

**SOCIAL STIGMA AND REINTEGRATION OF OBSTETRIC
FISTULA SURVIVORS IN WEST POKOT, KENYA**

BY

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DECLARATION

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

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This research project is submitted for defence in partial fulfilment for the award of Master of Arts degree in Gender and Development studies with my approval as a university supervisor.

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DEDICATION

This research project is dedicated to my late mother. You always believed in me and kindled a fire that burns on; an unrelenting quest for knowledge.

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ABSTRACT

Obstetric fistula is a medical condition in which a woman develops a hole between the vagina and rectum or the bladder during delivery. In West Pokot, this condition attracts social stigma, abandonment, seclusion and isolation of the woman from family and general community. In this sense, obstetric fistula which is a medical condition has caused a social problem in the region. The condition is treated by corrective surgery.

This exploratory study examined the problems faced by obstetric fistula survivors and challenges of re-integrating back into the community women who have undergone corrective surgery in West Pokot, Kenya. The main study objective was to explore the social stigma faced by obstetric fistula survivors and its effect on their reintegration into society. In-depth interviews, key informant interviews and focus group discussions were used to collect data. Eight women, aged between seventeen and thirty years, who had previously undergone obstetric fistula corrective surgery were interviewed. Questions about their experiences of living with obstetric fistula and the factors that influenced their reintegration after surgery were posed. Particularly, their experience of social stigma was explored. A focused group discussion consisting of obstetric fistula survivors, some who had earlier participated in the in-depth interviews was held to shed more light on the topic. Community members participated in a separate focus group discussion. Key informant interviews were held with two traditional birth attendants, surgeons, nurses and social workers in the district. The focus of the interviews was to provide information on how they manage/ support women with obstetric fistula, particularly the reintegration of fistula survivors into the community. The interviews and discussions were taped then transcribed. In addition note taking was also employed to guard against technological failures. Thematic data analysis based on grounded theory techniques was used to analyze the data.

The obstetric fistula survivors were mostly young women aged between seventeen and thirty years, with low literacy levels and were either divorced, separated or living with their husbands. Most of the survivors developed obstetric fistula delivering their first child. However a few had other children before the birth that caused the fistula. Survivors

interviewed had lived with the condition for periods ranging between two to five years before surgery. The study established that social stigma which continues even after surgery is a major challenge that the women have to deal with daily, posing a great challenge to the reintegration of survivors. The stigma originates from the cultural beliefs and practices of the Pokot community. Fistula survivors who experienced social stigma after surgery were more likely to have problems coping with reintegration than those who didn't. There were other challenges of coping with after surgery instructions; divorce and separation; poverty and infertility that must be overcome before a survivor is sufficiently reintegrated. There is an apparent lack of a comprehensive reintegration program for obstetric fistula survivors that would address their needs after surgery in this region.

The study recommends that after surgery, obstetric fistula survivors should be helped to reintegrate back to the community and proposes several avenues through which this could be done. Of these, long term counselling, income generating activities and education and skill training were proposed. Family and community support were vital in the reintegration of obstetric fistula survivors. The community is a major participant in eliminating social stigma; given that stigma is a social construct. Furthermore, many of the proposed reintegration strategies largely depend on the community for their success. The study therefore recommends that reintegration programs must be participatory, with an integrated approach amongst the various government sectors and NGO's in the region.

CHAPTER ONE: INTRODUCTION

1.1 Introduction

The term fistula means an abnormal duct or passage resulting from injury, disease or a congenital disorder that connects an abscess, cavity, or hollow organ to the body surface or to another hollow organ (Mosby's, 1995). An obstetric fistula is an opening in the wall of the vagina connecting to the bladder (Vesicovaginal Fistula - VVF), and sometimes to the rectum (Rectovaginal Fistula - RVF) (Tiran, 2003). Both types of obstetric fistula are a result of prolonged obstructed labour; when the baby's head stays in the birth canal for hours to days it presses against the bladder and/or rectum, causing tissue damage. The dead tissue eventually falls away, creating one or more holes that leak urine and/or faeces uncontrollably (UNFPA, 2005). In most cases the babies die leaving women with constant pain, incontinent of urine and/or faeces, bearing the sadness of their stillborn children, abandoned by their husbands and their societies, and they live without friends and without hopes (Wall *et al.*, 2005).

More than 2 million women worldwide are living with the problem of obstetric fistula (WHO, 2005) mostly in Africa and Asia, with an addition of 50,000 – 100,000 new cases every year. In Africa alone, recent estimates from a population based survey of severe obstetric morbidity suggest that at least 33,000 new cases occur each year in sub-Saharan Africa (Vangeenderhuysen, 2001). Obstetric fistula is amongst the most severe childbirth complications (WHO, 2005).

Obstetric fistula is less prevalent in the developed and affluent countries due to availability of skilled attendants at childbirth and availability of emergency obstetric care. In these countries fistula occurs mainly due to congenital abnormalities, or from surgery, radiation, or in some cases as a result of unskilled abortion (Cook *et al.*, 2004). On the contrary, millions of women in the developing countries suffer from the condition because obstetric care is either unavailable, inaccessible, underutilized or of low quality (Donnay and Ramsey, 2006).

The national prevalence rate of obstetric fistula in Kenya has not been established (MOH and UNFPA, 2004). However, prevalence of the condition in West Pokot is estimated at 1 in every 1,000 women (Mabeya, 2004). According to the needs assessment carried out in Mwingi, Kwale, Homabay and West Pokot Districts, women living with fistula face stigma and isolation (MOH and UNFPA, 2004). The report however noted that while the women with fistula in other districts were regarded with pity and isolated themselves out of embarrassment from the foul smell, the condition is different in West Pokot where they were stigmatized and isolated by society. These facts have serious implications given the high prevalence of the condition in the region.

Stigma poses a great challenge to the healing process in mental illness and during rehabilitation of drug abusers (Kleinman *et al.*, 2006) and on the general health of the public (Link and Phelan, 2006). Stigmatization necessitates a social support system to facilitate the reintegration of fistula survivors into the community after surgical repair. Reintegration is important to the psychological and economic well being of fistula survivors as demonstrated by Mohammad (2007). This study aims to explore the challenge of social stigma faced by fistula survivors and factors that enhance their social reintegration into the community in West Pokot, a region with a high prevalence of obstetric fistula. The study is expected to demonstrate the effect of stigma on the reintegration process among fistula survivors. This is an exploratory descriptive study. The study results will go a long way in filling in gaps on what is known about social reintegration of obstetric fistula survivors in this region.

1.2 Problem Statement

The prevalence rate of obstetric fistula in Kenya has not been established. However in West Pokot district, the estimated prevalence of women living with fistula is at 1 in 1,000 women, translating to about 30 women per Km². Although there are outreach services that carry out fistula repair, few reintegration efforts have been documented so far.

There has been a great achievement in the physical treatment of obstetric fistula (AMREF, 2007). However, the long term emotional, psychological, social and economic

needs of women after surgical repair have received little attention to date. These women may also face problems reintegrating into their local communities that may desert them or regard them as unclean or cursed. In many cases the situation is aggravated by the increasing poverty women with fistula may face due to their limited income generating resources (WHO, 2005).

Women living with fistula experience seclusion and stigma owing to the offensive smell and taboos. Social stigma is still a challenge to fistula survivors (MOH and UNFPA, 2004) as there is established stigmatization of women living with fistula in West Pokot. Some women have even been abandoned by their husbands and secluded by family. To this effect a medical condition has caused a social problem which takes away social support from those suffering from obstetric fistula.

Social reintegration strategies largely depend on the elimination of stigma and society giving support to survivors. This is an ideal situation which can be achieved if the real extent of stigma and its effect on reintegration is established. This study aims at establishing the stigma that fistula survivor's face and the influence of stigma on their social reintegration into the community.

