treatment will only be diagnosed after two years following treatment. (www.ehow.com)

# 2.3: Factors associated with Vulnerability to OF development

Vulnerability can be defined as the state of being susceptible to physical or emotional injury or attack. In reference to OF there are several factors that can pre-dispose a woman susceptible to getting OF. Some of these vulnerability factors may be caused by a certain belief system or culture, bio-physical, gender based socio-economic status, demographic and vulnerability due to trauma or violence.

### 2.3.1: Vulnerability due to Gender Factors

Gender-based factors emerge due to the marginalized status of women in the community. Women often show inability to make decisions to access to obstetric care. In some situations girls are forced to undergo some harmful cultural practices such as FGM. Sometimes women may not have the right to make any decisions even those pertaining to their very existence and when faced with a situation of seeking health care in pregnancy, or even after prolonged labour, the husband or other family members make such decisions.

#### 2.3.2: Vulnerability due to Cultural Behaviour

Different cultures have belief systems harmful to the obstetric health. Some of these may facilitate an increase in development of fistula. For instance, in Malawi (be specific)a woman who develops prolonged labour is accused of having had extra-marital sexual partners, and she is required to shout their names in order for the baby to be 'released' through the birth canal (UNFPA 2002). The husband is also required to name his secret sexual partners. This practice could also discourage delivery at the health facilities for fear that a woman who seeks institutional assistance at delivery anticipated difficult labour due to her own or her husband's past infidelity. The very behaviour leads to labeling and a verdict of "guilty" Similarly in some parts of Nigeria women choose to give birth in churches, although the care they would receive at the church would be unskilled, they believe that being in church protects them from 'spiritual attacks by evil forces or witchcraft enacted by jealous neighbors (UNFPA, 2002).

Closer home in Uganda, the same study reveals that about 60% of the women living in the rural areas deliver their babies at home as they believe that 'one is not a real woman unless she can push out the baby on her own.' Among the Duruma people of Kwale district along the Kenyan coast, a woman has no role in deciding when and where to seek assistance during child delivery. This is the prerogative of male head of the household, irrespective of the progress of labour (Kimani 1995). Such beliefs and behaviour are important determinants of health seeking behaviour for maternal services.

#### 2.3.3: Vulnerability due to demographic factors

A study conducted in West Pokot by Mabeya in 2003 found that prolonged labour was a major causative factor of obstetric fistula. The majority of fistulas in West Pokot were seen to occur in women aged 20 years and below. The majority of fistula incidents occurred in women delivering their first child. These were also women who had no formal education or had attained primary education at the lowest level and had no specific occupation.

Early sexual debut may cause coital injury to the young girl penetrated by an adult man. Such injuries are apparently easier to repair than childbirth related injuries. In some traditional communities girls are married off as early as age ten years, and get pregnant as soon as menarche sets in. In Ethiopia and Nigeria over 25% of fistula patients had become pregnant before the age of 15, and over 50% had

become pregnant before the age of 18 (UNFPA 2002). This is further compounded by extreme poverty and consequent malnutrition resulting in stunting.

#### 2.3.4: Poverty and Socio-economic Status

Improved access to and use of efficient obstetric care is an important step towards preventing occurrence of obstetric fistula (UNFPA, 2002). UNFPA and UNICEF assessments of basic and comprehensive emergency obstetric care in a number of African countries found inadequate facilities for basic emergency obstetric care. In the extreme situation there was one comprehensive emergency obstetric facility per 500 000 inhabitants. The cost of the costs of an emergency caesarean section was crippling to some of the families. The study established that in rural Tanzania the estimated average cost of an emergency caesarean was approximately US\$135, compared to the average family annual income of US\$115 (UNFPA 2002). A combination of poor access, poverty, lack of awareness and low levels of education are underlying causative factors of obstetric fistula. Women who suffer from this condition tend to be impoverished, malnourished, lacking basic education and living in "hard to reach" rural areas. The situation is further compounded by lack awareness that surgical repairs are possible. A study done in West Pokot revealed that about half of the women were in primegravida (55%). Fifty nine (59%) percent had no formal education and 72% had no formal occupation.

According to an article in The Ecologist (Sept, 2000) about a fifth (1.3 billion people) of the world's population live below the international poverty line of \$1/day and a further 1.6 billion (or a quarter of the world's population) survive on between one and two dollars. Despite the high number of people living below the poverty line the world population has continued to grow. The UNFPA estimates that in the period 2005-2010 the population increase by 2.3 from a figure of 6.8 billion in 2008 thus total increase will be 9.1 billion people in 2050 with nearly all of that increase coming from among the poorest populations in the least developing countries. The same article states that in 56 developing countries a fifth of the poorest women will still have six births compared to those in the developed world that have on average 3.2 births. It is also in these developing countries that there a high number of reproductive issues many relating to pregnancy and childbirth. A vicious circle exists between poverty and treatment seeking as the former limits chances of obtaining competent preventive and treatment services. Being poor not only limit the choice and utilization of available health services, but also dehumanize the person. The situation is farther complicated by gender issues that limit women from control of household

resources even though women contribute to generating the income. Way back in 1999 a key note speech on gender inequality and economy revealed that a majority of the poorest of the poor households were female headed (Professional Women's League of Kwa Zulu, Natal, 1999).

#### 2.3.5: Violence and trauma

Violent rape especially that occurring in time of war is gender oriented. The WWFF describes cases in Sierra Leone where soldiers raped women then inserted assault weapons into their vagina and fired. The new Fistula Medical Centre in Sierra Leone treats many women with VVF resulting from serial rape that occurred during that country's Civil War. Rape also results in sexually transmitted infections, including HIV. According to worldwide fistula fund tissue destruction diseases such as lymphogranuloma venereal can be particularly virulent, eating into the genital tissues and causing fistulas which are generally irreparable.

Some fistula cases develop from direct tearing caused by rape or other forms of vaginal trauma. A study conducted at the Addis Ababa Fistula Hospital, which treats about 1,200 fistula cases per year, found that over a six-year period, 91 fistula cases were caused by rape or sexual abuse within marriage. Estimating the prevalence of fistula caused by sexual abuse may be a tall order as many victims do not seek treatment, often fearing stigmatization or lacking access to health care.

The extent and severity of trauma to survivors of rape in times of armed conflict continues to vary. For instance, vaginal destruction is considered a war crime in the Democratic Republic of Congo. Due to internal conflicts, increased gang rapes, use of guns, branches and broken bottles inserted into women, girls and men, for purposes of violating the victim, were on the increase. Among the women these culminate in vaginal fistulae (Women's Commission 2006). A survey of survivors of rape in South Kivu region of DRC revealed that (91%) of the women had suffered from one or more rape-related illnesses (Women's Commission 2006).

In Kenya the 2007/2008 post-election violence subjected women living in low income areas to violent gang rape, for some resulting in OF and other severe damages. According to the United Nations office for the coordination of humanitarian affairs, rape reporting increased markedly during this period. British Broadcasting Corporation (BBC) reported that cases of rape had more than doubled. Half of the victims were reportedly below the age of 18 years (Women's Commission 2008). In an attempt to suppress a

local rebellion in Shah State since the 1990s Burmese government used rape as a weapon of war (Women's Commission 2006). Additionally displaced Sudanese men and women continue to report abduction and widespread rape in Darfur (Women's Commission 2006).

#### 2.3.6: Socio-cultural perceptions of cause

Some societal belief systems are harmful to women's obstetric health and may contribute to increase in development of obstetric fistula. The Hausa of Niger and northern Nigeria believe that there must be an appropriate body balance between sweet and sour, bitter and salty substances. Obstructed labour is attributed to an imbalance in the woman's body resulting from "too much salt or *gishiri* that produces a membrane over the vagina inhibiting the baby from coming out." In order to treat this condition the vagina is cut with a sharp instrument such as razor, knife, and others objects, sometimes inadvertently, causing injuries to the urethra, bladder or rectum that result in OF. The same procedure may also be done for a variety of other perceived "women's problems," with similarly disastrous results.

In many communities childbirth is followed by ritual cleansing believed to "cleanse and restore" the woman's vagina for intercourse. Some communities do this by packing the vagina with salts which end up producing a severe chemical reaction such as shrinking and stricture formation. Sometimes the materials used are so caustic that vagina tissues are destroyed and a fistula develops. These cultural practices are intertwined with poverty and low education levels. Substantial changes in the world socioeconomic order and education communication could contribute to the reduction or eradication of these tragedies.

#### 2.3.7: Harmful Traditional Practices

Female genital cut remains a common practice among many societies. An extract from an article in the New England Journal of Medicine reports that 26 countries in Africa practice the female cut today, with prevalence rates ranging from 5% to 99% (Nihad Tourbia, Sept 1994). Public health experts consider the female genital cut causes more damage to women. There are various types of female cut, such as clitoridectomy, anatomically equivalent to amputation of the penis. (Nihad Toubia 1994). Infibulations involve surgical cut and closure of the labia majora (outer lips of the vulva) by sewing them together to partially seal the vagina, leaving only a small hole for the passage of menstrual blood.

All types of circumcision may result in complications, such as hemorrhage, severe pain ultimately leading to shock and death. Prolonged less severe bleeding may lead to severe anaemia and can affect the growth of a poorly nourished girl child. In poor hygiene the wound can get infected resulting in abscesses, ulcers, delayed healing, septicemia, tetanus, and even gangrene. Some forms of female cut interfere with the normal drainage of urine and menstrual blood; this could result in chronic pelvic infection, dysmenorrheal, back pain and infertility. Long-term complications are associated more often with infibulations than with clitoridectomy alone, because of interference with the drainage of urine and menstrual blood. Chronic pelvic infection causes pelvic and back pain, dysmenorrheal, and possibly infertility.

The legs are bound together for approximately two weeks to allow the labia to heal into a barrier. This procedure is usually performed at the same time as removal of the clitoris. The barrier produced by infibulations is meant to be penetrated at the time of a girl's marriage forcibly by the husband. This is meant to give him the sensation that his wife is a virgin. According to the United Nations' *End Fistula Campaign*, this particular form of female genital cutting results in organ damage, urinary incontinence, and obstetric fistula. (UNFPA 2005)

Young women are abandoned when obstetric fistula occurs. For instance, the UNFPA study established that 53% of women with obstetric fistula in a hospital in Addis Ababa had been abandoned by their husbands and one in every 6 women said that they had to beg for food to survive (UNFPA 2002). In India and Pakistan some 70% to about 90% of women who had developed fistulas had been abandoned or ultimately divorced (UNFPA 2002). It is therefore not surprising that some women who develop fistula may find it too difficult to cope and resort to suicide

The study in West Pokot Mabeya found the affected women (80%) had also undergo the severe form of female genital cut, specifically infibulations (Mabeya 2003). While some argue that there is no clear evidence that FGM is a direct cause of obstetric fistula the practices involves removing large amounts of vaginal or vulvae tissue, thus causing the vaginal outlet and birth canal to become constricted by thick scar tissue. The practices may increase the likelihood of gynecological and obstetric complications, including prolonged labour and fistula. In this study in West Pokot, Mabeya found that (56%) percent of women with fistula were still married at time of admission.

#### 2.4: Other Causes of Obstetric Fistula

The interplay between biophysical, social-cultural and economic factors is the root cause of obstetric fistula. This multi-factorial interaction predisposes young women to early sexual debut, either in or outside marriage before they attain full pelvic development. Early engagement in child bearing in an environment of limited resources and poor awareness and virtually no access to quality maternal health care exacerbates the predicament. This unhealthy combination requires combined action.

#### 2.4.1: Poor access to skilled birth attendants

Fistula was once a common occurrence in the Western countries but it was eradicated towards the end of the 19<sup>th</sup> century. This was possible because problems related to labour can be anticipated during antenatal care and a difficult labour can be avoided through a caesarean section. In developing countries large numbers of women continue to develop fistula due to inaccessible or simply absence of antenatal care for the vulnerable women. Improved access to and use of efficient obstetric care is an important step towards preventing occurrence of obstetric fistula (UNFPA, 2002).

According to the KDHS survey, a large proportion (56%) of women continues to deliver at home while only 44% deliver with skilled attendant (KDHS 2008/09). Delivery under unskilled midwives continues to expose the women to the risk of developing OF, since these midwives are neither skilled nor equipped to provide EmCO care. Regular monitoring of pregnant women during antenatal care followed by delivery under skilled attendance would reduce maternal and infant mortality greatly. Skilled birth attendant would be a position to monitor the progress of labour and take decisions to transfer the mother to a higher level to avert impending complications. Access to maternal health services differ even one country. A study on the coverage of basic emergency obstetric care (EmOC) services showed the ranking of 0—1.1/500,000 population compared to the UN-recommended level of 4/500,000. Countries with the highest coverage of EmOC was Rwanda (4.3/500,000), followed by the /north eastern Province (NEP) in Kenya (1.6), Uganda (1.2), and Southern Sudan (<1). Despite this however, there was a huge gap in the coverage of basic EmOC services as most of the health centers could not perform assisted vaginal delivery and removal of retained products (Pearson & Shoo, 2004).

### 2.5: Factors Contributing to OF in Kenya

In order to describe the current successful obstetric fistula repairs in Kenya, it is important to establish the perceptions of successful treatment by women who have undergone the treatment, and whether or not successful fistula repair is seen to re-instills the lost social status and facilitate re-integration to full social and family life.

An analytical framework by Thaddeus and Maine states that the underlying causes of MM in home-based deliveries can be classified under the "three delays" model; i) delay in deciding to seek medical care; ii) delay in reaching appropriate care; iii) delayed care delivery at health facility (Thaddeus and Maine 1994)

## 2.5.1 Delay in deciding to seek medical care

This delay is sometimes due to unskilled birth attendant's failure to recognize danger signs. The family may also be reluctant to take the woman with prolonged labour to a health facility following financial and cultural constraints, not to rule out general lack of awareness of the seriousness of consequences of unattended prolonged labour. Data obtained from a UNFPA & DRH study conducted in four districts in Kenya indicates that the majority of the women who have prolonged labour only realized that there was a problem 21 hours after the onset of labour (UNFPA, 2004).

#### 2.5.2 Delay in reaching appropriate care

Poor access to a health facility due to underdeveloped infrastructure, lack of appropriate means of transport or a lack of awareness of existing services also contribute to delays in seeking appropriate services. In the DRH and UNFPA study in Taita Taveta district, a man commented... "Sometimes a woman is about 20 km away from hospital. Since there are no vehicles, you have to carry the woman on your back or sometimes we use sacks to make a stretcher". Male FGD Taita Taveta (UNFPA 2004)

#### 2.5.3 Delayed care at delivery in health facilities

This refers to problems within the referral facility. When women with OF manage to reach a health facility they sometimes encounter negative attitudes from the health personnel, admission logistics, lack of trained personnel to handle their cases, inadequate equipment, emergency medicines or blood.

The study quoted above showed that women received care 5-11 hours after arriving in the health facility.

## 2.6 Organizations involved in OF Repairs

While fistula is a preventable and treatable condition many women are unaware of the existence of fistula treatment or where such services could be accessed. A number of hospitals specialize in fistula repair. These include Ethiopia, Nigeria, Pakistan, Sudan, Tanzania and Kenya.

Narratives from such beneficiaries would shed a light towards social re-integration in their respective communities. It has been established that women who develop fistula often delay presenting themselves for treatment, in some cases for months or years, thus reducing chances of successful fistula repair. Waaldijik (1993) advocated for early surgical intervention in VVF occurring from obstructed labour. The reasons for such delays could be traced to both the socio-cultural and physical environment of the woman.