In particular this study will answer the following research questions:

1. What are the challenges of living with obstetric fistula?
2. What factors influence the social reintegration of obstetric fistula survivors?
3. How might we improve the effectiveness of the reintegration process for fistula survivors?

1.3 Objectives

1.3.1 General objective

To explore the social stigma faced by obstetric fistula survivors and its effect on their reintegration into society.

1.3.2 Specific Objectives

1. To determine the challenges of living with obstetric fistula.
2. To identify factors that influence social reintegration of fistula survivors.
3. To establish strategies for social reintegration of fistula survivors.

1.4 Study Justification

Little research has been done on social reintegration of fistula survivors back to their communities after surgery. Particularly, the effects of social stigma on the reintegration process for fistula survivors remain unexplored in Kenya. There could be factors that enhance or impede this process, considering the fact that it is a condition that attracts a lot of stigma and isolation. Social reintegration is important to the psychological, social and economic well being of fistula survivors and to this effect, there ought to be minimal or no stigmatization of fistula survivors, a goal that can be achieved if there is a comprehensive reintegration program in place. Such a program can only be built from sound strategies developed from research findings as this study intends to elicit.

This study will generate a body of knowledge that will help social scientists, health care workers and development planners to plan and cater for the needs of women in the region as far as obstetric fistula survivors' social reintegration is concerned. The study findings and recommendations may also be utilized in areas of reproductive health, safe motherhood initiatives and gender and development activities. The study aims at generating a basis for further research on the social reintegration of obstetric fistula survivors in other parts of Kenya. The study will also highlight the plight of women living in endemic conflict prone areas in regard to health and development, an aspect that is unique to the West Pokot district in Kenya.

1.5 Limitations of the study

The study is limited by several methodological issues. The exploratory design of the study limits the sample size and yields qualitative data. Therefore, the results may not be statistically generalisable to the entire Kenyan population. Moreover, the study samples participants from a district with people of a predominantly one cultural background

further challenging the results generalisability to the entire Kenyan population. Further and broader studies on the topic are recommended to reflect the broader picture.

The data collection tools involve the researcher as a participant and not merely an observer, introducing a risk of researcher bias. This has been overcome by use of focus group discussion guide and in-depth interview guide that have questions which probe the discussants and participants along common general themes. The focus discussion group as a method is limited in meeting the ethical principle of anonymity as there will be a certain degree of disclosure of personal opinion by the participants to their peers, who may also be known to them.

The scope of this study is focused mainly on social stigma and social reintegration of fistula survivors. Other aspects such as medical management will not be considered in the study, as there have been numerous other study findings on the same.

1.6.0 Definition of Terms

Obstetric care – Health care given to mothers during pregnancy and delivery/ childbirth.

Social stigma - The societal activities or lack of that prevent a person's freedom of existing and operating within the society, based on the individuals characteristics such as health, race, colour, mental status or social status.

Social reintegration – Being able to fit in with other people and be accepted.

CHAPTER TWO: LITERATURE REVIEW

2.1 Literature review

2.1.1 Background information on obstetric fistula

The prevalence of obstetric fistula is estimated at 2 million globally (WHO, 2005), with a majority of these cases being in Asia and Africa. In Kenya the national prevalence rate of the condition is not known (MOH and UNFPA, 2004). However in West Pokot it is estimated that 1 in every 1,000 women suffer from the condition (Mabeya, 2003). Many women suffering the condition remain hidden because the condition is associated with shame and disrespect, and most of the literature available on the subject of fistula is mainly based on the stories and opinions of those who are working in the areas of high prevalence rather than firm scientific based evidence data (Hilton, 2001). There is a possibility that the prevalence is much higher than the estimated (WHO, 2005).

Obstetric fistula in Kenya has been studied in the medical context. However they are few, as between 1965 and 2009 only five studies have been conducted: - Mati (1968) in Kenyatta National Hospital; Orwenyo (1984) in Kenyatta National Hospital; Amoth (2001) in Kenyatta National Hospital; Mabeya (2003) in West Pokot and MOH and UNFPA (2004) in West Pokot, Mwingi, Kwale and Homa bay districts. These studies have unanimously brought out the challenges that women who live with fistula face, the greatest being that of stigmatization and isolation.

Obstetric fistula tends to affect marginalized poor women who have the least access to obstetric care (Donnay & Ramsey, 2006). They are mostly young, early married women, illiterate, with little or no access to obstetric care. They are mainly delivered at home attended by family members or unskilled birth attendant or traditional midwives (Wall *et al.*, 2005). The most common cause of obstetric fistula in developing countries is prolonged obstructed labour, which occurs in around 4.6% of pregnancies and cause around 8% of maternal mortality worldwide (WHO, 2005).

Several social, cultural and health system factors contribute to the prevalence of obstetric fistula in the developing countries (FIGO, 2006). These confounding factors have been

pointed out as: lack of emergency obstetric care, child marriage associated with early pregnancy, practice of severe forms of female genital mutilation (FGM), gender discrimination, poverty, malnutrition and poor health services. The evidence among the Pokot suggests a link between FGM and the development of fistula (Mabeya 2003). The Pokot perform Type III female genital mutilation (Infibulation), which leaves a very small opening that sometimes seals completely. At delivery, traditional birth attendants (TBAs) use arrowheads to perform bilateral upper episiotomies, which sometimes inadvertently extend to the bladder or to the rectum creating a fistula. The scars forming from FGM also cause obstructed labour owing to inelasticity and inability to stretch during childbirth. Other studies have shown that FGM causes obstructed labour (WHO, 2006b).

Services that have been identified to prevent maternal deaths and disabilities include the provision of reproductive health services and information using a human rights approach (Cook et al, 2004). Community education for women, families and their communities on safe motherhood initiatives and prevention of maternal complications is a key strategy towards preventing obstetric fistula.

Hospitals and NGOs that carry out fistula repair missions in Kenya include Ortum Mission Hospital, Kenyatta National Hospital, Jamaa Hospital and Moi Teaching and Referral Hospital and AMREF. AMREF is working towards safe motherhood initiatives and fistula prevention and repair in Kenya (AMREF, 2007). AMREF vesico-vaginal fistula (VVF) project that began in 1992 has been supporting repairs of fistulas in East Africa through their outreach program. However, there is no documented evidence of a comprehensive reintegration program for fistula survivors by the government or NGOs.

2.1.2 Obstetric fistula and gender inequality in Kenya

As part of the Millennium Development Goals (MDGs) the Kenya National Health Sector Strategic Plan (1996) has identified maternal health and reproductive health as social development priorities for the next decade (AMREF, 2007). The strategic plan calls for the commitment of stakeholders to alleviate the suffering of women, girls and

their families through increasing health systems capacity and capability to implement safe motherhood initiatives (SMI) and obstetric fistula (OF) interventions within the human rights context.

Recognizing the fact that obstetric fistula occurs only to women, gender issues have a great role on its formation. It is for a fact that only females can give birth, but there must be more inequality issues at play for women to not only bear the physical burden of it but also the stigma and isolation should the delivery go wrong. Stigmatization occurs under power relations that allow the phenomena to unfold (Link and Phelan, 2001) and only those who have power over others can stigmatise them.