### 2.6.1. Ministry of Health

Kenya Ministry of Health has been in the frontline in the improvement of safe motherhood initiative, including fight against OF. Many district hospitals in Kenya have the potential to conduct OF repairs though it is rarely done; perhaps due to shortage of gynecologists with expertise in obstetric fistula repair. In 2003/04 the Ministry of Health through DRH/UNFPA conducted a rapid needs assessment of the status of OF in selected districts, namely, Kwale, Mwingi, West Pokot and Homa Bay, spanning across four provinces, that is, Coast, Eastern, Rift Valley and Nyanza, respectively. The study applied a combination of qualitative and quantitative methods to gather the information and later produced a report in 2004. The study recommended expanding cadres of service providers to include Medical Officers of health, rather than perceiving this as a preserve for specialist Obstetricians Gynaecologists. A curriculum was developed to train these additional cadres. Other interventions through UNFPA include scaling up interventions such as renovating operating theatres, providing surgical repair equipment, installation of

radio equipment to ease communication, in Mwingi and Kwale districts, provision of ambulances for referral and the training of health care providers in the management/repair of obstetric fistula in Machakos district hospital, Nyanza and Coast Provincial General Hospitals and Moi Teaching Hospital in Eldoret.

Among various local and international NGOs' involved in OF studies and interventions, AMREF in collaboration with Kenyatta National Hospital (KNH) has taken a lead role in conducting VVF surgical repairs in selected regions in the country. Every year AMREF holds free medical camps for women requiring OF repairs. Jamaa Hospital in Nairobi provides treatment and care for OF with funding from the Safaricom Telephone Network, MSF – Spain and other smaller donations. Kenyatta National Hospital, Moi Teaching Hospital in Eldoret and Machakos Hospital in Eastern Province serve as Centres of Excellence and provide training for fistula repair teams (a mixed skill team of doctors, nurses and other medical support staff).

### 2.6.2 AMREF – role in Fistula management

Since it was founded in 1957, AMREF has been in reconstructive surgery through the initiative of three surgeons, namely, Michael Wood, Archibald McIndoe and Tom Rees. AMREF decided to take surgical services to remote regions in East Africa through air-based medical service to communities in remote areas in Kajiado and Narok districts. Over the years that followed AMREF has expanded outreach medical services to include mobile clinical and maternal child/health (MCH) services in addition to offering community-based health care (CBHC) and training community health workers on how to deliver primary health care. By 1980s that there was a move to community health development and collaboration with the ministries of health in the region and cooperation with international aid agencies was enhanced. This led to the establishment of a unique year-long training course in community health in the early 1990s as well as an expansion of disease control initiatives, focusing on malaria, HIV/AIDS and TB. AMREF has highlighted the fact that a number of Africans still have limited access to sufficient and quality health care. In light of this the focus in its 10 year strategic plan aims to find ways of linking health services to the people by 'making tailor made responses to meet specific community needs'.

In 1992 AMREF surgeons started repairing VVF through the Surgical and Specialist Outreach Programs. The first of the two VVF-projects is in Tanzania and was started in October 2000 through funding from the Royal Netherlands Embassy in Dar es Salaam. The second VVF-project that is active in Kenya,

Uganda and Southern Sudan, was started in May 2002 through funding from the Bill and Melinda Gates Foundation through the Averting Maternal Death and Disability (AMDD) program of Columbia University, and presently by AMREF Germany, AMREF USA, the Australian High Commission of Kenya, the Flying Doctor Society of Africa and Danida.

In the recent years AMREF flying doctors in collaboration with visiting volunteer doctors has continued to provide surgical treatment for OF survivors in collaboration with health institutions such as Kenyatta National Hospital, Machakos and Makueni district hospitals, Moi Teaching and Referral Hospital and Kisii Level Five district hospital, where regular surgical repairs camps are hosted at specific dates annually. In September 2008 gynaecologists from all over the country undertook training in fistula repairs at the Kenyatta National hospital and they have since participated in these annual events.

AMREF seeks to promote reproductive rights by helping women to make informed choices about family planning and promoting access to reproductive health services, family planning and management of pregnancy related complications, and obstetric care, including, regular fistula repair clinics in various parts of the country. Some of these sites include, Kitui and Kisii districts, Garissa, Mutomo, Mumias, Ortum and Nyanza, among many others.

### 2.6.3 Key Campaigners involved in Fighting Fistula

A global campaign towards international effort to address the problem of obstetric fistula in 2003 by UNFPA and her partners has expanded to more than 30 countries in sub-Saharan Africa, South Asia and the Arab states (UNFPA 2003). Campaign to End (FistulaFistulaNetwork.org) is a technical, information sharing site for partners working in fistula prevention, treatment and social re-integration. This site provides a forum for the exchange of technical resources, current and planned research, and new ideas.

#### 2.6. 3.1. The Worldwide Fistula Fund

The Worldwide Fistula Fund is an Illinois-based NGO supporting international medical education and research on OF trauma in the developing world. Founded in 1995 by Dr. Lewis Wall it was originally known as "The Worldwide Fund for Mothers Injured in Childbirth", until 2003 when it begun to operate under its current name. Dr. Wall is currently the President, and Managing Director of the Worldwide Fistula Fund.

The goals of the Worldwide Fistula Fund are:

- 1. To support the repair of obstetric fistulas at multiple surgical centres throughout Africa and other parts of the developing world where the problem is greatest.
- 2. To improve access to curative surgical services for patients who have developed vesico-vaginal fistulas and to ensure that knowledge of fistula repair becomes part of the routine training of African obstetrician-gynaecologists, urologists, and general surgeons;
- 3. To improve the surgical techniques used in dealing with routine fistula cases and to develop new techniques for treating patients with complicated fistulas and the problems associated with them;
- 4. To understand the social background of patients who develop vesico-vaginal fistulas and the cultural practices which permit the development of this condition;
- 5. To develop educational programs for vesico-vaginal fistula patients who are waiting to undergo surgical repair and for those recovering after surgery including (teach them to read or improve literacy; teach them skills that will facilitate earning a livelihood once they have been rehabilitated and facilitate their re-integration back into their society).
- 6. To develop education programs to improve traditional midwifery practices and change the beliefs that have promoted the development of vesico-vaginal fistulas in the past as part of an on-going grass-roots movement to aid the empowerment of African women regarding childbirth.

### 2.6.3.2. The United Nations Population Fund (UNFPA)

The UNFPA slogan is "because everyone counts" it is their mission is to promote the right of every woman, man and child to enjoy a life of health and equal opportunity. Working internationally the UNFPA uses population data for policies and programmes to reduce poverty and to ensure that every pregnancy is planned for and every birth is safe and that our youth are free of HIV/AIDS. Ultimately UNFPA wants to ensure that every girl and woman is treated with dignity and respect. They do this through an initiative called "Making motherhood Safer." This initiative aims at preventing maternal deaths through a three pronged approach: i)use of family planning so as to reduce unwanted pregnancies; ii) ensuring the presence of skilled care at all births; iii) ensuring timely emergency care for all women who develop complications during childbirth. UNFPA leads the global "Campaign to End Fistula", a collaborative initiative to prevent fistulae during childbirth and restore the health and dignity of those affected by fistula.

#### 2.6.3.3. United Nations Foundation (UNF)

This foundation was formed in 1988 through a historic gift of 1 billion dollars from entrepreneur and philanthropist, Ted Turner's, to act as an advocate for the UN and a platform for connecting people, ideas and resources to help the United Nations solve global problems. The foundation helps the UN take its best work and ideas to scale—through advocacy, partnerships, constituency building and fund-raising. Working closely with the UNFPA and grassroots organizations to end fistula in this generation, the foundation spearheaded the formation of the Adolescent Girls Cluster of faith and community leaders, international organizations and provided a grant that helped create an NGO called One by One that advocates for fistula awareness on the grassroots level. In 2007 the foundation hosted fistula surgeons from Kenya and the DRC including a Kenyan fistula survivor (Sarah Omega Kidangasi), for events in Washington D.C and New York.

A remarkable point to note is that the foundation supported a Capitol Hill film screening and reception for a 2009 Emmy award winning documentary titled *A Walk to Beautiful. This is a* documentary film that follows several young Ethiopian women as they attempt to have their fistula repaired.

### 2.6.3.4. Engender Health

This is an NGO that has been around for over 65 years and focuses mainly on improving the lives of men, women and families through family planning, maternal health, HIV and AIDS and gender equity. In Kenya, Engender Health begun its work in 1982 and focuses on maternal health care, HIV prevention and child survival initiatives, in addition to training doctors on client-centered surgical sterilization methods and counselling. In Benin, Engender Health focuses mainly on obstetric fistula through a project called "Fistula Care Project" in collaboration with the Mercy Ships International (floating hospitals mounted on ships) Engender Health provides fistula repair to women who have been referred to them through local NGOs and also engage in providing training for fistula surgeons around the world. The Mercy Ships provide free corrective surgery for obstetric fistula patients onboard the Africa Mercy as well as at a dedicated fistula centre in Sierra Leone where Mercy Ships works in partnership with another organization. When a patient is discharged there is a time of great rejoicing and each woman is given a gift of a new dress in her choice fabric. This signifies a new beginning, while dancing and singing reflect the change!

#### 2.6.3.5. Women's Dignity

Women's Dignity is located in Dar es Salaam, Tanzania, and works at the local, regional and international levels. Its mission is to enable marginalized girls and women to realize their basic right to health. Women's Dignity has been a firm advocate of promoting fistula as a human rights issue and it believes that girls and women have the right to live without fear of death or disability in childbirth, and to be cured of fistula when it occurs. Women's Dignity also believes that all people living in poverty have the right to affordable, accessible and high quality health care so that conditions like fistula - and others affecting the poor - cease to exist.

#### 2.6.3.6. The White Ribbon Alliance for Safe Motherhood.

This international coalition of individual and organizations was formed in 1999 to increase public awareness on the need to make pregnancy and childbirth safe for all women and children in developing countries. It also holds institutions and governments accountable for the tragedy of maternal mortality. The White ribbon has two meanings; i) on one hand it symbolizes all the women and children who have died in pregnancy and childbirth related problems, ii) and on the other it symbolizes hope and life! The White Ribbon Alliance seeks to advance women's health and women's rights everywhere by educating its members and member organizations through seminars, working groups, creating educational, communication and technical materials for use by members and others interested parties. Organizing policy efforts directed at national and local governments to increase funding and programs for Safe motherhood and finally supporting and assisting countries to create a national White Ribbon Alliance.

#### 2.6.3.7. Freedom from Fistula Foundation (3F)

The end of 2007 saw the gathering together of women whose main aim was to make a difference in the lives of the Sierra Leone women who were suffering from fistula. Under the leadership of Ann Gloag one of the co-founders of the Stagecoach transport group the Freedom from Fistula was born.

The Freedom from Fistula has projects in four African countries, namely Sierra Leone, Liberia, Kenya and most recently Malawi. In Kenya FFF has partnered with Jamaa Catholic Mission Hospital situated in Eastlands, AMREF and the Kenyatta National Hospital to finance free fistula repairs to women, who would otherwise not afford. Additionally FFF funded the renovation of an old family clinic at KNH to a state of the art fistula theatre currently known as clinic 66. At this clinic fistula repairs are conducted all

year round and a major annual event is performed annually, in the month of June with the technical assistance from AMREF. In order to reach more women with Fistula, FFF and AMREF hold joint free surgery camps in Kisumu, Kisii, Eldoret and Nairobi once a year at each site. The theme during these camps during data collection was that "VVF has a cure".

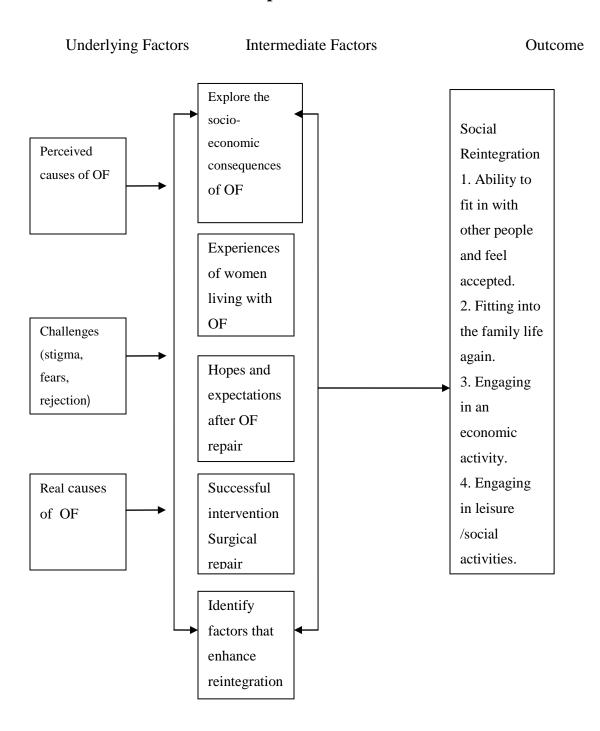
Social re-integration refers to the process of assimilation of the women back into their communities after undergoing successful OF repair. Evidence of re-integration would be seen in their resumption of economically productive ways of earning a living, as well as in the social and psychological re-integration back into the community significant achievements in improving access to OF treatment and repairs, the long-term emotional, psychological and economic support needs of these women after their initial OF repair have not received adequate attention to date.

This study attempted to establish levels of re-integration into the community after successful OF surgical repair. It has been established that many of the women who develop fistula come from poverty stricken background and are thus limited in income earning capacity (WHO 2003).

Current re-integration programs include provision of new clothes, basic literacy and crafts training and in some cases the women may receive some bus fare to facilitate their travel back home. In a two day UNFPA meeting held in Niger, Mali for example was conducting many projects aimed at reintegrating the women who have been successfully treated for OF back into society. In one project, an NGO trains fistula patients in tie and dye, weaving and other artisan crafts and then markets the items to tourists while another project provides women with micro-grants to buy animals, materials for crafts and for trading. These efforts may be good but it is important that strategies are developed so as to also provide the women with emotional, psychological and economic support they may need.

WHO notes that these interventions should be based, first and foremost, on the realities of girls and women living with the stigma attached to fistula even after surgery so they may receive meaningful return to a life of social dignity.

# 2.7 Conceptual Framework



# **Chapter 3: RESEARCH PROBLEM**

#### 3.1. Statement of the Research Problem

Existence of Obstetric Fistula highlights the failure of health systems to provide high quality maternal health care including skilled medical attendants and timely emergency obstetric care. It is also a reflection of socio-economic and gender based inequities that hinder women from accessing high quality services. Complications of pregnancy and childbirth are a leading cause of death and disability among women of reproductive age in developing countries. In addition to the more than 500,000 maternal deaths that occur annually, it is estimated that 15 - 20 million women develop disabilities as a result of pregnancy and child birth. The WHO report adds that obstetric fistula as a disability affects an estimated 2,000,000 women worldwide (WHO 1999). A survey done by UNFPA in 2003 in Kenya estimated that there are 3000 new cases per year, with approximately one to two fistula per 1,000 deliveries and only about 7.5% of women with fistula are able to access treatment (UNFPA 2003).

A study done in West Pokot indicated that the number of fistula operations performed annually during the ten years between 1992 and 2001 increased steadily from a low of 36 cases to a high of 479 cases (Mabeya 2003). The situation becomes even more paradoxical since the condition is preventable through provision of quality and accessible maternal health services and empowerment of women and communities through promotion of reproductive health, prevention and treatment of obstetric fistula.

Obstetric fistula has lately begun to generate interest in reproductive health (Njoroge et al 2005), and AMREF among other surgical teams has continued to perform surgical repairs to women affected by this condition. The repairs therefore offer a new lease of completeness to the affected women. What is unclear so far is whether or not the women regain their womanhood through experience of full social reintegrated in their own families and communities after the repairs. There is inadequate data to establish whether or not the stigma associated with obstetric fistula continues after successful OF repair.

Systematic transdisciplinary documentation of the extent and the deeper meaning of living with OF are lacking. Stigma associated with OF may continue to limit the women to a life of isolation and low self esteem for the rest of her life even after a successful surgical treatment. For instance, it has not been

established how well such women resume normal marital roles successfully. The emotional suffering might not end with a successful fistula repair.

This may remain, unknown even to her closest family and friends. From the survivors perspective specific community systems might be required in order to accelerate full recovery and embark of reintegration to social life.

## 3.2. Justification for the Study

Efforts by AMREF on OF treatment focus on physical repairs with little, if any, focus on the social impact of the repairs to the beneficiary women and community. The investigator undertook to assess the role of successful OF in facilitating social re-integration back to society. The investigator embarked on the study with the assumption that probably not all women who underwent successful OF repairs regained their lost dignity in society. It was envisaged that the study would provide information of this, otherwise neglected component of intervention activities on OF. The same information would be useful to both OF survivors and health care providers, and specifically contribute to inform policy implications at national and regional levels. This would probably pave ways for attaining Millennium Development Goals number 3 and 5, also contribute towards the achievement of vision 2030.

# 3.3. Overall study Aim/Objective

The overall objective of this study was to establish social re-integration of the women back into the community after undergoing successful obstetric fistula repairs at the three AMREF intervention sites, namely New Nyanza General hospital, Kisumu; Kisii Level Five Hospital in South Nyanza and Kenyatta National Hospital (KNH), Nairobi.

# 3.4. Specific Objectives

These were to:

- 1. Determine demographic characteristics of women at the selected sites.
- 2. Identify factors influencing choice and use of institutions/site for Fistula repairs.
- 3. Assess knowledge, attitude and behaviour of women undergoing OF repairs.
- 4. Estimate the social re-integration levels of women after successful OF repairs.
- 5. Document hopes, expectations and fears of women reporting for OF repairs

## **CHAPTER 4: STUDY METHODS**

### 4.1 Study sites

This study was conducted in close collaboration with the AMREF team conducting OF repair at selected three of AMREF intervention sites in the period between 2008 and 2011. Primary data were collected from three selected hospitals, all of which are referral institutions in their representative counties. AMREF surgical team holds surgical repairs clinics at these facilities annually. The study team followed these AMREF schedules in order to access the clients. The three sites selected are discussed individually as follows:

Kenyatta National Hospital (KNH) the oldest referral and teaching hospital in the country, provides a national outlook in the sense that the clients will have a national representation, it is also houses the Centre of Excellence in Obstetric Fistula repair. KNH has fully designated clinic 66 for VVF screening and surgery on routine bases. Additionally KNH records an average of 80,000 inpatients and over 500,000 outpatients annually and also provides a medical research environment.

Kisii General Hospital is located in a community where female genital cut (FGC) is still practised. The investigator would have liked to interview women who have undergone different types of (FGC) and those free from FGC altogether. In the literature the debate on the possible contribution of (FGC) to obstetric fistula (OF) is not yet conclusive. From the Kisii website (Kisii.com) approximately 90% of girls aged 6-10 years in Southwest Kisii have undergone FGM. The practice of FGC is rampant in Kisii due to deep rooted cultural practices.

New Nyanza Provincial hospital or JOORTH as its currently called is likely to provide women free from (FGC) altogether since the community does not culturally practise this. This will provide an important comparison in the study.

This meant that study sites were purposefully selected.

## 4. 2. Study Design

This was a descriptive study conducted in close collaboration with AMREF surgical team. Face-to-face administered questionnaires were conducted to new and follow up clients who visited the institutions for obstetric fistula surgical repairs and on follow up visits after surgical repairs.

## 4. 3. Study Population

The studies involved new and follow up clients in selected AMREF intervention sites as per the scheduled surgical repair lists. Due to uniqueness of this particular morbidity and the stigma associated with its perceived causes and effects on a woman's overall life, the investigator could only access clients through close collaboration with AMREF surgical teams and abides to their schedules. Respondents were assured that their names and other identity would not be disclosed in connection with the information they shared. Data were therefore collected during the AMREF annual VVF medical clinics at each of these intervention sites visited. New clients reporting for surgery were interviewed on admission to the hospital and after the surgery. The investigator made initial interactions with the clients as they were screened out and followed them in the wards as they awaited surgery; in convalescence stage after the surgery. Follow up clients were interviewed at the outpatient clinics. Quantitative data was obtained though use of prepared questionnaire, while narratives and in-depth interviews (IDI were obtained through use of interview guides. Whenever possible, persons accompanying the clients were also interviewed. Additionally institutional-based health providers at the sites were interviewed about institutional capacity and activities related to OF.

#### 4. 4. Data collection

Socio-demographic and environmental characteristics of the clients were obtained through the records kept by AMREF team, prior to the surgery. Quantitative data were collected through face to face administered questionnaires. Interview guides were followed to collect in depth information from the

clients and selected key informants such as close family members. Key informant interviews were conducted among health professionals. Qualitative data were gathered through use of discussion guides and case narratives of the clients. The interview guides probed for perceived and real causes of obstetric fistula, perceived meaning and management, real and perceived risks, fears, hopes and expectations behind the decision to undergo the operations.

### 4. 5. Data analysis and presentation

Quantitative data were checked, cleaned entered in computer and analyzed using SPSS software version 16. The services of qualified data clerk was sought to assist in the process of data management. Frequency distributions were calculated for the relevant variables. These are presented in form of frequencies, tables, charts and graphs to illustrate the findings in relation to the research questions and specific objectives. Where necessary, chi-square (x2) test has been applied. Probability value (P-value) is used to determine levels of significance of the results. Confidence interval were applied, where necessary, to determine if associations are real or by chance. Qualitative data from FGDs, in depth interviews and case narratives were packaged into thematic context and analyzed manually. Critical quotations are presented verbatim to underscore levels of consensus among participants. Selected case narratives are presented verbatim.

# 4. 6. Variables of analysis

The variables studied included; i) demographic, ii) cultural, iii) economic and iv) environmental including physical and social. These are presented under socio-demographic characteristics of the respondents.

## 4. 6.1. Independent Variables

These were age, Marital status, age at marriage, age at first pregnancy, number of live births and place of delivery; educational level and circumcision status were considered.

### 4. 6.2. Dependent variables

These included knowledge, attitude and practices, perception of causes, mitigation strategies, care seeking for OF repairs, religion orientation and reasons for preferred place of delivery.

## 4. 7. Sampling procedure

In order to determine the sample size a random sampling technique were used based on the fistula surgical records at AMREF intervention sites, the investigator used the estimated fistula rate calculated by Mabeya (2003) for rural west Pokot that is possibility of there being a fistula rate of 1 per 1000 deliveries. Thus the formula used to determine the sample size is as follows:

$$n=z^2pq/d^2$$

N=the desired sample size

Z=the standard normal deviate (in this study 1.96 corresponds to 95% CI)

P=the proportion in the target population with certain characteristics (0.1).

$$Q = 1.0 - p$$

D=degree of accuracy desired (0.05)

$$N=1.96^2x0.1 (1.0-0.1)/0.05^2 = 138$$

This was rounded off to a minimum of <u>140</u> respondents. To cater for attrition and non conformity a 15% was factored in and this calculated to an extra 21 respondents. A total of 161 respondents were interviewed from the three identified sites, namely Kenyatta National Hospital, New Nyanza Provincial Hospital and Kisii District hospital. The proportions were as follows: KNH 88 (54.7%), Kisii Level Five 42 (26.1%) and New Nyanza Provincial General Hospital 31 (19.3%).

### 4. 8. Training of research assistants

Prior to data collection, the investigator trained two female research assistants with experience in health related research (one a social scientist and the other a nurse), both of whom worked with AMREF Project at the time. The investigator reviewed the instruments with them to ensure the concepts were clearly understood and questions found to be ambiguous were revised to ensure improved clarity.

#### 4. 9. Ethical Considerations

Collaboration with AMREF team was essential in this study in order to access the respondents, thus making it institutional based. Ethical clearance was obtained from KNH and University of Nairobi ethical and research committee before embarking on data collection. Permission to talk to the patients was also obtained from the health institutions and the director of AMREF Outreach Programme.

Respondents' informed consent to participate in the study was sought and treated with utmost care. Only those willing to take part in the research were interviewed. Confidentiality was assured and observed to avoid identification, unless they chose to come out. Most of the data collection was qualitative and interactive. The investigator sought permission from the respondents to use audio-visual recording. Verbatim quotes are presented by using pseudo names to protect the identity of the respondent.

Surprisingly though, many of the clients undergoing surgical repairs reported that they had nothing to hide including their identity as they would like as many women as possible to hear their stories and thus come forward to seek care and fistula repair. A good rapport was established between the investigators and the clients to the extent that a number of them invited the investigating team to their homes. Such visits provided opportunity for the researchers to interact with the clients' family, listen to their concerns and answer a number of questions, in the process.

## 4.10 Study Limitations

The study was institutional based and the data used here was obtained from clients, institutional personnel and where possible, family members accompanying the clients. The investigator could only access the clients for data collection and other interactions during AMREF scheduled medical clinics at the selected sites.

The investigator had very limited opportunity to observe real social interactions of clients and family and community either before or after the repairs. The investigator acknowledges this as the major limitation in the study because re-integration is a continuous process that would require long term follow up, probably lasting several years, after OF repairs. In order to minimize possible negative effect on the quality of the study the investigator made special effort to encourage discussions to get deeper into clients' perceived levels of re-integration through reports, inspirations and hopes for future.

The investigator also made every effort to understand each client as an individual and their special desire to get assimilated back to society.

#### **CHAPTER FIVE: STUDY FINDINGS**

The findings are presented against the stated objectives and themes. Quantitative and qualitative data are presented alongside to complement each other. This is the pattern followed in this dissertation.

#### 5.0 Demographic characteristics of participants

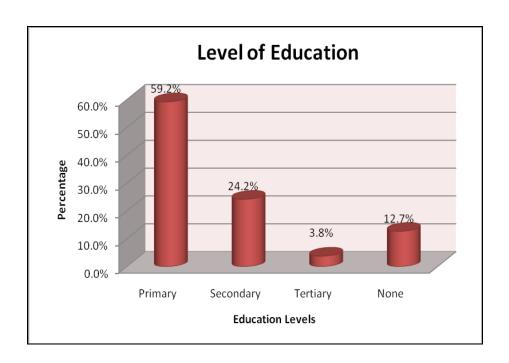
A total of 161 respondents undergoing OF surgery at 3 intervention sites were interviewed. These were in the proportions as follows; KNH 88 (54.7%), Kisii Level Five 42 (26.1%) and New Nyanza General Hospital 31 (19.3%). distribution of respondents by ethnic background was Luo (33.1%), Kisii (20.5%), Kamba (12.6%), Kikuyu (9.9%), Luhya (6.6%), Meru (6.6%), and others (9.9%) composed of a combination of assorted backgrounds, namely, Kalenjin, Kuria, Maasai, Mbeere, Somali and Congolese. Respondents age ranged from 14 to 80 Years, category of 25 years of age had the highest proportion at 6.2%. In addition age at first marriage ranged from 12 to 44 Years, with a proportion of 19.4% having been married at the age of 20 years.

#### 5.1. Marital status

Over one third of the respondents 37.3% were in monogamous marital relationships. This is closely followed by single status 36% occasioned by choice, widowhood or divorce. Polygamous marriages come third at 22.4%. A few individuals seven 4.3% did not disclose their marital status.

**Table 1: Marital status** 

Marital Status	Frequency	Percent	
Married Polygamous	36	22.4	
Married Monogamous	60	37.3	
Single	33	20.5	
Divorced	20	12.4	
Widowed	5	3.1	
None Response	7	4.3	
Total	161	100	



For the majority of participants the highest academic achievement was primary level 59.2% followed by secondary 24.2%; and only 3.8% had obtained tertiary level. A total of 12.7% had no school education whatsoever. This tallied well with occupation and income levels, where the majority 75.5% were in farming industry or were engaged in odd jobs.

In terms of residence close to eighty percent 79.7% of the participants reported living in rural residence as opposed to 20.3% urban dwellers. This also indicates that the majority of clients travelled long distances to the intervention sites.

Over half of the participants 58.8% lived with their spouses regularly while 41.2% did not live with their spouses, for various reasons. Only 35% of clients living with their spouses confirmed engaging in regular sexual relations. Of these 15% reported experiencing difficulties having sex such as painful intercourse 9.3% and discomfort due to soiling 4.3%. The rest 3.1% reported not having had any sexual intimacy since the development of fistula. Interviews with accompanying male spouse indicated that a number of them found it arduous to put up with sexual denial and resorted to clandestine extra-marital relationships or kept surreptitious arrangements with concubines. The attitude of secrecy appeared quite mutual, for instance, a number of women reportedly tried to keep their status undisclosed to husbands, albeit, unfeasible. In one FGD there was consensus among the women that the male spouses changed their

attitude towards their wives on realizing the leakage of urine, faeces or both. Mercy, 25 years old and having lived with fistula for seven years had this to say...

"My health deteriorated immediately I developed this condition, and this partly explains the discrimination by my husband, his family and the entire community. My relationship with my husband worsened and we had no sexual relations. It was at this point that we parted ways, and he remarried soon after...an act that affected me so much that I decided to go back to my parents' home and they have been taking care of me since".

Occupation

5%

3%

Farming
Odd jobs
Business
House wives
wage employment
christian pastoral duties

Figure 2: Occupational and Income levels

A large number of the respondents 45.3% were reportedly farmers and another 30.2% were engaged in odd jobs that could not be regarded as any particular occupation, 15.8% were in business with only 2.9% in wage employment and 5.0% were reportedly house wives. A small proportion 0.7% was in Christian pastoral duties.

Asked to indicate monthly income those in business reported a range of Ksh. 280/= to 15,000/= per month, with 17.5% earning an average of Ksh. 2000/= per month.

In the qualitative interactions, clients narrated experiences that impacted negatively to their income

generating activities, after developing fistula. For instance, Cecilia had to close her grocery shop and restaurant. She mused rhetorically... "how could I continue serving customers at my restaurant with a trail of faeces dropping from me?"

#### 5.2. Types of Fistula presented for repair

Information gathered from hospital records showed that the majority of the women seeking OF repair had developed VVF 72% followed by RVF 16% and 5% having a combination of VVF and RVF condition. The records were incomplete for 6.8% of the clients as shown below.

Table 2: Types of Fistula attended to at the three Sites

Туре	Frequency	Percent
VVF	116	72.0
RVF	26	16.1
VVF& RVF	8	5.0
Non Response	11	6.8
Total	161	100.0

A surgeon at New Nyanza General Hospital, Kisumu informed the investigator that RVF is much easier to repair and that during the free surgical camps surgeons dealt with RVF first, followed by VVF while the combined cases come last as they are the most complicated. The outcome of surgical repairs was basically good for the majority of clients interviewed during post operative stages and a brief review of records showed similar pattern. A few isolated cases, however, experienced poor outcome, and expressed sorrow and disbelief that skilled surgeons at KNH were unable to achieve full restoration of their health.

#### 5.3. Factors Influencing choice and use of health facilities for delivery

The investigator learnt that by and large most of the clients were unaware that fistulae are treatable and even cured. In situations where the client realized the leakage after being discharged from the maternity facility, the tendency was to go back to the maternity for treatment. However, maternity services referred the client to the general hospital, much to the frustration of the perplexed clients.

It was noted that use of maternity services had a role in determining whether or not clients sought services immediately they developed fistula. The situation was different for women who delivered under unprofessional care. A number of the women reportedly stayed at home trying to cope with the situation. Some of the clients, under the coercion of family and close friends, sought help from health facility nearest their residence especially as emergency. It came out clearly that the decision to seek care by young, single clients was made by other party such as parents, spouses and elder siblings. Major factors determining choice of health facility were severity of the condition, cost of services and beliefs about underlying causes. For instance, Fatima stated as a matter of fact that in her community women deliver at home, without any problems. She had already successfully delivered eight babies at home and had no plans to deliver at a health institution. Some women stated that previous experiences at a district hospital influenced their future decisions on facility choice.