The major underlying causes/ contributing factors to occurrence of obstetric fistula in Kenya can be summarized in the following points:

- The most important factor that contributes to fistula formation is poverty, especially in rural areas where the majority of the women with obstetric fistula come from (AMREF, 2007). Most of the affected women in obstetric fistula repair camps and clinics come from extremely poor families and they have limited or no access to financial resources. They are completely dependent on their families. Cook *et al.*, (2004) point to the existence of poverty as a key factor to the incidence of fistula and its harsh impact on women's lives. Marginalization of women with fistula is yet another contributing factor.
- Cultural factors like the existence of deeply rooted harmful traditions such as female genital mutilation (FGM), early girl child marriage, high illiteracy rate among women, and the influence of men in a highly patriarchal society also contribute to occurrence of fistula (Donnay, 2006; AMREF, 2007 and FIGO, 2006). Political instability and conflicts greatly affect the health care services provided to women (Pike *et al.*, 2010). Destruction of social and health services is one of the serious impacts of conflict on women's health in West Pokot.

- Availability, accessibility and the quality of the health services during pregnancy and child birth influence the outcome of childbirth. In cases of difficulty accessing these facilities due to inaccessibility and/or unavailability of transportation and the lack of emergency obstetric care (EmOC) facilities the woman's risk of developing obstetric fistula is increased (AMREF, 2007). In this sense, West Pokot still lags behind in terms of transport and health facilities within the recommended radius.

Community and individual level factors influence health-seeking behaviour (MOH and UNFPA, 2004). In some instances, the expectation to have the first baby at home as proof of womanhood and bravery contributes to prolonged labour as is the case in West Pokot (Mabeya, 2003). This is reinforced by the cultural expectation that a woman is supposed to deliver in her husband's hut for legitimacy of the child. In this community Female Genital Mutilation (FGM) was also cited as one of the contributors to obstetric fistula through crude incisions (episiotomies) using arrowheads to release scar tissue from infibulation, often injuring the bladder and/or the rectum. This practice further perpetuates gender inequality as it predisposes women to unnecessary health risks.

Vulnerability to obstetric fistula violates women's human rights to reproductive health (Cook *et al.*, 2004; Cook *et al.*, 2003). As is now recognized internationally, it is a woman's right to access appropriate health care services that will enable her go through safe pregnancy and childbirth. For instance, the UN Convention on the Rights of the Child (2001) is often violated by girls' early marriage and premature pregnancy. CEDAW also aims at protecting women's rights to health services, especially those living in the rural areas. The International Covenant on Economic Social and Cultural Rights (The Economic Covenant) also directly provides for special protection of mothers for a reasonable period before, during and after childbirth.

High prevalence rates of fistula demonstrate injustice violation of human rights, and the inequality of life between men and women, older women and younger women, poorer and wealthier women and even between women living in poor countries to those in the

developed countries (Cook *et al.*, 2004). While some countries invoke the excuse of lack of financial resource and personnel to prevent fistula, it is notable that the very countries spend so much more on other expenditure like militarization in apparently peaceful situations. The incidence of fistula in such cases signifies a country's failure to value, recognize and protect women's human rights, their health, dignity and their lives.

2.1.3 Socioeconomic Consequences of Obstetric Fistula

The psychological consequences of obstetric fistula are substantial, with depression and early death from suicide (FIGO, 2006). Holtz and Ahmed (2007) demonstrate that women suffering the ordeal of fistula are abandoned by their husbands and family, and are shunned from their communities. Fistula is considered a "social calamity" and women with fistula are often ostracized by their husbands, families, and communities. The condition is often considered a sexually transmitted disease and viewed as a punishment from God. Most women with fistulas report disturbed socio-psychosexual lives and are usually deserted by their husbands. Often, until they are cured, married women with obstetric fistula are sent back to their parents' home where they are not allowed to cook food, participate in social events, or to perform religious rituals. Not only that mourning a dead child is almost inevitable for a woman with a fistula from obstructed labour, but she soon finds herself fighting for her own survival, social position, and value in society. Mentally she is tormented and devastated.

Physical/ medical consequences of obstetric fistula include ulceration, infection, foot drop, kidney diseases and dehydration. In almost all cases of obstetric fistula the leaking of urine and the offensive smell makes the women highly stigmatized and ashamed of themselves (Bangser, 2006; Holtz and Ahmed, 2007; Cook *et al.*, 2004). Consequently, eating, sleeping and praying alone (social isolation), abandonment and divorce, loss of self esteem and economic deprivation occur. Due to misperceptions surrounding the condition, many of the women survivors see themselves as wretched or cursed, isolating them from their communities and preventing them from seeking help and treatment.

According to the needs assessment carried out by MOH and UNFPA (2004) stigma is an elusive concept, but one that is increasingly recognized as a major component in the perception of the ill person. In Mwingi, Kwale and Homa Bay districts the issue of stigma is not so explicit. The general feeling was that their immediate families did not reject women with fistulas. However, the women, out of their own volition segregated themselves from others because of the embarrassment occasioned by the foul smell. However, having a fistula among the Pokot attracts a social stigma from the community in that the women cannot stay with others or even cook for the family. Worse still is the situation where a husband returns the wife to her father and demands a refund of the bride price especially if the fistula occurs at birth of the first child.

Fistula is invariably devastating to the lives of women who survive and endure it (Cook *et al.*, 2004). Affected women are frequently driven from their marriages, families and communities to a point of becoming socially invisible and forgotten. They experience a foul smell that results from leaking urine and faecal incontinence and are barred from family activities like cooking and at times driven into isolation. Denied family support, the malnutrition and poverty is aggravated and at times when they can, such women have depended on begging, prostitution or stigmatizing employment. Arguably, social stigma contributes further to women's poverty and gender inequalities.

Women living with fistula experience seclusion and stigma owing to the offensive smell and cultural taboos and this may still be a challenge even after corrective surgery. These women may also face problem reintegrating into their local communities that may desert them or regard them as unclean or cursed. In many cases the situation is aggravated by the increasing poverty women with fistula face due to their limited income generating resources (WHO, 2005).

2.1.4 Strategies for social reintegration of obstetric fistula survivors

Various reintegration strategies for fistula survivors have been recommended. A meeting report tabled by the UNFPA (2005b) working group on monitoring and evaluation of obstetric fistula identified reintegration into social life as one of the group's three major

goals, beside prevention and treatment. Reintegration is aimed at ensuring that all treated women, regardless of outcome are empowered and reintegrated into social life free of stigma. This would be achieved through ensuring increased financial, logistical and political sustainability of rehabilitation and reintegration services. The women must have access to these services and their communities urged on supporting the survivors. However the group was keen to point out that while integration services focus on all women who present with fistula, community level activities will increase support available to these women. The key outcome should focus more on reintegration to society rather than to a woman's original community. Efforts should go beyond counselling to include economic empowerment and community wide education. The report noted that reintegration indicators are difficult to develop but should be survivor oriented reports rather than based on the number of organizations offering reintegration services. New data collection and follow up at community level is needed in order to determine the extent to which a fistula survivor has been reintegrated back into social life. To achieve this, a strong linkage with NGO's that offer reintegration services is needed.

Respect for women rights as human rights is an important strategy for all stakeholders to consider adopting when developing programs towards fistula survivors (Cook *et al.*, 2004). In this light, women's reproductive health should be a right as contained in several international protocols, to which Kenya is a signatory to. Beyond physical treatment, there has to be efforts towards gaining the fistula survivors smooth re-entry to their communities.

As demonstrated by a program in Nigeria (Foundation for Women's Health, Research and Development) a good intervention package in a suitable environment has the potential to turn around the lives of women with fistula from hopelessness to good physical and mental health (Mohammad, 2007). Over the seven years that the program had run, a hundred percent of patients had been successfully reintegrated back into their communities. The project utilized a holistic approach with community participation to address a problem whose causes are multidimensional. The program had inbuilt health components such as raising awareness on sexual and reproductive health issues and rights

which are necessary for the eradication of fistula. The project also focuses on the reintegration of women into their communities following rehabilitation with a twelve month follow up period. The rehabilitation program focus is on gaining the women a form of empowerment and improvement in their socioeconomic status. Local women's organizations, community based organizations and nongovernmental organizations participated in the follow up and training of fistula survivors for this project, hence affording it very high success rates. While the author notes the high popularity of women specific projects to address women's problems, they have little success hence need for integrated approaches. There is growing evidence that interrelated projects focused on efforts to improve the health and overall status of women will provide substantial benefits in terms of human welfare, poverty alleviation, and economic growth.