It also became clear that at the onset of labour a majority of the respondents reportedly waited for hours before decision was made where she would seek delivery services. The delay in seeking care often led to prolonged labour and development of fistula. Reasons for this delay were varied, but in most cases distance to the facility was mentioned, additional to lack of resources. Rebecca who realized she had developed fistula, a fortnight after the birth of her third child had experienced prolonged labour. The onset of labour pains reportedly began on a Thursday and three days later she was still at home and baby was not forth coming. On the fourth day, Sunday she was taken to the hospital where a dead baby boy was removed through an operation. On noticing urine leakage Rebecca knew that her life was now in shambles and she remained in isolation and shame at home thereafter.

#### Rhoda also narrated having experienced prolonged labour...

"I went into labour of my first delivery one night in 1992. The following evening I was taken to hospital in Narok town where I was operated to remove a dead baby boy. I realized shortly after that I was leaking of both urine and faeces. The following year, 1993 I was taken to Kijabe mission hospital for treatment through surgery".

In a different scenario, Patricia who did not attend the ANC regularly went to a district hospital with labour pains. She chose district hospital because she knew there were qualified medical personnel at level. It occurred to her that there were many women in labour that day and the medical personnel appeared overwhelmed by the sheer numbers and she did not receive the care she anticipated. She was in labor for many hours and finally when the baby was born she noticed involuntary urine leakage. She

attributed the problem to negligence of the health personnel and decided never to visit that particular hospital again. True to her word she chose a small, poorly equipped clinic to deliver her second baby.

Millicent, an orphan and unemployed sought refuge at her grandmother's place when she realized she had conceived before marriage. At the onset of labour pains her grandmother consulted a traditional birth attendant to assist with the birth since the TBA was trusted and also charged little. As the baby came out the TBA stated as matter of fact... "You have broken my hand".

Initially Millicent had no idea what that statement meant until she realized later she had lost control of her bowel movement. She asked her grandmother what was happening but the old lady angrily scolded her with...

"keep quiet and stop annoying me with silly questions".

This concept of 'breaking midwife's hand" could be interpreted to imply deep disappointment on midwife's part. While both the midwife and the grandmother may not understand the real cause of fistula, they both appreciated the serious implication of this outcome on the client and the reputation of the traditional midwife in the community, especially the damage to her source of income, thus figuratively, "breaking the hand that earned her livelihood".

The fury of both the grandmother and the TBA towards Millicent may insinuate the damage brought about by this unfortunate episode extended beyond the main actors to the larger community in general. For instance, this would become common knowledge to the entire neighbourhood, impacting differently on different people. For Millicent, already physically devastated, this would further limit her chances of getting a suitor, locally. For the grandmother it was unfortunate to have an incompetent offspring who got damaged and delivered a dead baby. Others may attribute this to Millicent's undisclosed sins of commission or omission. For the midwife she will have lost not only the income, but also the confidence of future clients. This may further complicate the process of Millicent's re-integration back to the community, with the widespread social damage. This further confirms that re-integration is a social process, impacting on a wider complex network.

While the real issues here appear to be early sexual debut, lack of competent maternal health services and early sexual debut, the delay in seeking competent services for delivery and fistulae treatment is

surrounded by socio-economic, emotional and cultural meaning that have to get some form of restitution as a matter of priority.

While the study looked into re-integration of women back to community after successful OF repairs, the investigator realized the important role of other factors in this process of re-integration. For instance, delays in seeking health care for maternal services, including OF treatment were analyzed and presented below.

Table 3 Factors associated with delays in seeking health care for maternal services

	< 24 Months	>24 Months	Total	P Value
Area of residence				
Rural	22(18)	100(81.9)	122	P = 0.348
Urban	4(12.9)	27(87)	31	
Number of children	23 (37)	39 (63)	62	
≤2	8 (25)	24 (75)	32	P= 0.597
≥3	23 (37)	39 (63)	62	
Marital Status				
Monogamous	8(22)	28(77)	36	1.0
	, ,	, ,		
Polygamous	9(15)	51(85)	60	0.700
Single	3(9)	30(90.9)	33	0.146
Divorced/Widowed	5(20)	20(80)	25	0.028
Receive counseling?				
Yes	15(20.2)	59(79.7)	74	P = 0.185
No	7(12.2)	50(87.7)	57	
Level of Education				
Primary	14(15)	79(84.9)	93	D 0 004
Secondary	7(18.4)	31(81.5)	38	P=0.091
Tertiary	0(0)	6(100)	6	
None	3(17)	17(85)	20	

A number of the variables were categorized because they had very few patients.

There is a significant association between being divorced or widowed in relation to consultation time compared to those in a monogamous marriage.

Age at first marriage ranged from 12- 30 years, with a mode of 20 years. This category reported developing fistula at the delivery of their first baby. The situation further affected marital relations negatively and reduced chances of subsequent conception and deliveries.

Risk of developing fistula was highest at the birth of the first baby (41%) and decreased with subsequent births down to the sixth birth with only (2.5%). Approximately (20%) of the respondents did not reveal order of birth of that caused fistula. In the case narratives, however, women narrated having developed fistula much later in their reproductive life.

Table 4: Order of birth that caused OF

Birth order	Frequency	Percentage
1 <sup>st</sup>	66	41.0
2 <sup>nd</sup>	21	13.0
3 <sup>rd</sup>	17	10.6
4 <sup>th</sup>	12	7.5
5 <sup>th</sup>	8	5.0
6 <sup>th</sup>	4	2.5
Missing	33	20.5
Total	161	100.0

Delayed service at the health institution was not unusual as illustrated in Muthoni's narrative below, in a situation of prolonged labour. She was taken to Pumwani Maternity and was immediately wheeled to theatre for CS. Muthoni continued in deep frustration...

"I was left unattended on a trolley inside a room. I delivered alone on that trolley while everyone was busy preparing for the operation. The baby girl was alive and well but I developed a big tear, which was repaired hurriedly and after two days I was told I could go home. At home I had difficulties sitting and passing urine, a week later I started discharging pus. I was taken back to Pumwani maternity but the personnel rejected me saying I should go the Kenyatta National Hospital".

Muthoni was booked for VVF surgery at the KNH June 2011 and that is how the investigator got to interview her.

One of the commonly reported constraints by the women was scarce communication from health providers to clients. Key infromant interviews with maternity personnel revealed that Pumwani maternity may not have the best facilities to manage post delivery infections, once the patient has been discharged. The patients are often unaware of these facts. However, instead of expalining this to the patient the health providers simply advised the patient to seek help from KNH, thus causing more frustration, confusion and anxiety to patients and their families. Muthoni was faced with a similar situation and she expressed the same to the investigator in detail.

Muthoni strongly believed that the problem need not have occurred had the health personnel managed her better. She developed a low opinion of the Pumwani maternity hospital and vowed never to go there again. In her case, however, taking home a healthy baby was a big consolation compared to those who developed a fistula and lost the baby.

#### 5.2.1. Birth outcome and fistula formation

While the study focused on social re-integration after fistula surgery was necessary to establish the outcome of the birth that caused fistula. The most frequent outcome of the birth that caused OF was loss of the baby as reported by 60.7% of respondents while 39.3% of the babies survived. Close to three quarters 72.2% of the deceased babies were in contrast to girls at 27.8% of the total number of children.

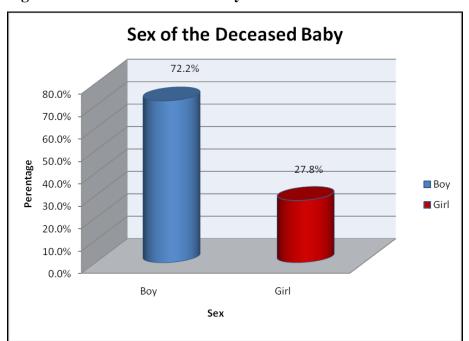


Figure 3: Sex of the deceased baby

In the interactive FGD participants explained that male babies are generally much bigger and known to cause difficulties to mothers during birth. What came out clearly was that there was a general consensus that any baby too big for the mother, irrespective of the sex, is likely to cause her problems such as bad tears or obstetric fistula.

Twenty five year old Mercy had lived with fistula for 7 years before she got the opportunity for surgical repair at KNH. Asked what she thought caused the fistula she blamed the struggle she underwent delivering at home for the loss of her baby boy who was quite big. Mercy, wiping tears, hesitated for a brief moment before concluding...

"It was such a horrible experience, I lost my baby son at birth". Another participant concurred ..." my mother narrated to me how she got a big tear giving birth to my brother who comes after me. ...judging from my experience, continued the mother of two girls and one boy..."I can say with certainty labour for a male baby is different from that of a girl. Boys are fast and rough right from birth".

Other women in the FGD nodded in agreement.

The investigator met Kanini at the KNH free medical clinic in June 2011, as she waited to go to theatre. She had been referred from Makindu district hospital where she had been operated to remove a dead

baby. She arrived at Makindu hospital after three days of labour under the assistance of a traditional birth attendant (TBA), locally known as mukunga. Kanini narrated...

"I was at home in Kaskeu in April 2011 when the labour pains came at around nine in the night. Mukunga was called in to assist but the labour continued for another two days. The TBA advised my parents to take me to Makindu hospital where I was operated to remove a dead baby boy. Soon after the operation I noticed that urine was leaking uncontrollably. The doctor inserted a catheter and told my parents to take me to KNH for further treatment"

Although her parents were disappointed that she conceived so young and out of wedlock, they had been very supportive and brought her all the way to KNH for the fistula repair as the doctor advised. The parents knew of another woman from their village who had undergone a successful VVF repair about 3 years earlier. For Kanini her greatest hope after recovery was to go back to school and continue with her education. It appeared that the role of supportive family, in this case parents, facilitated easier reintegration back to community. The parents had made plans to enroll their daughter back to school and had saved money for the purpose. As of the time of the interview she had yet to recover before resuming her education. To her resuming school would mean re-integration.

Josephine, another beneficiary of successful surgery at KNH in 2011, hoped her marriage would be reinstated now that she had physically recovered and was able to work and earn money to raise her children. She reported that just a day before she was discharged from the hospital her husband came with other relatives to visit. To her that was a significant gesture towards salvaging their marriage. She hoped that the friendly relationship would improve so that they get reunited back as family again.

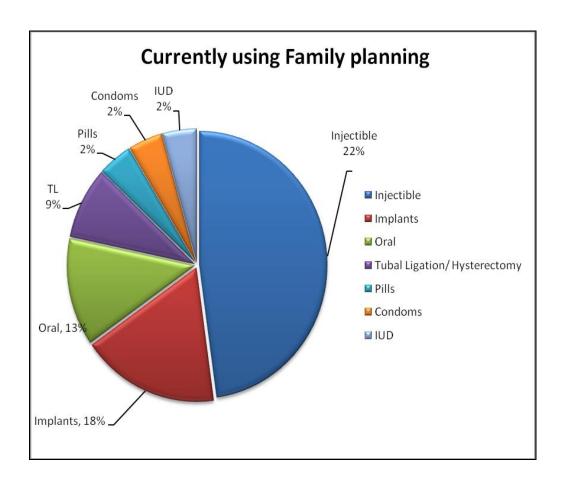
The level of re-integration appears to be influenced by a variety of issues in diverse scenarios and actors. In marital relations interpersonal communication between the couple contributed largely towards reintegration. Some reported to have discussed how to control fertility in order to avoid subsequent child births until the woman recovered fully. In other situations the male partner singly declared there would be no other births, whatsoever.

It was, therefore crucial to establish whether or not the concerned individuals used contraceptives to ensure fertility control. This concurs with a statement made during a discussion with a representative from UNFPA that family planning is an important component in dealing with OF.

### **5.2.2.** Contraceptive use

A large proportion 79.2% of the respondents were not currently or ever enrolled on any contraceptive method. Only 20.8% confirmed to have ever enrolled in a birth control method, among whom 19.2% was currently using a family planning method. Among those on contraceptives, injection (depo provera) was the most popular method at 22%, followed by implants 8.0%, oral contraceptive 6.0%, tubal ligation 4.0% and finally male condoms at only 2.0% as illustrated in the figure below.

Figure 4: Respondents contraceptive choice and current use



## 5.3. Respondents' beliefs on fistula causes

Perceived beliefs on OF causes were found to have a relevant role on the level of re-integration back to community. In situations where the cause was seen as socio-cultural the blame was directed to the woman in some way. In this study the majority of respondents appeared to be knowledgeable on real and tangible causes such as obstructed and prolonged labour, large baby, among others, in comparison with a small proportion attributing fistula to socio-cultural causes such as witchcraft.

A proportion of 55.2% of the participants reported fairly correct and scientifically feasible causes of fistula. This could most likely have come from frequent interactions with health personnel during recruitment for fistula repairs.

However, diverse perceived causes were reported and are shown below as reported by participants.

Table 5: Reported Common Beliefs on Fistula Causes

	Frequency	Percent %
Delivery	38	23.6
Big Baby	15	9.3
Prolonged Labour	14	8.7
Home Delivery	10	6.2
Obstructed labor	6	3.7
C/S Delivery	9	5.6
Witchcraft	8	5.0
Forceps Delivery	4	2.5
Cancer	2	1.2
Others	8	4.8
Don't Know	13	8.7

The top five listed causes adding up to 51.5% are feasible contributing factors to fistula development. Another 39.1% showed knowledge gaps, portrayed either through none response, total lack of knowledge or misconceptions about causes. The rest 9.8% of the response were based on cultural beliefs. Reported continuous awareness creation appeared to serve as an essential tool for reducing knowledge gap and promoting prevention and care seeking for OF management among the survivors.

Obstructed and prolonged labour accounted for the highest reported causes of fistula development. There was consensus in the FGDs and also among several case narratives on the same. However, as revealed from several narratives, there was inadequate knowledge on real causes and lasting effects of fistula by both the survivor and their spouse. For instance, when Patricia started leaking of urine involuntarily, after she was discharged from hospital, she had no idea what had gone wrong with her body or what caused it. She started leaking urine after the delivery of her first baby at Thika Level 5 District Hospital. She kept the condition to herself, though it was difficult and got much worse during menstruation, thus she eventually decided to find out from her mother but to no avail.

"I asked my mother what this could be but she said she had never heard of such a thing in all her life. I conceived again and during one ANC visit I gathered enough courage to tell the doctor what I was going through. He said that he would fix it during the delivery of the second baby.

This was never to be because Patricia had already decided never again to deliver at Thika Level 5 after the earlier incident.

In another incident Aurelia's husband, an evangelist, labelled her and her second born child as people 'under a curse'. Aurelia elaborated that whenever she and husband had an argument he accused her of being abnormal, and responsible, jointly with the child, of all the problems in their marriage. She felt badly about this especially since the child was innocent. Fatuma wondered why the ninth delivery should be different from the earlier eight. An important finding to note here is knowledge gaps appeared to contribute to care seeking and thus reduced chances of taking advantage of free surgical repairs and getting re-integration back to social life.

### 5.3.1. Sensitization through mobilization for OF repairs

Knowledge of real causes is getting increasingly improved among the average Kenyan, through open mobilization of OF cases for surgical repairs. Since year 2007, the month of June every year, is dedicated to free fistula repair at the KNH clinic 66. The event is launched in pomp and ceremony with the Prison's band leading a 5 km walk from KNH, around the hospital neighbourhood, down Uhuru Park and back. Huge posters are posted at strategic places and the media is used to highlight this on TV, radio and dailies as part of mobilization. Pamphlets giving briefs of VVF basic data are distributed generously to motorists and pedestrians on the way. Samples of volunteer beneficiaries and past clients with a success story briefly address the gathering composed of AMREF, KNH and Ministry of health officials, invited parliamentarians, hopeful VVF survivors, accompanying family member or friend and the general public.

Sharon, full of gratitude for the successful repair addressed the gathering and stated her commitment to mobilize, through her Church network, women she knew to be suffering the devastation of fistula and introduce them to the AMREF surgical team. Sharon is among women who portrayed clear understanding of the real causes of fistula and were willing to train others, informally, especially create awareness of causes and prevention of fistula. Sharon stated...

"I promise to educate my community, because they are unaware, that fistula is attributed to home delivery. When delivery is prolonged the mother will develop fistula, or even death of both mother and baby. I will also educate young girls and advice them to avoid early pregnancies. This way they will avoid what I went through".

This is complemented by Jennifer, who had lived with fistula for 8 years before she underwent repair. She reminisced...

"people said I had been bewitched and that was why the problem occurred. I clearly recall being told I would not live more than one year as a result of this condition".

The Church came to her rescue; providing food and for her and her children, money for medical care additional to social support. Jennifer too vowed to take every opportunity to teach young girls especially her daughters about the dangers of early marriage and home deliver.

In the narratives a few respondents attributed fistula development to breach of social order.

### 5.4 Reported source of information on free VVF clinic

The study established the source of information for the beneficiaries of free surgical repair camps. Respondents were asked to list one main source through which they obtained information on OF repair services. The commonest sources listed were the media, announcement in the others were through informal sisterhood networks and grapevine communication.

For instance, Patricia heard about KNH free VVF clinic during Church during announcements. Others read from the daily from the Daily Nation and decided to attend...

"I saw the advertisement for a VVF repair camp to be held at KNH in June 2010. I asked a friend to baby- sit for me as I went to seek help in KNH. On the material day I woke up at 3am to embark on the work of emptying my bowels completely. That was the only way I could manage the trip to the hospital by public means. I left my house at 5am and was among the early arrivals. I was booked and taken in for surgery."

Sarah learnt about the clinic from the TV...

"In 2010 as I was watching the TV I saw a lady being interviewed. She talked of having suffered from a condition of leaking with urine but had been successfully fixed at KNH. They spoke of a free camp at KNH and I decided to give it a try since I had nothing to lose. I thank God that the surgery was successful and I was able to return home a new person. I no longer had the bad smell of urine. My clothes were dry!"

Kageni learnt about the free VVF clinic from the radio...

"I heard on the radio about the free repair camp that was to take place in KNH. I saw that as a way out of my miserly and decided to look for some bus fare. As I was leaving I heard people say that I was going to die at KNH. I was directed to the clinic and met the person in charge, Sister Muthengi, who really took me under her wing and assisted getting me admitted into the ward. I was in the first lot to be operated on and what a miracle it was to on waking up and checking my bed and finding it dry!"

Aurelia was informed of the free VVF clinic by a friend. She was introduced to a doctor who referred her to KNH. In her own words she admitted...

"my fear was that my husband would begin extra marital affairs and now bring home a bad disease like HIV. I did not want to die so young and leave my two children thus I spoke to a friend who told me of a doctor in Kitengela who handles cases such as mine. I went to see him and he referred me to KNH. I came to KNH in the company of my friend and young baby and was screened and scheduled for surgery".

### **5.4.1.** Counseling services

Most of the respondents 56.5% confirmed having received counselling about the surgical procedure, while the rest 43.5% reportedly never received any counselling before the surgery.

Close to two thirds 65.1% of the respondents confirmed that counselling was done in privacy while the rest 34.9% reported total lack of privacy.

Half of the health personnel were reportedly trained to handle fistula case while the other half 50% had no specific counselling training.

There was no consensus over what composed counselling; some cousellors limited it to preparing clients for theatre. Others advised clients on how to care for themselves at post-operative stages, especially abstaining from sex for a period of not less than six months. It was noted that There was very little effort to address people accompanying clients, and significant others, such as spouse and immediate family.

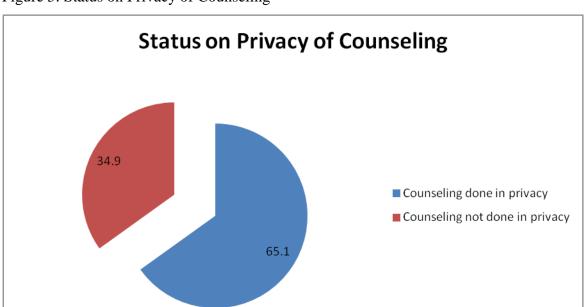


Figure 5: Status on Privacy of Counseling

Clients were also encouraged to create fistula awareness in their communities. Close to half of the clients were aware of other women living with fistula who would benefit from surgical services. Sharon reported that she was impressed by the health personnel reception of clients. She was educated about the causes of fistula and ways of prevention. She promised never to deliver at home again now that she had learnt the importance of hospital delivery, safety and assured of assistance, whenever needed.

Asked if she got any special advice after the operation, Sharon responded in the affirmative...

"Yes. I was advised by the doctors on how to manage myself. I was told to abstain from sex for a period of six months, take plenty of fluids and also come back for follow up check after six weeks. My prayer is that these doctors continue helping more and more women!"

Timing for counseling was unclear. Sporadic patterns and practice emerged regarding the period taken to receive counseling before or after surgical intervention. For instance 6.8% reported receiving counseling within 1 day of admission or surgery; 5.0% after 3 days; 3.7% after 2 days; while the rest 5.8% took between 7 to 120 days before receiving any form of counseling after admission and surgery.

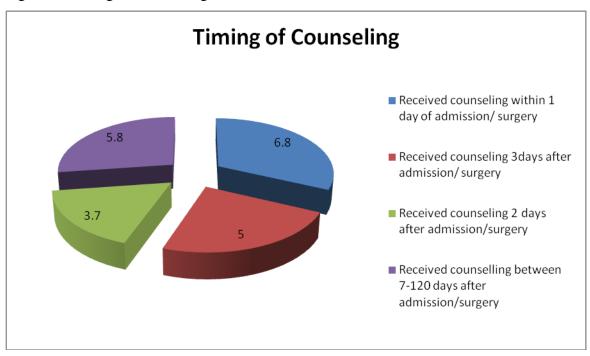


Figure 6: Timing of Counseling

Additionally 64.1% of the participants reported having ever come back for follow up after surgery as advised; while only 35.9% came back within the stipulated period of at least a fortnight after surgery. Finally 90.7% of significant family members confirmed never having received any counseling before or

after their clients' underwent surgical repairs. Only 9.3% of family members reportedly received any form of counseling before or after the surgery.

Information from qualitative interactions complemented the above data. For instance, Muthoni sought assistance from several private clinics before she learnt about KNH clinic 66. She came over, was checked and booked for operation during the AMREF/KNH Medical camp scheduled for June 2010...

"After surgery and discharge I realized the repair was not successful because the pain and leaking persisted".

A second surgery was conducted in October 2010 at clinic 66, and this time it went on successfully. Muthoni was happy to be well again.

"I was advised to avoid sex during the period of recovery from surgical repair, for complete healing...my husband was cooperative and we abstained from sex for more than six months".

She is now fully recovered after 19 months. She is so happy to be normal again. Her friends tease her that she has gained weight. She proudly confirms... "I am now stress- free and I am glad to advise other women to come for repairs".

Carolyn was advised by her father to go to KNH for review. Her father knew about VVF clinic at KNH because he works at KNH. She was booked and repaired in April 2011 after 4 months of developing fistula. She stated...

"I feel so happy I can move around, visit friends and relatives without fear. I know I am valued and I have resumed going to Church. I intend to resume the course on beauty. If ever I get pregnant again, I will attend antenatal clinics".

# 5.5. Experiences of VVF Survivors

This section presents experiences of some of the VVF survivors through their narratives. Through the stories of these women we clearly see the events preceding the development of the fistula. They narrate how they developed the fistula through childbirth and in some of the stories the 3 Classic Delays are well documented. Women are many times denied the right to decision making even on matters of their own health. One woman tells her story and says that she had been in labour the whole night and it was only in the morning that her relatives felt she had labored long enough and decided to take her to the hospital!

One woman tells of how she developed a fistula due a rape ordeal. The feelings of rejection and abandonment from her own mother are heart wrenching.

Eunice had tried to get help from many sources, including private clinics. Eunice delivered her first baby girl in 2003. Seven days after her return home from the hospital she went to the toilet for a short call. She heard something fall from inside her into the toilet....

"This was when I realized what it meant to leak of combined urine and faeces. I could no longer contain the faeces, they would just drop everywhere. Whether I was washing clothes or doing the dishes they would just drop everywhere. I thought that perhaps if I reduced my food portions the problem would cease, but it did not. I decided to eat light meals, rice and ugali. My husband was very disturbed about this and he sought help at a private hospital who asked for Kenya shillings forty thousand (40,000/=) to perform a surgical repair. We were unable to raise such a huge amount of money immediately. My husband asked me to just try to bear with the situation until year 2009 when he would qualify for a SACCO loan. I conceived again and delivered another baby girl. Unfortunately my husband passed on in 2008 thus I never had the opportunity to get repaired. To contain the feaces I would wear a lot of padding and I could not travel as no one wanted to be near me because of the stench".

Sarah M had lived with VVF for 12 years. It all began in 1998 when she had her 1<sup>st</sup> delivery. The pains began late in the evening and lasted throughout the night. She was staying with her relatives who preferred she delivered at home because it was much cheaper. In the morning they took her to Tabaka hospital in Kisii. The doctors informed her that the baby was already dead in the womb and they would have to remove it through CS. The wound got infected thus taking too long to heal and she had to get it opened up again.

"By the time I was discharged urine had already began to leak uncontrollably. Due to this condition no one wanted anything to do with me. I was forced to return to my parents' home in Ogembo. I stayed in hiding and isolation for 3 years then a woman came to my parents' home and asked if I could work as a maid for her. This was a great opportunity for me as I saw a chance to make some money and seek medical treatment for my condition. My good fortune was not to last for long as the woman got tired of the house smelling of urine all the time and asked me to leave".

Jennifer suffered humiliation and emotional torture meted by the husband after she developed the fistula. The situation got so bad there was no communication between her and her spouse. Jennifer narrates...

..."We stopped talking altogether. After a while my husband brought another wife to live with me in the same house for a period of 2 years...we even shared the bedroom".

Jennifer continued...

"this was now too much for me and I decided to separate completely from him. The problem was I had nowhere to go so I hang on in my house. My husband built a new house for the other woman and moved in with her. He swore never to provide for me and my 5 children".

Other fistula survivors narrated similar sad experiences perpetrated by spouses, family and community in general, on account of the fistula condition.

Mwende, a 32 year- old mother of four, and a vegetable vendor, developed a fistula during the birth of her fourth child. She had reached the hospital in good time but there was much delay before she was assisted thus ended with a fistula.

"I went to the hospital on time but after 10 hours of labour I was told there was little progress as the baby was not descending".

She was informed she would undergo a CS because the baby was in distress.

"All seemed well following the operation but after two days when the catheter was removed I started leaking urine. I was catheterized again for ten days but the condition only got worse".

She was discharged and advised to return for follow up in six months. On return she was re-admitted for fistula care. A catheter was again put in place for 14 days following operation. For the subsequent 3 months the leaking reduced and she was put on antibiotics. She has now stopped leaking urine altogether.

Kageni was working as a house help in Isiolo and reported she conceived as a result of rape. On realizing her status her lady employer ordered her to abort to avoid circulating rumours that her husband was responsible. Kageni refused to abort and she was chased away. She went back home but she did not disclose to her mother that she was pregnant. Her mother became suspicious and asked her but she denied. The mother gave her a thorough beating before escorting her to the hospital for a pregnancy test. Kageni pleaded with the doctor not to reveal the facts to her mother but to no avail.

When labour pains came she labored for over 8 hours before she was taken to Chuka hospital. Kageni continued...

"At the hospital the doctor performed a CS and removed a dead baby boy. As I lay on my hospital bed I realized that it was all wet with urine. I was discharged before they fixed me up. I feared my mother might beat me to death now that I had not only disgraced her but was also leaking of urine. I stayed like this for almost one year. It was a very lonely existence".

Aurelia delivered her 1<sup>st</sup> baby at Pumwani maternity hospital and her husband felt that the hospital charged far too much money, not to mention other charges for small items like plate, cup, pads and basin.

When she was due to give birth to her second child her husband took her to a small private hospital at Kayole near where they lived. The assisting midwife did not perform episiotomy and as Aurelia pushed the baby she developed a huge tear that stretched all the way to the rectum. She was hurriedly stitched and discharged the very same day.

At home she began to experience pain and also noticed faeces and urine came out involuntarily. She found it difficult to be with people because of the foul smell. Aurelia continued...

"My husband is an evangelist and one of the major challenges I had was that people kept coming to the house to see him. I could not even serve them tea because my husband felt I would embarrass him so he ensured that he was always out of the house so that the people in his congregation would not get to know of my condition. I lost so much weight as I did not want to eat well yet I was lactating. My life was not a happy one as I could no longer have relations with my husband".

Fatima is a 40year old Ethiopian who had delivered 13 times nine of which were alive. The last four were all still births. She never had an opportunity to go to school. As per the culture in rural Ethiopia she delivered all her babies at home and the process of labour, in her view, was usually short. Fatima developed the fistula during delivery of her ninth baby. She believes that it was the will of God for her that it happened.

Harsh living conditions forced her and her family to become refugees and reside at IFO camp. It was at this camp that arrangements for the fistula repair were made, by UNHCR who brought her to KNH for surgery in June 2011.

"Although my husband did not divorce me he did not want to be seen to associate with me. He would sleep in a separate tent from me and the children. Life in the camp was tough as the community no longer had any respect for me; they said I had been cursed. I could not engage in daily prayers as I was considered unclean".

Fatima could not socialize with people because nobody wanted to be around an unclean woman. Her children were threatened with death.

Twenty year old Carolyn lives in Kawangware went into labour pains in February 2011. She went to a nearby private clinic labour extended for a whole day. In the evening she was referred to Pumwani maternity hospital.

At Pumwani she again laboured for another whole day before a CS was conducted to remove a 5kg, dead baby boy. They fitted her with catheter because she was leaking urine.

"When I was discharged from hospital I continued using sanitary pads and hoped the problem would heal. My life changed drastically. I even abandoned a course I had enrolled in beauty training"

She stayed indoors to avoid other people due to leaking with urine. She would not visit anybody's house as she would wet the seats. She avoided drinking any water to reduce urine output. This resulted in serious constipation. She also stopped going to church. Her father who works at KNH enquired about the VVF clinic no. 66 and advised her to go for review. She was repaired in April 2011 after only 4 months of living with the fistula....

"I feel so happy I can move around, visit friends and relatives without fear. I know I am valued and I have resumed going to Church. I intend to resume the course on beauty. If ever I get pregnant again, I will attend antenatal clinic at KNH and deliver the baby there."

### 5.5.1. Unsuccessful Repairs

A few clients did not obtain successful repairs as narrated by Rhoda during year 2010 KNH camp. Her case is a classical example of repeated but unfulfilling surgical repair. She narrated her story tearfully...

"The first surgery in Kijabe hospital was expensive because the hospital charged me for everything, including pampers and the nylon sheet on my bed. I continued wearing pampers like a baby! My husband could not bear it anymore and he abandoned me at the hospital saying I was under a curse. My family paid the hospital bill on my discharge. Kijabe hospital advised me to return after three years for a follow up surgery. After the surgery the feacal leakage reduced a little bit but urine leakage continued as before. Back home people said I had been divorced because my womb was cursed and I could not bear any children. I returned to Kijabe hospital in 1996 but even after the repeat surgery there was not much change. I was referred to KNH where the doctor told me to report at the hospital during the camp in June 2010. My brother refused to accompany me to KNH this time but I looked for a way to come alone!"

Complete recovery cannot be assured all the time in all OF cases, especially in the combined VVF and RVF. Affected survivors kept hoping that one day they too would benefit and lead normal life after successful repairs.