Reintegration program designers should bear in mind that all girls and women with fistula are not the same (WHO, 2006a), though they may share a number of common experiences. As such, reintegration strategies need to address the different situations in which these women may find themselves. For example, the varying need for family and social support, livelihood and income generation, and education and training. In addition, their reintegration experiences may be impacted significantly by previous experiences of living with a fistula prior to the repair. The degree of isolation, stigmatization, etc. experienced while living with fistula could well affect the situation after the repair. If the initial disruption experienced by the woman is low (e.g. her husband is supportive and she has other children), then she may continue in her normal life. On the other hand, the future is less clear if a woman is divorced, has lost employment, is back living with her relatives, has no future child-bearing capacity, does not have a normal vagina for intercourse or has stress incontinence and is still leaking. Research on reintegration and financing reintegration activities is another strategy that has been recommended by several studies (WHO, 2006a; Mohammad, 2007).

2.2 Theoretical framework

The study is guided by Erving Goffman's stigma theory (Goffman, 1963). Goffman defines stigma as an 'attribute that is deeply discrediting', reducing the person that possesses a particular quality 'from a whole and usual person to a tainted and discredited one' whereby consequently the person is socially discounted. For Goffman, the stigmatized can be either discreditable or discredited. The former refers to people that possess a stigmatizing characteristic but have not yet been discredited, mainly because this quality has not yet been fully revealed. The latter relates to those who have been socially judged and marginalized by their surrounding social world.

Stigmatization is the result of a socialization process whereby the person with the quality generally holds the same identity beliefs as normals (i.e. persons without a stigmatizing characteristic) and may in fact feel normal when alone. This is then displaced by a sense of deep abnormality in the presence of normals, frequently resulting in feelings of self-hate, self-isolation, depression and/or hostility (Carnevale 2007). Goffman describes the socialization of the personal identity of a stigmatized person as a process of information control. The discreditable person manages information, continually judging whether or not to reveal their stigmatic quality. When the person is actually discredited, they are faced with managing the tension that will ensue. Passing is a central concept developed by Goffman, which he uses to help describe information control. This refers to when a person with a stigmatic quality manages information so that they can partly or fully 'pass' as a normal. Given the rewards of being normal, the stigmatized will attempt to pass if they can. Passers draw on several information control strategies. These can include the concealment of stigmatic symbols or use of disidentifiers.

The relationship of the stigmatized with normals highlights their deviation from societal norms. Consequently, the stigmatized manage their social deviance by either creating their own social norms that they will measure themselves against, alienating themselves from the community that upholds the stigmatizing norms, or employing a variety of passing techniques to manage information and their status among the stigmatized and normals.

Link and Phelan (2001) expounded on Goffman's stigma theory. They conceptualise stigma as the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination – and further indicate that for stigmatization to occur, power must be exercised. In their definition 'stigma exists when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows these processes to unfold.'

2.2.1 Relevance of Theory to the Study

Goffman's theory is relevant to this study as stigma is the independent variable being studied. Therefore the concept of stigma as put forth will guide the conceptualisation and measurement of variables. Interplay of the four components of stigma is often seen in the lives of fistula victims: - they are labelled to negative stereotypes as not being woman enough to give birth normally or cursed: they are alienated from family and society; and they experience status loss and discrimination by the society due to their condition. As is evident that fistula survivor experience stigma, it is important to examine the influence of unequal power relations in this process and its unequal outcomes socially, economically and physical and psychological well being of survivors. Furthermore, the reintegration process for survivors relies on change of attitude and practice by the stigmatiser. It is therefore necessary to examine the perceptions of stigma by the community in the West Pokot comparing it with the conceptualised components. Furthermore, fistula survivors may alienate themselves more by information control to avoid further labelling, a concept Goffman describes as 'passing'.

Although a number of critiques have been directed toward Goffman's conception of stigma and various alternative forms have been published (Link and Phelan, 2001; Fine and Asch 1988; Gill 2001), Goffman's original model still remains highly respected and dominant. Goffman's representation of the social difficulties faced by persons with stigmatic qualities is still considered highly valid. Thus, it has been retained as the theoretical framework to guide this study. Goffman's stigma theory is relevant to this study as the study intends to elucidate the social stigma that fistula survivors face in their effort to reintegrate back to mainstream society after surgical repair.

2.3 Study Assumptions

1. Fistula survivors are more likely to face social stigma during reintegration.
2. Social stigma has a negative impact on the social reintegration outcomes for obstetric fistula survivors.
3. Community support for fistula survivors improves reintegration outcomes.

2.4 Definition of Key Concepts

Social Stigma

The occurrence of labelling, stereotyping, separation, status loss, and discrimination of fistula survivors by their families and communities

Reintegration

Reintegration will be defined using the following criteria:

1. Being able to fit in with other people and be accepted
2. Being part of the community, family, group, friends, neighbours
3. Having things to do for leisure with others
4. Having productive activity or working with others.

Obstetric Fistula Survivors

Women of reproductive age and post menopausal age who have had an obstetric fistula repair done at any facility, both successful and unsuccessful.

CHAPTER THREE: METHODOLOGY

3.1 Study site

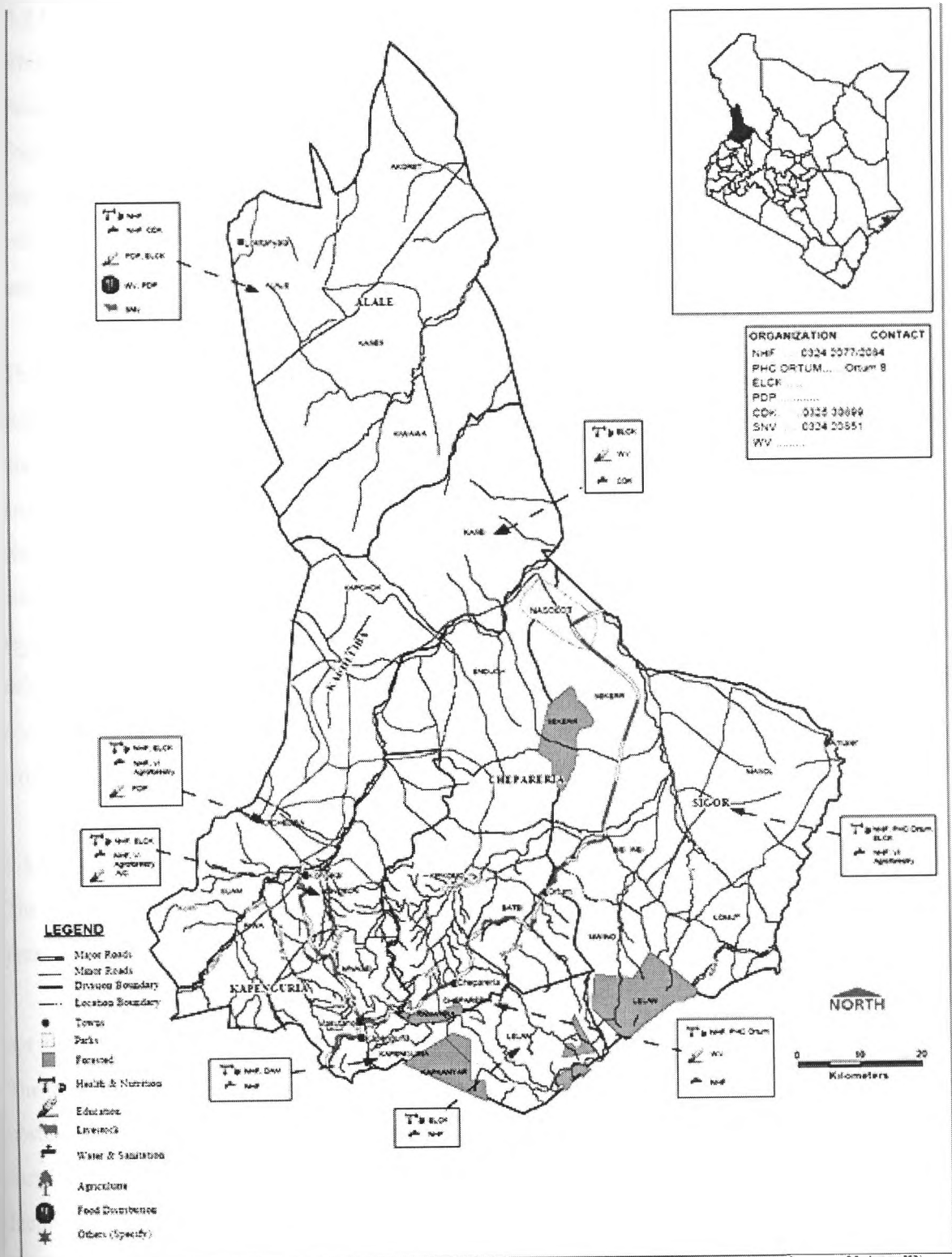
The study was conducted in West Pokot district, Kenya an area inhabited by the Pokot people. West Pokot District is an administrative district in the Rift Valley Province of Kenya with headquarters in Kapenguria. A map of West Pokot district is shown in figure 3.1. The district has a population of 308,086 (1999 census) and an area of 9,064 km². The administrative divisions and their respective population sizes is summarised in Table 3.1. The entry point was at Sentinelles NGO which sponsors fistula surgery and conducts follow up visits for the survivors and Ortum mission hospital which holds frequent fistula repair missions in the area.