To these women re-integration process will start once they get successful physical repair. It would appear the health personnel did not give such clients a complete picture once the situation turned out to be unfavourable. For instance, at some stages surgery could become more harmful than restorative, according to the surgeons. However, in the study it was observed that such information was not adequately released to client; or rather came out in scarcity. This meant some of the affected clients were inadequately prepared to come to terms with their situation. For instance, Rhoda kept revisiting KNH for review in the hope of further surgery. Although her case is beyond help she still anticipates that one day she will be repaired successfully like other women she has met. She summed up with optimism in her eyes...

"I came back to KNH on the specific camp date and after I was reexamined I was told that no further surgery could be performed on me. I still leak though not as badly as before. I am disappointed that they are not willing to get my problem fixed. However, I will never give up and I'll keep coming whenever I hear of a free VVF camp. One day I believe the doctors will book me for further surgery"

The majority had success stories that they eagerly shared with the investigator. Rebecca's surgical outcome represents the majority lucky ones who undergo successful surgery at the various intervention sites and who remain grateful to the medical team. Rebecca stated that her life has really changed since the repair, as she concluded...

"I still wake up in the morning with disbelief that my beddings are dry - I no longer have this stench around me always and followed me everywhere I went. I am now a transformed woman"

Rebecca concluded that her situation is like a bright torch shining rays of hope of full social reintegration back to the community.

### 5.6. Re-integration into the Community

The levels of re-integration back to community was measured variously by different clients depending on social background, severity of problem and support from those considered significant in their life. It also involves more people than the individual client, thus complicating its appraisal. Surgical repairs brought about full physical recovery to the majority of the clients and this recovery from the ravages of fistula was appreciated by all the clients.

Interactive discussions with clients revealed that the road to re-integration is long and winding, combining excitement and disbelief. Re-integration was manifested in the ability to fit back into famly life again, fit in with other people and feel accepted again and engage in an economic, social or leisure activity.

Clients who had been reintegrated were full of excitement and hope and were able to resume their lives again after successful surgery. The following verbatim statement by a client reflects excitement and hope...

"It felt like I had been born anew. It took me a while to believe that finally I could sleep like a baby throughout the night with no worries of soiling the bed"

#### Ability to engage in an economic activity

Some of the younger girls talked of plans to go back to school and complete their studies. Others looked forward to reinstate training and business ventures they had abandoned on developing fistula as seen in the extracts below.

Josephine 39 years old comes from a small village in Kisii district and has lived with RVF for 13 years...

"My life changed completely after onset of this problem... I was stigmatized by the community. Marital problems started. As a mother of 3 life became very difficult, toiling in my condition to put food on the table. My husband offered minimal support for our up keep and after a few months of my developing the problem of leaking faeces I was sacked from my job because of the inconveniences caused by my condition".

Josephine promises to encourage others to deliver in hospital so that they avoid getting fistula/RVF...

" I also intend to talk to women during church gatherings and tell them about the free treatment for fistula patients".

She is grateful to the doctors and AMREF for offering free medical care to patients, "May God Bless you for your good work".

Ability to work for oneself was seen as part of re-integration back to community for many women. Eunice stated...

"My greatest joy is that I can work and get some money to raise my two children. I can go to church again and mingle with other people. I no longer incur huge costs buying pieces of cloths for padding. I now smell fresh"

#### Sarah M concurs...

"I was able to get a job as a house help and I now fend for myself! People in the village who used to vex me saying that all that was left for me was death are now ashamed to see how transformed I look! I am not afraid to meet with people and go to church. I feel like I have been born again. I believe that I can even get another child now as even my periods have resumed!"

### Mwende is happy now that ...

"I am completely dry and can run my own errands as just as before. I resumed my vegetables business. I am very grateful to my husband, my mother and mother-in-law who gave me moral, psychosocial and financial support when I needed it most". She is also grateful to the hospital staff.

#### Kageni said ...

"I still did not believe I was healed and got off the bed and checked at the spot in which I was standing and indeed it was dry. I was dry and no longer smelled bad. My greatest joy is that I was able to get a job as a waitress and can be my own person. I live alone and am comfortable. I walk like other people, attend church service and am not afraid to go in front and take my offertory as I am not leaking any more".

#### Ability to engage in a social activity

Aurelia was happy that she could resume the role of an evangelist's wife...

"I was operated and no longer leak of anything. I can now go back to entertaining my husband's guests; I can even go out and evangelize with him. I am excited that I can now eat solid foods to my fill and can breastfeed my baby well and my health has been restored. Above all my marriage has been saved!"

#### UNHCR brought Fatima and a few other women from a refugee camp to KNH for treatment.

"I look forward to returning to IFO and leading a normal life now that the surgery has been successful". Her children will no longer be threatened by other refugees in the camp and most importantly she will no longer be excluded from religious rites of praying and fasting!"

A number of clients requested the investigator to openly document their case narrative and use them to disseminate information to assist others who may still be hiding their fistula status. Telling one's story indicated not only a physical healing but an all rounded healing and a full re-integration into the community. One such show case is documented below.

Sarah Omega's story is recorded here, not only with her permission, but at her own request. She is convinced that disclosure and indeed focused involvement with fistula control activities is essential.

On recovery from fistula repair Sarah dedicated her life to educating all and women particularly, that fistula development is preventable and for those who accidentally develop it there is free surgical treatment. Sarah calls herself a fistula survivor and ambassador with a mission. Her narrative hereby recorded verbatim:

My name is Sarah Omega, a fistula survivor and an ambassador committed to control of fistula. My desire is that all women may know that fistula is preventable and treatable. My parents died when I was quite young, leaving my eight siblings and I struggling in extreme poverty and emotional pain. I dropped out of school in primary class and started looking for odd jobs just to get food for us. Taking advantage of our plight two men, one of whom was my former teacher, asked my relatives to give my hand in marriage. I ran away from home to stay with my elder sister so I could escape early marriage.

Unfortunately this turned out to be like the proverbial jumping out of the frying pan into the fire! In company of teenagers and peers we visited a night club where I was raped by a man I recognized as a religious leader in the area. I conceived at age of 19 years. When time to deliver came I labored for about 20 hours before I was taken to a small health institution with very limited basic equipment and supplies. I was checked by the nurse but it was after another 18 hours that I was referred to a hospital with a gynecologist. I was delivered through caesarian section of a dead baby boy weighing 4.8kg.

Three days later I realized I was leaking of urine uncontrollably. I was admitted for two months, treated and discharged still with urine leaking. I was informed there were no specialists in Kenya who could repair my condition. I was devastated and felt useless with no hope of ever resuming normality.

The rape, loss of baby and now the fistula made me regret being a born a woman. For 12 years I lived a life of misery, pain, rejection and frustration. I had no control of my body functions. The foul smell of urine, ulcers between the legs due to the effect of urine and perpetual tears added to my dejection. Instead of welcoming a new day with a smile I struggled to face it with humiliation, gloominess and depression.

In April 2007 I was admitted in Moi Teaching and Referral Hospital psychiatry ward with severe depression. The admission turned out to be a blessing in disguise because the doctors noticed my bed wetting and on investigation I admitted my status. I was referred to the VVF free clinic in the same institution.

In the month of May 2007 I underwent a successful VVF repair conducted by one of the few specialist VVF surgeons. I recovered completely from depression. I felt like a woman once again.

I decided to dedicate my life to help others with similar situation. I was lucky to have been presented before the American Congress a few years back on a funds drive mission.

Together we can prevent this unnecessary morbidity and facilitate a life of dignity for fistula survivors. Let all know fistula is preventable and treatable!

Sarah Omega is an excellent example of a reintegrated OF client. As a result of her successful surgery she is free from depression and has made it her mission to make it known that fistula has a cure. She is a common sight whenever AMREF sets up a free OF repair camp.

### Ability to fit into family life

Disclosure through accepting one's status and talking openly, discussing experiences assisted in the process of complete healing and re-integration. As per the focus group discussions at the KNH in June 2011, the following sentiments support the importance of disclosure.

Patricia, on the other hand kept her status to herself, much to her detriment. She narrates...

"All this time I never told my husband that I had this condition. I simply kept quiet because I did not know of any other woman who had a similar. I tried to hide my condition by wearing cloth pads but how long could I sustain it?"

When Patricia's husband finally discovered her status he wanted nothing to do with her. He would no longer invite friends home because she was an embarrassment to him. Patricia continued...

"we no longer had any relations. My husband began to have extra-marital affairs.

I called our best couple so that they could talk to him but it was in vain as one day he just woke up and left me and the 2 children. He filed for divorce and went ahead to marry another woman with whom he has two children. I suffered in silence for a long time since I felt nobody would ever comprehend what I was going through"

Millicent said that her grandmother prevailed on her to look for a man to marry me. ...

"I experienced problems with the step mother of my husband who kept telling him to remarry because I could not conceive but my husband never divorced me saying he was willing to wait until I delivered the baby...I no longer feel valued or appreciated in the community since I got this condition".

Later after coming into terms with her condition and learning how to manage the RVF, Millicent decided to get married but she never told her husband about the condition.

"For 3 years he used to ask me why I always run to the toilet but I told him I was pressed", he learnt about my condition when he came to hospital".

She came to the hospital alone and did not remember receiving any advice at admission.

"I came alone to the hospital but later my family members, including my husband came to visit me."

The family never supported her to get treatment for her condition, partly due to financial difficulties and partly because she never really told anybody her true story. She kept the suffering to herself.

The diversity and meaning of re-integration would require longer period of follow up of the client, their family and community in general. The story of Millie indicates re-integration as another chance at motherhood after a successful OF repair.

Millie was repaired at KNH in June 2010, she narrated how desperately she has tried to convince her husband they can get another child now that she could deliver through caesarian section. She is unhappy that her five year old son is growing as an only child but the husband will not hear of it. He is emphatic that the real cause of the OF was due to... "Incompatibility of his seed and her egg", thus the problem

will definitely reoccur if she gets pregnant with him again. He is unwilling to attend counseling at KNH despite much pleading by Millie.

This has been frustrating for Millie as she recounts sadly...

"My husband developed a phobia over baby birth. He swears he will never make me pregnant and ensures it does not happen by using as condom whenever we have marital relations"

In conclusion Millie stated that she sometimes contemplates divorce...

"While my body is finally wholly back to normality...my marital life remains incomplete. Why does he deny me a chance to fulfill my greatest desire for another child?"

Patricia on the other hand elaborates a combination of joy, victory and sorrow after OF recovery ...

"I never told him (my husband) that I was now fully recovered since he was no longer part of my life. I am now well in the body but socially incomplete as I lost my marriage on account of the fistula".

## Case of no re-integration

The story of 17 year old Winnie was used to demonstrate a lack of re-integration. Winnie became pregnant at only 14 years old and lived with fistula for 3 years before surgery; she had to drop out of school as a result of this. She delivered a still birth baby weighing 4.8kg through C/S. After delivery she was hospitalized for 6 months and was unable to walk. Her single mother angrily scolded her... "Don't cry at me. I am not the one who sent you to get pregnant"

With nowhere to go her grandmother advised her to seek refuge at her aunt's place, where she still resides to date.

Winnie was discriminated against by the community because of fistula and accused of all sorts of things...

"Most said I procured an abortion, others said I got fistula as a result of having sexual encounter with old men and that I will never get married because I leak urine. This made me isolate myself from people as much as I could to avoid criticisms and insults but once in a while I would go to church with hope that I will recover and even have my own family in future"

As part of care seeking Winnie tried traditional medicine given by a man who claimed she would be cured in 3 days. She did this in desperation but it never worked and she too never paid him. She had

undergone a previous repair that was unsuccessful. She expressed her hopes for re-integration and in conclusion she said...

"I intend to go back to school and complete my studies and even proceed to secondary school God willing. I will encourage other young ladies to abstain from sex until marriage to avoid going through what I have been through. I will also encourage other ladies in my village to deliver in hospital to avoid getting fistula".

Re-integration in the eyes of Winnie will happen when she has a chance to undergo another OF repair, this time successfully. She will then be able to complete her primary school education and proceed to secondary school.

## Ability to regain complete physical healing

Mary Maria was interviewed at a referral VVF medical camp in Kisii district hospital. She had learnt of the VVF camp from a VCT counselor at Kendu Bay after living with the fistula for 7 years since 2003. The 33 year old initially lived in Kisumu city but after the death of her husband she decided to relocate to Nairobi. She became a fish vendor in Gikomba market and later met a new boyfriend and in the course of their love affairs became pregnant. Mary Maria underwent a difficult and prolonged labour and as a result of which she developed a fistula at the delivery of her fifth baby. In her words Mary Maria continued...

"This was the beginning of my problems". The relationship with the boyfriend started to deteriorate. "Things got real sour when the man started ailing and on learning that he was HIV positive, I decided to go back home with my baby boy, now 7 years". She was accommodated by her relatives for 2 years. It was during this period that she developed leg paralysis and was abandoned by her family to live alone in her late mother's home. Her elder sister took the child to live with her in Homa Bay. Mary Maria laments that... "my leg problem has reduced me to the level of a child, and my hopes of getting back on my feet are dwindling with every passing year. I depend totally on well-wishers".

On learning about the VVF camp she left for her sister's home in Homa Bay to ask for transport money to Kisii. During the camp she depended on other patients in the ward to assist her carry her drinking water, she was always in pain, especially when walking. Initially she underwent physiotherapy at Kisii district hospital but was referred to Nyaburi for disabled in Kendu Bay District, to undergo physiotherapy. She was determined to get back on her feet in order to be reunited with her children. Mary Maria understands re-integration to mean complete healing of her leg paralysis so as to be reunited with her children.

### 5.7. Respondents' Hopes, Expectations and Fears

The greatest hope and aspiration expressed by the majority of women reporting at KNH for surgical repairs in June 2010 was to regain normality, bodily and socially. Asked to name the top most challenging experience since they developed fistula, the following factors, listed here in descending order, summarizes sentiments mentioned: i) to regain total womanhood, and live like other women; ii) to enjoy improved marital relationship; iii) to regain physical/bodily healing and functioning;

iv) ability to attend church & fellowship; v) ability to conceive & deliver normally; vi) resume or complete education. There was consensus that the biggest challenge experienced is the silent loneliness and desire to be a total woman, known only to those who have experienced the condition. The following verbatim quotes elaborate this accurately: Jane stated...

"Although I still attended church, somewhat irregularly, my biggest problem was breaking wind loudly and involuntarily yet no one would understand"

During a FGD sessions participants brought out the problems they faced with the onset of fistula. Patricia had to close her business once she developed the Fistula. She mused ...

"How do you serve food to a customer with faeces dropping uncontrollably?"

She had stopped going to church to avoid embarrassment of feacal droppings when she stood to sing. At home things were not any better; for instance, her husband abruptly stopped inviting his friends to dinner at their home for fear of being embarrassed by her breaking wind uncontrollably. He would usually scold her on account of the bad habit of breaking wind any time any place as stated in Kiswahili... "Wewe uko na tabia ya kunyambanyamba ovyo ovyo!", meaning that she has a bad habit of breaking wind anywhere and anytime. Patricia concluded that this was simply cruelty...".such unkindly statements precipitated tears of loneliness"

Additionally, for the same reasons Patricia would find it unfeasible to assist with cooking chores at her neighbours' functions, thus increasing her isolation in most aspects of societal life.

Deborah whose marriage had deteriorated over the years of her sickness looked forward to successful repair...

"I really hope relations with my husband will improve and save my marriage. I look forward to feel like a woman again ...arguments with husband will cease and I will be happier"

An elderly client, popularly known as Mama Rose, and who had lived with the fistula for fourteen years hoped to enjoy marital relations after treatment...

"I wish I was younger to enjoy my marriage life more. I hope my love life will return to normal. I hope he is clean as I am. Before the Lord calls me home I want to enjoy my marriage".

#### Mama Rose continued...

"I will change from a life of isolation to a normal and socially interactive life. I will be able to laugh out loud. People will no longer label me a prostitute because I will not have any more bad smell."

In contrast a younger woman who had broken up with the husband on account of the fistula had different aspirations.