Table 3.1: Administrative Divisions of West Pokot District

Division	Population	Urban population	Headquarters
Alale	29,679	0	
Chepareria	68,518	900	Chepareria
Chesegon	21,343	-	-
Kacheliba	20,151	-	-
Kapenguria	62,746	12,438	Kapenguria
Kasei	9,879	-	-
Kongelai	20,018	-	Kongelai
Lelan	32,931	-	-
Sigor	42,821	-	Sigor
<i>Total</i>	<i>308,086</i>	<i>13,338</i>	-

Source: Government of Kenya, 1999 census

http://en.wikipedia.org/wiki/Main_Pagehttp://en.wikipedia.org/wiki/Main_Page



The boundaries and names shown on this map do not imply official endorsement or acceptance by the United Nations

Prepared by OCHA June 2001

Figure 3.1: Map of West Pokot District

3.2 Research Design

This was an exploratory study. The study explored how the obstetric fistula patients describe their conditions and experiences after surgery by using in-depth interviews and focused group discussions (Creswell and Clark, 2007). Selected narratives of obstetric survivors were also obtained. Thematic data analysis was used to analyze the data collected along emerging general themes of social stigma, perceptions of obstetric fistula, and reintegration strategies among others.

The study participants were interviewed individually using an in-depth interview schedule on their experiences on returning home after corrective surgery. Focus group discussions were later held with the survivors in one session and community members in another, to gather more information in detailed discussions. The focus group discussions were used to further clarify issues that had been raised in the in-depth interviews. An understanding of the challenges faced by obstetric fistula survivors before and after the repair was of high interest in order to generate knowledge that may be used to support reintegration programs. Key informant interviews with people knowledgeable on the condition were also held amongst health caregivers, traditional birth attendants recruited from the communities and social workers.

3.3 Study population

The study population included all obstetric fistula survivors living within the catchment areas of the health facilities in West Pokot district.

3.4 Sample population

The study targeted women of reproductive age and post menopausal women who had an obstetric fistula and repair done. They participated in in-depth interviews and later on, in focus group discussions consisting of 8 -12 members.

Inclusion criteria:

The study included women as study participants using the following criteria:

1. Women who were living in West Pokot district and its environs.

2. Women in the reproductive age range (average 15 -49 years) and post menopausal age ranges.
3. Women who had a fistula repaired at any fistula repair facility.

3.5 Sampling procedure

The study utilized purposive sampling. Study participants who met the criteria were selected for in-depth interviews and later invited for focus group discussions. 8 women were interviewed and another 10 invited to a Focused Group Discussion. The FGD discussants consisted of obstetric fistula survivors; some of whom had participated in the in-depth interviews and others who had not. Key informant interviews were held with 2 traditional birth attendants from the community and the care givers to fistula patients at Ortum Mission and Kapenguria District Hospitals. Caregivers interviewed included 2 obstetrics & gynaecology surgeons who carry out fistula repair surgery at the two hospitals and a VVF specialist nurse; 1 nurse and 2 social workers at an NGO that carries out follow up for fistula survivors.

3.6 Methods of Data collection

3.6.1 In-depth Interview

8 Obstetric fistula survivors were interviewed using an in-depth interview guide. The focus of these interviews was on the experiences of fistula survivors, comparing felt versus enacted stigma and their long term reintegration needs. Information about obstetric fistula from the perspectives of culture, social and economic challenges was gathered. Note taking and a tape recorder were used to record the interviews.

3.6.2 Focus Group Discussion

This method was used to collect normative data about the experiences, attitudes, and perception of women with obstetric fistula and other family and community members about stigma and social reintegration. Two focus group discussions were held; one with the survivors to obtain their views and further clarify issues that arose in the in-depth interviews and another consisting of members of the general community to gather views on obstetric fistula from the perspectives of culture, stigma, social and economic

challenges and possible solutions to these challenges. Prior clarification of whether the member of the community understood what obstetric fistula is was made before they were recruited into the focus group discussion. A group of 15 discussants were involved in a guided discussion. A moderator who also acted as translator guided the discussion using a focus group discussion guide. Note taking and tape recording were used to record the discussions.

3.6.3 Key Informant Interview

Key informant interviews were held with two of the following category of caregiver's in the district - traditional birth attendants, surgeons, nurses and social workers. The focus of the interviews was to provide information on how they manage/ support women with obstetric fistula, particularly the reintegration of fistula survivors into the community. A key informant interview schedule was used and the interviews were recorded using a tape recorder and note taking.

3.6.4 Narratives

A narrative by one obstetric fistula survivor was recorded to obtain a detailed life profile and the experiences she had in the community. A narrative guide was used to prompt for a detailed profile of the survivor since childhood, nutrition, cultural beliefs and practices, marriage, experience before and after surgical repair.

3.7 Data processing and analysis

The tapes recorded from survivors were translated then transcribed while those recorded directly in English from key informants were transcribed. Data collected was coded along general themes emerging from the study and entered (Strauss and Corbin, 1990). Thematic data analysis was used to analyse the study results in line with grounded theory procedures and techniques. The results were then organized for presentation along emerging themes. Data presentation utilized both descriptive narratives and analytic accounts. It was divided into two chapters; the first describing and illustrating the study findings and the second, discussion is an analytic account of the study findings.

3.8 Ethical Consideration

Information obtained was treated confidentially and the right of the study participants to withdraw at any point in time was preserved for the women. Anonymity of the study participants has been maintained throughout the study by avoiding use of real names especially in dissemination of results. The report utilizes fictitious names for all participants and interview schedules and tapes have been labelled using code numbers. Informed consent was sought before any interview or discussion took place. The study participants who were identified to be in need of medical attention and counselling were advised, invited to the Sentinelles NGO offices for further medical help and scheduled to be visited by a nurse and social worker for follow up and counselling.

Ethical approval from the KNH/ University of Nairobi Ethics Research Committee was obtained to conduct the study. Approval from the Ministry of Education, Science and Technology was sought and a research permit was issued to conduct the study. An agreement in writing with the Sentinelles NGO detailing commitment to preserve anonymity of the study participants was made before accompanying their team into the field. Permission from the medical superintendent at Kapenguria District Hospital and the head nurse at the Ortum Mission Hospital was also obtained prior to interviewing the key informants.

CHAPTER FOUR: STUDY FINDINGS

4.1 OBSTETRIC FISTULA SURVIVORS CHARACTERISTICS

The study interviewed women who had undergone obstetric fistula corrective surgery in West Pokot. This section describes the demographic characteristics of the study participants. Owing to the exploratory nature of the study and the small sample size, I have found it prudent to use numbers only as fractions of the total number of participants rather than percentages.

The obstetric fistula survivors interviewed were mostly young women aged between seventeen and thirty years. Out of the eight women interviewed, two had never been married; one was living separately in the same compound with her husband; three were divorced and only two were married. All survivors who were single or divorced were living with their parents, with the exception of one who had been chased away from home. All married survivors had experienced periods of separation from their husbands during their illness and after corrective surgery.

Study participants had low literacy levels with formal education attained ranging from primary class three to class five. 1/8 survivors was pursuing vocational training in tailoring at a local polytechnic. Only 3/8 of the survivors were involved in direct income businesses of farming, vending vegetables and groceries. The rest depended on family and well-wishers for economic support. All survivors interviewed had low socioeconomic background and their surgeries had been sponsored by NGOs.

6/8 survivors had no other children as the fistula occurred during the first child birth. However, two survivors had had other children prior to the pregnancy that caused the fistula. Seven out of the eight women experienced prolonged obstructed labour. Only one woman's baby survived, notably from the survivor who had precipitate labour. During labour, all the survivors had been assisted by an unskilled birth attendant, with 7/8 having been attended to by a traditional birth attendant. Notably, one of the survivors who had a fistula delivering the first child got a second one while being monitored during delivery

of her second child. She had previously undergone corrective surgery and healed. Of the survivors interviewed 5/8 had completely healed while three others were awaiting further surgical correction. All the survivors had undergone more than one corrective surgery, and had lived for the condition for periods ranging from one to six years prior to the first corrective surgery.

4.2 THE CHALLENGES FACED BY OBSTETRIC FISTULA SURVIVORS

Women living with obstetric fistula face a number of challenges in their community. These challenges, some of which linger on after corrective surgery, relate to their physical illness and the social stigma that is associated with the condition. It is worth noting that some challenges cease after the corrective surgery. However, there are other new challenges that emerge once a survivor has undergone corrective surgery. The following part of the report describes the three categories of challenges faced by fistula survivors.

4.2.1 General challenges

4.2.1.1 Social stigma

The women living with obstetric fistula are stigmatised and isolated by their communities. There is little interaction between a survivor and her community. When there is any form of interaction the survivors are ridiculed and made to feel less of human beings. They are isolated and at times live on their own in a hut outside the compound. Here they eat and sleep alone, taking away any little interaction that may have existed. Narrating their challenges, one fistula survivor expressed her experience thus:

I felt bad. It was painful; and I preferred to stay childless if this is what it means to get one. I got many problems. I couldn't sit with people, go anywhere with them or associate with them in any way. Once you go where they are, they leave one by one. Even going to the market, I couldn't, even going to fetch water nobody will drink it. Nobody would purchase my goods. What people believed it is a disease without cure (Semew). I pitied myself because of the smell and the people. I prayed death to come and release me! (Cheptiros¹, a 20 year old obstetric fistula survivor)

¹ The names of all obstetric fistula survivors who participated in this study have been changed. Fictitious names have been used to protect their identity.

Another survivor described her experience while living with obstetric fistula this way;

Some looked down upon me. They looked down upon me and laughed at me. They said look at her. She is torn. She is torn at the buttocks! That time I couldn't talk to people, because they would throw bad words at me. (Tingoyi, a 30 year old obstetric fistula survivor)

Some survivors felt the greatest challenge while living with the condition came from their interactions with society. Three survivors narrated their experience this way:

The greatest was the society. When walking with people then in the middle of the journey urine just comes out. They alienated me. It was an embarrassment to me. (Cheptoo, a 23 year old obstetric fistula survivor)

It was really bad. Because somebody leaking urine is abnormal and relating with society was another great problem. They didn't like me because of the smell. (Katiraya, a 26 years old obstetric fistula survivor)

“[They say] her buttocks are tight, a child cannot pass. They don't believe it's a curse, you [survivor] are just cursed yourself, why can't you deliver normally?” (Cheptios, a 17 year old obstetric fistula survivor)

This was corroborated by key informants who reported that women living with obstetric fistula face social stigma and isolation. They are alienated from their husbands, their parents, the other family members and the community at large. In some cases the women are built for houses outside the compound so as not to bring shame to their families; they eat and live on their own. Secluded, they also face other challenges such as lack of food or even drinking water. The community ridicules the survivors for not having been able to deliver normally and even claim that they are cursed or had extramarital affairs during pregnancy. All these pose a great psychological burden to the survivors and may at times lead to their contemplating suicide.

The social stigma, labelling and isolation continue after surgery. Obstetric survivors are labelled as having had an illness that left them blemished. In this sense they are therefore not fully accepted back by their communities. They are isolated albeit in a subtle manner, after surgery. Though survivors may be healed and no longer leaking urine or faeces, they are not totally involved in communal activities. They are permitted into social circles

only partially and cautiously. It is as though the illness had left a permanent stigmatising label on the survivors.

For example, a survivor said that even though she was invited to social events like weddings and rites of passage, the hosts won't let her help with the cooking or serving the guests despite the fact that she had healed and was physically able to help. She described her participation in social events; "But you see you can't go to touch people's food. They will say [the guests] what is that they have put in the food? These hands have passed many different problems!" (Tingoyi, a 30 year old obstetric fistula survivor)

4.2.1.2 Reduced sense of social worth

For a survivor, her clan members are worried that she may not fetch bride price as a result of her condition. It appears as though her social worth has decreased. This is because the husband, or if she is separated, potential suitors are not assured of her future fertility. This has at times led to a husband reclaiming his bride price, as in this community the bride price is directly pegged on the woman's ability to bear children. In the eyes of the community her value is decreased. The community's devaluing perception of obstetric fistula as an incurable curse on the woman is a great source of stigmatisation. They often regard her as "spoilt". Survivors described this feeling in their interaction with society in these excerpts:

Some were bad to me, some treated me with pity. They looked down upon me. They said I am spoilt; they said I was spoiling the ward. At first it's the nurse who insulted me. She said 'For how long are you going to stay here? You know you have really spoilt this ward?!' She said it every day.
(Chepkiror, a 24 year old obstetric fistula survivor)

It was really bad. When one leaks urine she is not at peace. I have many thoughts. It is because of the leaking of urine. According to my husband I can't bear another child. (Chepengat, a 17 year old obstetric fistula survivor)

According to key informants obstetric fistula survivors are often become infertile. This poses a challenge to them socially, because in the Pokot community a woman is valued by her ability to bear children. According to a surgeon, the infertility occurs as a result of excessive bleeding, infection of the uterus or at times, rupture of the uterus which

necessitates its removal. The infertility is a source of ridicule and being looked down upon by the community and family. For unmarried survivors it lowers their chance at a future life in marriage as potential suitors will be reluctant to pay bride price over them because they doubt their ability to give birth.