..." I want to get fixed and be able to mix with people and perhaps conceive again. Yes I know I have to wait for six months after surgery before I engage in sexual intercourse. I pray to get some money and start a business"

A twenty year old girl who had conceived at age sixteen had to abandon school on developing fistula. She also lost her baby at birth but her priorities were different...

"I want to go back to school and complete my education – that is my ultimate desire".

**CHAPTER SIX: DISCUSSION** 

**6.0 Discussion of findings** 

This section discusses the findings of the study as presented, starting with quantitative data and moving

on to the qualitative information.

The total number of respondents interviewed exceeded the minimum of 140 by 21 arriving at a total of

161. Since the study was based in AMREF's preselected sites, it is not feasible to generalize the findings

since the picture is not reflective of the national socio-cultural dispersal; this is usually a concern in

purposive sampling. For instance, ethnic distribution was influenced by the study sites, AMREF's

previous interventions, including client mobilization. Every June during the annual national fistula repair

at KNH the local FM stations participate actively during the weeks preceding the event to mobilize and

enlighten people about OF and the fact that there are free services for it. This has been going on since

year 2007 through AMREF, with funding from DANIDA. The Ministry of Health supports the event and

other partners, such as FFF donate materials and T-shirts, making the event colourful. Clients who have

previously undergone successful treatment introduce friends and relatives through sisterhood

mobilization as they call it to also benefit from the free services.

Socio-demographic characteristics

Close to (60%) of the respondents were in marriage relationships. The rest (40%) were single and young

and under the care of parents and relatives. In a number of occasions the relatives reported frustrations

based on socio-cultural determinants of what is perceived acceptable unacceptable behaviour of the

clients.

Age category 12-30 years presented the highest number of clients developing fistula at the birth of their

first baby. This corresponds with Njoroge et al 2004 on early sexual debut and high maternal morbidity

and mortality, including fistula development. This same category is additionally unprepared to cope with

the demands of pregnancy and child bearing (Njoroge et al 2004). In this study the risk of developing

fistula was highest at first birth and decreased with increasing births down to the ninth birth. This concurs

issues of vulnerability as cited by Mabeya in his analysis of data collected for one month at the KNH,

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where 26.6% of the women were 20 years and below and 81.3% were 30 years and below (Mabeya 2003).

A study in Ethiopia found that OF patients were of an average age of 17years with a mean of 27 years. A total of 70% were shorter than 156 centimetres. In 45.1% the fistula patient was primigravida and perinatal survival was 11.5% (Muleta et al 2010). Muleta though does not state how he calculated perinatal survival rate. A study conducted by the Women's Dignity project in Tanzania found the mean age of 23 years for women who developed fistula, with the youngest being 12 and the oldest 46 years. The majority of the women were 20 years and above when they developed their fistula. These findings are significant as they place emphasis on the common belief that fistula mainly occurs at a young age. (Women's Dignity Project, 2006).

Low levels of academic achievement determined, to a large extent, the occupation and income levels of the clients in this study. The majority 75.5% had low academic achievement and mainly engaged in farming and odd jobs that earned low income. The vicious cycle of poverty once women developed fistula was therefore perpetuated. This concurs with Muleta's Ethiopia study where only 30.8% had completed primary education and 59% of the fistula patients had no formal education and a majority 72% had no occupation.

A study by UNFPA and Population Council also found that women living with OF had a poor education background and were unlikely to be employed or engage in income generating activity (Warren and Mwangi 2008). According to UNFPA obstetric fistula affects the most marginalized members of society, namely poor illiterate girls and women mostly aged between 13-20 years (UNFPA 2003).

The majority of the deceased babies 72% were boys and in the FGDs participants concurred that boy babies are generally more vulnerable whenever problems arise. This had not been reported in other studies but it would be an interesting observation in a large population in future to see if the pattern is maintained. Further research is recommended using a different study design to validate this further.

Clients' residence and delay in care seeking showed that the majority 80% resided in rural areas. This population was also reportedly resource poor and had poor access to health services due to difficult terrain and lack of means of transportation to health institutions. The same population had generally lower levels of awareness of causes and prevention of fistulae.

Mabeya also found some association between poverty and clients with fistula. These factors are consistent with the famous three delays underlying maternal morbidity (UNFPA 2002, Njoroge et al 2004). Kenya Demographic and health Survey 2008/09 also shows that a large proportion of women 59% continue to deliver at home.

The study showed that the majority of clients 79% were not on any form of contraceptives, including those living with spouses. This may confirm several issues; lack of sexual life since the onset of fistula, desire for subsequent babies, poor re-integration and reclaiming back one's life and also laxity towards protection against unwanted pregnancies, among others. Contraceptive use is still low among women, irrespective of their status of health. This finding is similar to KDHS (2008) finding that showed 61% of Kenyan women were not using any contraceptive methods. The findings also concurs with a study by Ngure among HIV positive and negative women in Thika where he established that 74.3% and 75.7% of positive and negative women, respectively were not on any non-barrier contraceptive method (Ngure Kairu 2012).

Awareness of fistula and the underlying causes was at 51% with a closely equal proportion 49% giving incorrect reasons for fistula occurrence. Those showing some level of knowledge gave this only in part. At the onset of fistula, it appeared that neither the client, nor the family, especially spouses were clear what was happening. This is similar to the Tanzania study by where the women attributed the cause of their fistula to witchcraft and use of traditional medicine to speed up labour (Bangser et al 2006). In the same study an 18 year old women felt her fistula occurred because the doctors used instruments to deliver the baby. This shows that many women are still lack knowledge on the causes OF and that it can be cured. It is estimated that about 80% of women living with OF do not seek treatment and live with the condition for many years because of lack of knowledge. (Miller et al 2005)

Fatima of Ethiopian origin developed a fistula during the delivery of her ninth baby. She attributed her fistula to divine reasons or supernatural punishment as she said she believed that it was the will of God for her that it happened.

Sometimes they were also blamed for breach of taboo, curses, witchcraft, accused of previous abortion and immorality, among other. In a study done in Tanzania a certain woman from Ukerewere believed that

her fistula occurred because she was bewitched as she used to deliver on her own without the help of a TBA, thus her act of denying the TBA gifts and privileges received from helping women deliver resulted in her fistula. The types, presentation and observed consequences of fistula may influence community's response to the survivors. The institution of marriage appeared the most negatively affected by the ravages of fistulae and for the married women this was a major contribution to the level of re-integration back to social life. Re-integration meant different things to different clients depending on family background, severity of the fistula and effects thereof, and the client's future hopes and expectations.

Physical, bodily recovery was reportedly only half of the healing agenda, the other and more important aspect of healing was composed of full reclaiming of one's life and status in society. This aspect was not a priority in any of the study sites. The emphasis was on surgical repairs.

The most common type of fistulae presented was the VVF, followed by RVF and finally combination of the two. This concurs with a study done by Wall et al 2005 on 309 fistula patients that showed that isolated VVF are more common than combined VVF & RVF. In that study 78% presented with VVF, 15% had a combination of VVF and RVF while only 7% presented with RVF.

According to the AMREF surgeons, RVF is the easier one to repair. The combination is a bigger challenge to manage, but fortunately this type was also the least common, at least among the respondents studied. The majority of clients who presented at the free medical clinics were repaired successfully. The few who were not so fortunate remained hopeful that some day they will be repaired successfully.

In the FGDs women concurred that when effects of fistula disabled them from participating in such chores as cooking during social functions, they were rendered totally inadequate and this reduced the dignity of a woman greatly and increased social isolation. Mobilization worked best through sisterhood approach by clients who had previously undergone successful repairs. They were able to convince others that indeed there is hope for complete recovery of the survivors who seek help from the free clinics.

Outcome of index child causing fistula shows that the majority of the deceased babies were boys. In the FGDs it was stated that in many cultures there are beliefs to the effect that boy babies are generally bigger, rougher and more vulnerable to death, whenever a problems arises. It would be interesting if further research was undertaken here so as to shed more light as to whether this is because male babies

are generally much bigger in size than their counter parts thus they cause more pressure to the during delivery due to the prolonged labor.

Client's residence and delay in seeking health care by close to 80% of the participants was in rural areas, faced with resource poverty, poor access due to difficult terrain and lack of transportation to health institutions additional to low levels of awareness of fistulae causes and prevention. These factors are consistent with the famous three delays, cited in literature as underlying maternal morbidity and mortality (Thaddeus and Maine 1994).

# **Contraceptive Use**

A majority of clients 79% were not on any form of contraceptives, including those living with spouses. This may confirm several issues such as lack of sexual life since onset of fistula; desire for subsequent conception; poor re-integration and reclaiming of marital and sexual life and general laxity towards protection against unwanted pregnancies.

Contraceptive use is still low among women, irrespective of their status of health. This finding is similar to KDHS (2008) finding that showed (54%) of Kenyan women were not using any contraceptive methods. Awareness of fistula and its underlying causes was at 51% with a proportion 49% giving incorrect reasons. Those showing some level of knowledge gave this only in part. At the onset of fistula, it appeared that neither the client, nor the family, especially spouses were clear what was happening. Some of the clients were reportedly abandoned, harassed, rejected, called names and generally isolated from social circles. This concurs with Warren et al who noted that about 23% of women with fistula faced abuse from their husbands and another 23% were deserted or abandoned by their husbands (Warren et al 2008)

This study showed that a large proportion 79.2% of the respondents was not currently or ever enrolled on any contraceptive method, although some did not wish to continue with child delivery. This concurs with a study by Ngure among HIV discordant couples in Thika where he established that 74.3% and 75.7% of positive and negative women, respectively, were not using any non-barrier contraceptive method (Ngure Kairo, 2012 unpublished PhD thesis).

Underlying wrong perceptions and explanations rotated around supernatural punishment for breach of taboo, witchcraft related, curse, previous abortion, abnormality and immorality. Irrespective of the perceived causes, the survivors received very little, sympathy. The type and consequences of fistula appeared to impact on community's response towards survivors. The institution of marriage was the most adversely affected. This concurs with the results of a meta analysis study done by Ahmed and Holtz in 2007 which found that women suffering from VVF reported disturbed socio-psychosexual lives and are more often than not deserted by their husbands. (Ahmed and Holtz, 2007).

## **Counseling**

A great deal of couselling by professionals trained specifically to handle OF clients is required to assist these few come to terms with the reality. Type and composition of counselling appeared neither structured nor systematically administered. The type of couselling administered tended to focus on the client singly, failing to include the component of spouses, and significant others. For instance, abstaining from sexual relations for six months post operation cannot be observed by a woman single handedly. At any rate the spouse is ordinarily the decision maker, in sex matters. This was a great omission that calls for urgent redress. Key informants reported that a number of clients returned to the hospital with damaged repairs, after a forced sexual activity by the spouses. Such unfortunate incidents would be avoided if the spouses were more actively involved in the treatment of the clients.

Counselling plays a vital role in re-integration thus husbands and key family members of the OF survivors should be given direct counselling so that they can help their wives fit back into the community life. There should also be follow up counselling say 6 months after surgery.

In addition to that it is imperative that counselors assisting fistula clients are trained specifically to handle OF as a special issue. Women need to be advised that they can still have another baby after their fistula has been repaired provided they adhere to the no sex policy for 6 months after surgery and avoid falling pregnant for at least one year after the surgery.

To avoid the recurrence of the fistula emphasis should be made to the women that they should seek medical care throughout the duration of their subsequent pregnancies and should always deliver at a health facility so that any difficulties can be dealt with promptly.

An OF survivor should always inform her medical provider that she has had an OF repair done on her so that she is scheduled for a CS. Counseling will play a big role here as it will ensure that the woman understands that attempting a vaginal birth after an OF repair could cause the tear to reopen due to pressure being exerted at the point of repair.

## Re-integration into the Community

Social re-integration is a complex and continuous process that meant different things to different clients depending on family background, severity of the fistula and effects thereof and the client's future hopes and expectations.

Physical, bodily recover, while essential step towards re-integration was reportedly only half the healing agenda, the other and more important aspect of healing was composed of full reclaiming of one's life and status in society. That aspect was equally neglected in the study sites. The investigator made every effort to understand each client as an individual and their special desire to get assimilated back to society.

A similar situation is reported by Muleta et al in their Ethiopian study whereby they report that though successful treatment of OF resulted in women improving their status individually and at a community level it was, it was still difficult for some women to fully enjoy family and community life even after treatment (Muleta 2008).

Social re-integration should be inclusive of the rest of the family and community in general, thus making it even more difficult to measure especially in a study like this. Women are still not the major players in making decisions concerning their health. This study showed that men still play a major role in determining when and where a woman will have access to health care services especially in homes where the man is the bread winner. There is need to create awareness in men on the importance of their women delivering in a hospital. They need to know what an OF is and how it can be prevented.

Once the OF repair is done women are advised to abstain from sex for 6 months so as to facilitate complete healing. This is usually very difficult for the women to enforce as men demand the fulfillment of their conjugal rights.

This usually results in the women running away from their matrimonial homes until the 6 months elapse. If men know the reason for the abstinence and the risks of opening up the fistula again they will corporate and give their women a chance to heal.

A successful OF repair is a milestone in the life of the affected woman as she feels she now has a new lease on life. The fact that the woman has gone through a successful surgery and is no longer leaking is not an end in itself she now needs to be empowered to earn a living. Prior to the repair the OF survivor may have faced stigma, social isolation and marital breakdown. All these have negative consequences on the survivor.

Re-integration was expressed by participants' hopes and aspirations after successful surgical repairs. These are as diverse as the individuals interviewed such that for re-integration rotated around body and social normality.

Respondents top most desires and hopes after successful treatment embraced sentiments such as i) to regain total womanhood, and live like other women; ii) to enjoy improved marital relationship; iii) to regain physical/bodily healing and functioning; iv) ability to attend church v) ability to conceive & deliver normally; vi) resume or complete education. There was consensus that silent loneliness and desire to be a total woman could only make sense experientially. A few verbatim quotes support this...

"Although I still attended church, though irregularly, my biggest problem was involuntary breaking wind loudly since no one would understand"

OF clients whose injuries are not repairable can be directed to counselors. Once the client is well informed they will come to terms with their status and try to live a normal life. It is particularly important that such clients are assisted to earn a living in a manner that does not resume rejection. Probably through AMREF Project such women, being few, could assist in community mobilization and education on fistula.

The media can play a very big role in increasing knowledge on the causes of the condition and places where treatment of the same can be obtained. Due to the fact that media has a very wide coverage area this would not only help in reducing the backlog of women seeking OF repairs as more women would be mobilized but it would also remove the mystery surrounding the condition.

Also on mobilization at the community level previous OF patients could be trained to act as peer educators so as to identify and bring other fistula clients to treatment facilities

A look at the case of Sarah Omega proves that empowering former fistula patients to act as powerful advocates for change by raising awareness on the issue and working as community activists can help in bringing in donor funds not only for treatment but also for the creation of institutional based reintegration centres for the women.

There are currently no centres in Kenya dedicated to offering re-integration services to women who have undergone fistula repair. When a repair has been successful the survivor is discharged to go home one week after. There is no follow-up done on this woman so as to check how she fitted into the community life. In the absence of rehabilitation centres for fistula re-integration services women were discharged to their homes one week later with instruction to come back in a specified period, usually two weeks, for medical follow up and management. The follow up focuses basically on physical healing with little or no attention on social and community life.

The women go home to diverse household background, some supportive and others not so supportive. There may be a need for shelters, somewhat half way between the hospital and home acting as linkage between new and past successful survivors.

The centers could offer life skills training to facilitate the women regain social and economic empowerment. Skills development to assist the women reintegrate back into the community after fistula surgery. OF survivors are mainly from poor backgrounds and the major suffering they endure is not the illness from the presence of the fistula, but rather the social isolation.