Community beliefs about obstetric fistula contribute to stigma and a reduced sense of worth. The community belief that obstetric fistula comes about as a curse to the woman; a bad omen to the marriage and/or a possible sequelae of witchcraft. In all these causes the woman is seen as having a reduced social worth and not deserving to mingle with other people. She is regarded as spoilt. This community perception often leaves the survivors having feelings of reduced social worth as seen in the excerpts above.

4.2.1.3 Economic challenges

The Economic loss due to fistula is a challenge to the survivors. Obstetric fistula survivors could no longer conduct their business and other income generating activities. This is because of the physical illness and their customers shying off. The survivors also isolate themselves and no business transactions are possible in isolation. They are also estranged from useful social networks like *harambee* or merry-go-round. For example, one survivor explained her economic loss in this statement: “When I was well I would dig and do small things for my money. I would sell vegetables and plait hair, but I was now sick!” (Chepkiror, a 24 year old obstetric fistula survivor)

Another survivor comparing her economic activities before and after surgery observed that her economic situation improved after corrective surgery, as she could sell groceries and attend merry go round meetings. In her words:

Before [the surgery] no one wanted me. They would say: “if she comes here, who knows? She is dirty! She is dirty!” [Merry go round members]. Who would you take to your products? Nobody would agree. (Tingoyi, a 30 year old obstetric fistula survivor)

These economic challenges continue after surgery. The survivors felt that lack of economic empowerment was a big challenge after surgery as they found themselves dependent on their spouses and other relatives. Often, they were not able to participate in economic activities as they used to before the illness; either because of lack of capital and physical strength or the negative label the community attaches to the survivors. They often find themselves without anything to do in form of generating income. They also find themselves estranged for long from social forms of fundraising like *harambee* or merry go round. Consequently, they reported that they needed help to meet their daily needs. One survivor expounded this challenge;

Economically I can't do anything like I used to before, not even *harambee* [social way of fundraising in Kenya]. I don't have anything to do for a living. (Chepengat, a 17 year old obstetric fistula survivor)

However, others were optimistic that it will be well socially and their economic status would improve once they were totally healed. A survivor demonstrated her optimism thus;

My chances [when I heal] my husband may come back. I am sure if he wanted to leave he might have married again by now. But he lives in the same compound with us though alone. My healing may let me go and be accepted at social events again. I would go for my business as usual". (Katiraya, a 26 year old obstetric fistula survivor)

As is common amongst most women in the Pokot community, fistula survivors experience poverty yet at the same time they take care of property such as land and cattle. They have little power to decide how it is sold, leased or how the money is spent. They often own little or no property and do not have any say over the little they own. Therefore getting money to go for a medical check-up is a big challenge to most survivors. For instance, one survivor described how her husband had leased out all their land and sold the cattle. She had no say in these decisions; when she objected he could not listen to her. Yet she did not have enough food and he would not give her the money to go to hospital for check up. The following is an excerpt from her interview:

You know a household has a lot of problems. Like if there is no money. You have to rear cows, goats, and a farm to cultivate. He would give me two *korokoros* [4 kg] of maize to do all the work. I ended up using it as porridge for my baby. The food wasn't enough. He would sell many cows or lease out our land. I couldn't

stop him, he couldn't listen. He took money for land behind my back and someone would arrive with a *jembe* [hoe] asking for his/her share of land, yet money is already taken. I couldn't say anything! You know life is all about wealth. So if you have no means of getting money, what is that? It is just wasting time! (Chepkiror, a 24 year old obstetric fistula survivor)

After surgery, most survivors believe their previous illness has lessened their life chances of a normal social and economic life. The survivors include both the successful and unsuccessful repairs. Socially, the survivors are often shy to relate with other people, possibly because of the felt stigma before surgery. Others explained that the self doubt stems from the perception that if one has been operated on she is not normal. It is worth noting that the survivors who reported this self doubt ended up isolating themselves from the other members of the community after surgery.

Since they shy away from social events, their reintegration is really challenged as they have little or no activities to do with other community members. For some survivors who get invited to such events they are not allowed to participate fully. For example, Tingoyi (30 years, obstetric fistula survivor) narrated situations where she was not allowed to help in the cooking or serving of food yet she had been healed and no longer smelled. Most survivors did not think they could get married again. Others believed that it would be difficult to get hired at any job, first because they cannot do heavy manual work and secondly because prospective employers could be reluctant to hire them as domestic servants or in hotels.

4.2.1.4 Loss of the baby

In all the survivors interviewed only one survivor's child had survived after the delivery that caused the fistula. For the rest of the survivors they are bereft of their babies and in some cases also lose their uterus and any future prospect of getting other children. Psychologically, the survivors mourn their loss and this may continue after surgery. A survivor who had lost two babies and developed obstetric fistula on both occasions said this was her greatest challenge. In her words:

“The greatest problem I faced was the smell of urine and not getting the baby! I lost that one [baby], now I have lost another!” (Cheptoo, a 24 years obstetric fistula survivor)

4.2.2 Challenges before Surgery

4.2.2.1 Abandonment

Married survivors often are abandoned or forced to separate from their husbands. While some in-laws support the survivors and are sympathetic to their plight, the majority contribute to their ostracising and at times advise their relatives to leave the women with obstetric fistula and marry other wives. Left without any social or material support, the survivors' situation deteriorates as they often find basic necessities such as food, shelter, water and soap out of reach. Some survivors cannot fend for themselves and could have benefitted from social and material support by the husband and extended kin.

A survivor described her strained relation with her husband and in-laws this way;

He never used to come. Even after operation, he left me. I had an operation and he wasn't there at all. I also lost the baby. Later, he insulted me. He said 'You wanted to give birth. I will leave you here'. That pained my heart. I got demoralized and went to my mother's home after surgery. I underwent the first surgery then went to my husband's house. But they didn't care for me as a sick person. (Chepkiror, a 24 year old obstetric fistula survivor)

Another survivor commented that her husband left her to fend for herself. Her house was in a dilapidated condition and getting food and soap was difficult. She depended on her brothers to help care for herself and her children. She narrated this bit of her ordeal;

He ran away and abandoned me completely. He left me when it was raining, in a house that leaks yet [I was] inside. He would stay up to this time [April] without even cultivating, ploughing my farm! He was not there! And that time I didn't have strength. It seems when you have this problem you feel sick, shivering. I wasn't well and couldn't do heavy work. When I could get any problem like illness, I would run there [seek assistance from her brothers], even the children. They helped me by giving me food. I had no food. (Tingoyi, a 30 year old obstetric fistula survivor)

4.2.2.2 Self isolation

Some survivors isolate themselves from the community. This removes the interaction they had with their peers before and any social support during their illness. It also

contributes to their being ostracised as it confirms to the community that she is not a normal human being. They feel lonely. One survivor put it this way “Not that people feared me. I was the one who feared people more than they feared me. I was thinking about what they thought about how I smelled. It was bad.” (Cheptoo, a 24 year old obstetric fistula survivor)

4.2.2.3 Helplessness

Other survivors felt helpless as they couldn't do anything about their problems. With their physical health compromised and their social status lost the survivors lives are often left to fate. Often, the survivors find themselves with a disease of which they do not know its cure, they are traumatised and can not intervene in their own situation. This survivor's comment about her situation captured her helplessness; “If now one backbites me, what can I do? The urine is flowing, let them continue! It is not my wish.” (Chepengat, a 17 year old obstetric fistula survivor) Other survivors expressed similar feelings of helplessness during their illness. One particularly was resigned to her fate because, in her words, “I didn't feel anything. Even when I pity myself what shall I do?” (Chebet, a 17 year old obstetric fistula survivor)