A re-integration Centre would act like a half-way home for the fistula survivor as she would in the company of other Fistula survivors learn life skills and a trade that will help her gain back her economic empowerment. The time she spends at the Re-integration Centre will also ensure that she is not at risk for engaging in sex before the waiting period has elapsed. These Centers would also be an ideal venue for offering counseling services to significant family members on how they can support the fistula survivor to ensure complete re-integration back home.

The hospitals or Centers at which the repairs are done may not have an opportunity to look into the issue of re-integration thus with the support of donors rehabilitation and re-integration centers can be setup with the sole purpose of teaching the OF survivors a trade or a skill that could enhance their source of income. Community based CBOs would come in handy at this point as they could be useful in tracking down the women and checking as to whether the skills they have acquired have been useful in ensuring they can make a contribution to the house budget.

The time a particular woman spends at the centre ensure that she is not at the risk of forced sexual interaction before expiry of the stipulated six months.

The center could additionally become an ideal venue for receiving rehabilitative counselling services both to the survivors and significant family members on supporting the fistula survivor towards complete re-integration. UNFPA and the MOH in Liberia have established The Fistula Project which in turn operates a rehabilitation center where fistula survivors who have successful undergone surgeries are often enrolled for easy re-integration in the communities. The fistula survivors are taught entrepreneuer skills such as tailoring, cosmetology, Tye & Dye, interior decorations, pastry and cake making. These skills empower the women economically and assist them fit back into the community life.

The idea of having a centre dedicated to treatment and rehabilitation of fistula survivors seems very attractive and with a dedicated surgeon on board, trained social rehabilitation officers, a continuous funding stream and support from the government through the MOH this could work. Dr. Mabeya is operating one such centre in Eldoret (Gynocare Fistula Centre), the Centre offers not only treatment but also rehabilitation services though faces a lot of challenges in terms of consistent funding. Stand alone centres may not be the best way to implement the aspect of re-integration here in Kenya because of the fact that donor funding is not sustainable. The focus should be a shift towards community based rehabilitation like what our sister country Tanzania is doing.

Comprehensive Community Based Rehabilitation (CCBRT) is NGO that was set up to offer disability and rehabilitation services to over 120,000 people with disabilities and their caregivers each year in and around Dar es Salaam. This NGO runs a disability hospital and two community based rehabilitation programmes in Dar and Moshi. They focus not only on the physically, visually and hearing impaired but also on OF patients.

CCBRT provides a holistic approach by providing services such as preventive health interventions, cure, awareness raising, empowerment, social integration and mainstream education, counselling and support. The services provided at CCBRT are made possible by funding from the Fistula Foundation, AMREF and the Ministry of Health and Social Welfare. CCBRT implements its work by following the WHO CBR guidelines. These guidelines focus on enhancing the quality of life for people with disabilities and their families, meeting basic needs and ensuring social inclusion and participation. (WHO 2010)

The idea of CBR is slowly picking up here in Kenya with NGOs like the Mumias Community Program (Mumcop) in Western Kenya. This organization focuses on reintegrating OF survivors by creating community awareness on the issue of Obstetric Fistula (prevention and management) and establishing community based economic activities that raise household income for OF survivors in the society. MUMCOP is largely supported by UNFPA.

Through the AMREF Project medical and nursing professionals have been trained in to provide surgery for fistula repairs and provide special post operative nursing care for the OF patients. A number of these were offering services during the annual clinics at KNH and the intervention sites. However, these are volunteers and the clinics tend to be quite heavy. There is therefore need for expansion of the training in order to reduce the backlog OF patients who seek the services from the various level four and five hospitals.

#### **CHAPTER 7: CONCLUSIONS AND RECOMMENDATIONS**

#### 7.0: Conclusions

This study clearly brought out the need to empower women further so that they may assume the role of major players in decision-making concerning their health. When a woman goes into the labour the decision to seek medical care and the choice of health facility was made, by others, such as spouse, parents, in-laws, among other relatives. In addition to empowering the women it is important to encourage male involvement in the repair and management of OF.

The classic delays pertaining to maternal mortality were demonstrated in this study. Lack of decision making power hinders women from seeking health care in timely manner and this would have catalytic effect on the likelihood of women experiencing obstructed labour and subsequently developing an OF. Some clients confirmed having received counseling prior to going into theater, but the extent and content of counseling fell short of their expectations. It excluded, for instance, significant family members, and thus impacted negatively towards promoting social re-integration after recovery.

It is important to note that there is need for well trained counselors to handle and manage OF clients fit back into the community. The nature and quality of counseling appeared to lack strategies and structure, perhaps indicating a gap in availability of counselors trained to specifically handle OF cases.

Stigma associated with OF causes the clients to live a life of isolation and many lost their livelihoods as a result. Therefore successful repair of fistula brings a lot of joy and a renewed hope not only for the survivor but also to her immediate family. There is however, the need to assist the fistula survivors fit back into community life by equipping them with skills that they can use to become financially empowered. An empowered woman will take charge of her health matters and those of her family; being aware of the risks involved, she will seek ANC services early and create awareness to others on the dangers of home delivery.

This study documented sad stories of women experiencing harassment, rejection, loss of marriage and income generating activities. There is a common misconception that OF is a women's affair.

There is urgent need for inclusion of men in the advocacy and fistula awareness and management. This involvement of men could be done through developing community based re-integration and rehabilitation

programs. For the majority of the clients, successful fistula repair and the consequent physical healing is inadequate in the absence of total reclaim of their social life.

It is imperative that counselors assisting fistula clients are trained specifically to handle OF as a special issue. This way the counselor can successfully handle clients whose injury is not repairable. Once the client is well informed they will come to terms with their status and try to live a normal life. It is particularly important that such clients are assisted to earn a living in a manner that does not result to rejection. Probably through AMREF Project such women, being few, could assist in community mobilization and education on fistula.

#### 7.1: Recommendations

The study held interactive discussions with women undergoing obstetrical fistula surgical repairs in selected institutions under AMREF initiative. The study established the OF survivors' expectations, challenges and levels of successful re-integration into the community after successful surgical repairs. The study undertook participatory analysis of the survivors after successful obstetric fistula repairs, assessing reported impact of the surgical repairs in facilitating re-integration into the family and community social life. The findings show the importance of timely interventions, using community structures for education and social re-integration after successful obstetric repairs.

The study made seven recommendations which are listed as follows:

- 1. Re-integration and involvement of significant others in order to reduce the stigma and improve the support structure for OF survivors.
- 2. Offer counselling services and training sessions to OF survivors on complications that can affect maternal health especially the causes and management of OF survivors. Their significant others should also receive counselling.

- 3. More enhanced use of the media namely electronic, print and social media networking sites in spreading the word prior to holding an OF repair camp. This will improve on mobilization and remove the mystery surrounding the condition.
- 4. Advocate for the establishment of more CBR programs around the country so as to ensure OF survivors fit back more easily into the community after surgery. This could be done through development of political will to devote resources to the establishment of CBR programs.
- 5. Encourage male involvement in fistula repair and management as they are still the main decision makers when it comes to women's health matters.
- 6. Further Research into possible association between incidents of prolonged labour and gender index baby. The study findings demonstrated that many of the index babies were actually male. Further research is recommended using a different study design to validate this further.
- 7. Strengthen the argument on maternal health and the visibility of OF within the Reproductive health policy.
- 8. Enhance the fistula prevention package by encouraging the practice of safe motherhood, ANC attendance and delivery with skilled birth attendants.

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# **CHAPTER NINE: APPENDICES**

### 10.1 Oral informed Consent Form

# **Purpose**

We are asking you to take part in research to help us understand the issues surrounding causes, beliefs and treatment of Obstetric Fistula, among women for have been treated for OF in this area. The information will help us understand how women who experience this condition in the community can be assisted to get surgical treatment and continue to lead normal family and community life.

In addition we are asking you to share your experience as a survivor of this condition and propose ways of encouraging other women to come forward and take advantage of the available services.

I would encourage you to speak as freely and frankly as possible. The responses you give in this interview will be confidential. We would also like to record your answers both by writing to help in the analysis of your answers.

#### **Risks and Benefits**

Please do bear in mind that there is no harm in not participating nor is there a direct benefit in participating except that the information will be useful to policy makers.

The interview will take about one and half hours. Do you all agree to participate in this discussion? Note that you may leave at any time during the discussion.

## Your participation is voluntary:

You do not have to participate in this study if you do not wish to. You may also leave the study at any time.

## **Compensation:**

Each participant will receive Ksh. 150 cash to cater for lunch and transportation costs.

### Volunteer Agreement:

I have been given an opportunity to have any questions about the research answered to my satisfaction.

# 10.2 Tools for data collection

# 10.2.1 Individual Questionnaire:

Questionnaire number	Date of surgery	
Site	Respondents identity	
Interviewer	Admitted/clinic Review	
Socio-demographic background	<del>_</del>	
1. Date of Birth	Or Age	
2. Marital Status Married	Poly/MonoSingle Divorced	
3. Age at first marriage		
4. Last delivery Order	of Birth(Circle birth that precipitated fistula)	
5.Outcome (tick): Baby aliveDece	ased Sex of baby: Malefemale	
6.Number of living children		
7.Completed years of schooling: Primary_	SecondaryTertiaryNone	
8. Occupation/work for living: Farmerspecify	Employedbusiness(others)	
8a.Average monthly income		
9.Participant's residence. (Tick one) Rural	_ Urban _	
10.Spouse/Partner		

i) D	oes participant live with spouse/partner regularly? Ye	es No
ii) N	Number of living children with Spouse/partner	
ii) A	Age at first pregnancy	
11.	Birth Control Methods at enrolment: Yes No	
Cur	rently using birth control? YesNo	
12.	Post operative respondents only	
	ce successful OF repair would you say your life has im	nproved?
	what ways? Socially accepted Women group	-
,		112021001
10.2	2.2. Institutional Information	
1.	Name of Health Facility	
2.	Province Where Facility Found	
3.	Type of Health Facility	[] Provincial
		[] District
		[] Faith Based
4.	Predominant Ethnic Group	
5.	Staff trained to treat OF	
1.	From the register: How many OF patients have been	l
	treated in the institution in the past three years	
2.	What were the recorded causes of the OF?	[Rape] [Obstructed
		Labour] [FGM]
		[Other]
3.	Average age of the OF survivors?	
4.	Average number of living children before OF?	
2 2	Institutional Counseling Services	
	. Institutional Counseling Services	[Nol [Voc]
טומ	you receive counselling about your condition and this	[No] [Yes]

surgery?		
Do the facilities offer privacy?	[No]	[Yes]
*Are there counsellors trained specifically for OF?		
Do you know other OF survivors who could benefit from this	[No]	[Yes]
counselling?		
What are the common believes about OF causes?		
On average how long did it take you to get counseling after		
before initial treatment?		
Did you receive follow up sessions after treatment?	[No]	[Yes]
Were any family members offered counseling?	[No]	[Yes]

# 10.2.3 In depth Interviews/Narratives with stable survivors

To be administered to stabilize OF survivors admitted in the hospital or attending clinics after successful surgical repair. Volunteer survivors will be encouraged to narrate their experience in their own words and (where agreeable) an audio recording will also be done. By the end of the interview, though not in question/answer form, the interviewer should probe for the following details:

Describe OF in your own view	Probe for real and perceived causes
What do family/community members say causes	Probe for knowledge of real causes,
OF?	contradictions, beliefs, blaming the
In your case what do you consider as the major	victim, social status loss, rejection
cause?	etc
How long did you stay with the condition before	
seeking any intervention?	
How did you learn about this medical	Estimated distance in km
camp/surgery?	
How far is site/institution from your	
home/residence?	
Initial reception at the institution/facility in their	Staff friendly? Polite? Kind?
perception	Was confidentiality ensured?

What challenges has the person experienced? (At domestic, community and Institutional levels?) List under (biological, reproductive Are you aware of indigenous knowledge, practices activities, social, psychological, and beliefs useful in reducing OF problems? esteem etc) Were the perceived causes of OF? Does the health Probe for both positive and negative provider mention different causes? Were the steps aspects in intervention explained clearly to you? Are you accompanied to the institution by Probe for the role the companion anybody? Tick (spouse? Family? Friend? Health personnel?) What has changed in your life since the OF Probe for biological, social, surgery? emotional Probe for self esteem, self Would you say you have regained self worth? **Explain** confidence Do friends, family & community in general, Probe for improved appear to accord you respectable roles/position? interrelationships What are your comments regarding success or /and Probe for biological social shortcomings of the surgery? emotional etc Probe for Subsequent deliveries What advice were you given on discharge?

# 10.2.4. Key Informant Interviews with health providers

This was conducted among the institutional departments. Interview included those involved in the care of survivors of Obstetric Fistula (OF): Surgery, nursing, gynecology, counselling,

The interviewer probed for the following details:

What are the commonest types of OF handled in this institution?

What are the general causes of OF in this community?

What are the main challenges faced in handling the survivors?

What extra resources or intervention would be appropriate for the survivors?

What are the constraints facing women willing to seek OF services?

What steps would you recommend to be taken at local level?

Which constraints would require external intervention?

What is your general comment on OF in this community?

Are you aware of indigenous knowledge aiming at reducing obstetric health problems?

# **Appendix 3:Ethical Approval**



Ref: KNH-ERC/ A/114

Mumb W. Mwakio P O BOX 2451 – 00202 NAIROBI

Dear Mumbi

KENYATTA NATIONAL HOSPITAL

Hospital Rd. along, Ngong Rd. P.O. Box 20723, Nairobi.

Tel: 726300-9 Fax: 725272

Telegrams: MEDSUP", Nairobi. Email: <u>KNHplan@Ken.Healthnet.org</u>

13th May 2011

Research Proposal: "Experiences, Challenges and Success in Social Re-integration of Women undergoing obstetric Fistula Repairs: A case study of three AMREF Intervention sites" (P439/12/2010)

This is to inform you that the KNH/UON-Ethics & Research Committee has reviewed and <a href="mailto:approved">approved</a> your above revised research proposal. The approval periods are 13th May 2011.

You will be required to request for a renewal of the approval if you intend to continue with the study beyond the deadline given. Clearance for export of biological specimens must also be obtained from KNH/UON-Ethics & Research Committee for each batch.

On behalf of the Committee, I wish you a fruitful research and look forward to receiving a summary of the research findings upon completion of the study.

This information will form part of the data base that will be consulted in future when processing related research study so as to minimize chances of study duplication.

Yours sincerely.

PROF A N GUANTAL

SECRETARY, KNH/UON-ERC

C.C.

The Deputy Director CS, KNH The HOD, Records, KNH

The Director, School of Public Health, UON

Supervisors: Prof. Joyce M. Olenja, Dept. of Public Health, UON

Dr. Dismas Ongore, School of Public Health, UON

Dr. Johnson Musomi, AMREF

# Appendix I Declaration Form for Students

### UNIVERSITY OF NAIROBI

# **Declaration of Originality Form**

This form must be completed and signed for all works submitted to the University for examination.

Name of Student MUMBI W. KIMANI
Registration Number 8141106
College of Health Sciences
Faculty/School/Institute School of Public Health
Department
Course Name Masters in Public Health.
Title of the work Social Reinlessaling is women underson of reports: A  Case study of 3 American Intervention Sites  DECLARATION
<ol> <li>I understand what Plagiarism is and I am aware of the University's policy in this regard</li> <li>I declare that this  (Thesis, project, essay, assignment, paper, report, etc) is my original work and has not been submitted elsewhere for examination, award of a degree or publication. Where other people's work, or my own work has been used, this has properly been acknowledged and referenced in accordance with the University of Nairobi's requirements.</li> </ol>
3. I have not sought or used the services of any professional agencies to produce this work
<ol> <li>I-have not allowed, and shall not allow anyone to copy my work with the intention of passing it off as his/her own work</li> </ol>
<ol><li>I understand that any false claim in respect of this work shall result in disciplinary action, in accordance with University Plagiarism Policy.</li></ol>
Signature Wikiwari
Date 8-11-2013
Date O // AC/