4.2.2.4 Physical illness

Obstetric fistula survivors experience physical illness, consisting of being incontinent of urine and/ or stool. They also feel pain and have general difficulty in performing their household chores. They are not able to lift heavy loads like water and sometimes even sweeping the house is difficult. This difficulty is experienced when they attempt to fulfil their gender roles as women in the Pokot community. For instance, Tingoyi described this challenge while living with obstetric fistula this way:

Many things were a problem. For example, my job at home, I couldn't lift very heavy loads. It was very difficult. Even cleaning my home was hard. I couldn't bend; it was painful; so I could go on my knees just to sweep. Even fetching water [was difficult]! (Tingoyi, a 30 year old obstetric fistula survivor)

4.2.3 Challenges after surgery

4.2.3.1 Psychological trauma

For obstetric fistula survivors the experience leads to long term psychological trauma. Long after they are physically healed they are still living with memories of fistula and make every effort to block any linkage to fistula. For instance one survivor denied absolutely ever having been operated on yet records showed otherwise (Chebet, a 17 year old obstetric fistula survivor). She had a lot of difficulty narrating her story and generally needed counselling, which we arranged with the Sentinelles team to follow up. Other survivors on recalling their experience when living with obstetric fistula broke down and cried. For these survivors the emotional scar seemed so fresh in their minds and they reported feeling pain just thinking of the past.

4.2.3.2 Coping with postoperative instructions

After surgery a woman is advised by the healthcare providers to drink plenty of water, eat a balanced diet and carry out pelvic floor muscle exercises so as to enable better physical healing. They are also advised to abstain from sexual intercourse for six months and withhold getting pregnant for at least two years. The informants think that the diet and exercise is not as challenging to the survivors as compared to the abstinence and delaying the next childbirth. For many survivors they have to live with the social pressures of living the life of a married woman. Often the husband does not understand why she is healed physically and no longer leaking urine, yet she has to abstain for six months. Reportedly, some survivors end up engaging in sexual intercourse much earlier than the recommended time with detrimental effect. To escape this, most survivors after surgery go to their parents' home so as to keep a distance between them and their spouses. This separation hinders the survivor's proper reintegration back to the community.

4.2.3.3 Separation

Some survivors are separated from their husband after surgical repair even though the repairs are successful. The women attribute this to their need to abstain from sexual intercourse as is medically recommended after the surgery. They go to their parents' homes to evade such, as they feel the husbands will not cooperate in abstaining. In other cases the husbands moved to live with other wives leaving the survivors without any social or material support. For one of the survivors who still stayed in her home after

surgery, her husband left her because in her words; “Why should he bring his sugar where there is nothing [no sexual relations]?” (Tingoyi, a 30 year old obstetric fistula survivor)

Other survivors attributed their marriage problems to having developed a fistula and not just the abstinence required for their proper healing. Their husbands perceived them in a different light after the fistula. It seems developing obstetric fistula was in itself a start of problems in their marriages and not even successful repair could save their strained relations with their spouses. The women’s perception is that their marriage was not the same again after having had an obstetric fistula. To illustrate this, one survivor narrated; “I mean I got married, I didn’t get a good life. My life went *kombokombo* [it wasn’t straight]” (Chepkiror, a 24 year old obstetric fistula survivor)

4.2.3.4 Low self esteem

After surgery the survivors experience self doubt and fear. They are not confident and do not believe that they are normal people. A survivor may not have been isolated in any way by her family or community but she still is not confident about herself after surgery. A survivor who had isolated herself before surgery described her post surgery situation in this way;

I had no problem with my husband. I am the one who had fears that I may smell urine again. Was I like someone else? If I have been repaired there is more than meets the eye. Could I be less [of a woman]? I just wondered if my body will be alright. (Cheptoo, a 24 year old obstetric fistula survivor)

4.2.3.5 Decreased chances at marriage

Six of the eight survivors interviewed reported that their chances at normal marriage were few; they do not think they can get married again as their social worth has decreased. Having got a fistula their bride price may not be paid at all as the suitors doubt their ability to give birth again. It is worth noting that in this community a woman’s worth is determined by her ability to give birth to children. The community may ridicule her for not being woman enough to bear a child normally. The community’s perception of obstetric fistula survivors gives them little chance of leading a normal life in marriage. One survivor explained this challenge:

It is not easy for me to get married. They [community] believe you won't deliver again, and you are smelling urine. The young men are worse; they're the ones interested in marrying and believe you will not deliver again. Bride price will not be discussed as I am now valueless. It is the fistula and smell of urine, not even the getting a child at home! The one who even gave me the child ran away. I have no love again, nothing! Employment is possible when am better and not leaking as now. It is hard now. I can't make a mistake to go to these social events. I smell urine still, they will not invite me. (Chepengat, a 17 year old obstetric fistula survivor)

It is worth noting that for this survivor, her future prospects of getting married is challenged by the societal perception of the decreased social worth of an obstetric fistula survivor. Her uncertain future fertility further complicates the survivor's situation as children are valued in this community and a potential suitor is not certain whether he will get value for the bride wealth price. Describing reluctance on the part of potential marriage suitors, Chepkiror (a 24 year old obstetric fistula survivor) said: "They will be scared. They will move away and think twice". Chepengat, (a 17 year old obstetric fistula survivor) comments about what her community think of her ability to get children; "Now this one [woman] is no good as caesarean section delivery limits the number of children she can get".

4.2.3.6 Infertility

Infertility as a challenge is manifest two fold in the survivors' lives. First, they experience infertility due to the complication following the birth that caused the fistula and secondly, the recommended two years before conceiving again. This poses a great challenge to their reintegration. In this community a woman is accepted by the value of her giving birth yet both herself and the community at large are not sure whether after the fistula she would give birth or not. This doubt hinders her from leading a normal life in the community and being respected as a woman. Furthermore, some survivors who conceive after surgery get miscarriages because of structural abnormalities to the cervix, as it may have been torn in the previous birth that caused the fistula. For other survivors they are sceptical of their normalcy as they have to undergo caesarean section delivery for their subsequent pregnancies. The women and girls are more hopeful if their periods return and their

fertility is not at stake. As it is, obstetric fistula poses a great challenge on the “social worth” of a woman in the eyes of her community as regards to her ability to get children.

A key informant explained the challenge of infertility and in this way:

Before surgery I think because for them as a woman is to prove yourself that you're able to have babies. For them whatever, I mean it is bad enough that they are ashamed that they are leaking urine but if they have hopes that their fertility is not at stake or will be returned and then they will stop leaking urine. Those are the things that will help them the stigma go down but if they are not seeing their periods much even after the surgery, it makes it difficult. And because the surgery is the time they take; the longer they take, the more they are stigmatized. (Surgeon; obstetric fistula repair programme)

Concerns about future fertility abound amongst the survivors and may take varied forms; they worry that they must undergo a surgical operation to be able to deliver safely, other times they are concerned that they may never get another baby. The psychological torture that comes with uncertainty over the survivors fertility is immense and often brought up several times in the interviews. Voicing her concerns about her future prospects of getting a child Chepengat (a 17 year old obstetric fistula survivor) said: “I am worried if I will get a baby afterwards now that I lost this one. I will be unhappy if I don't get another baby.” Key informants reported that survivors who remain childless after the surgery are ostracised.

4.2.3.7 Unsuccessful repair

The greatest challenge for obstetric fistula survivors is unsuccessful repairs. Here, there is the continued urinary and/ or faecal incontinence leading to social isolation and stigma. Unsuccessful repairs leave survivors suffering as before surgery; they still attract thoughts of being cursed, they are alienated and isolated. The community expect that after surgery she will be healed and be reintegrated back to society, but as is the case with unsuccessful repair the family and community at large do not accept the survivors back. At times they blame the survivors for their not having healed. A survivor reported that she still faced many problems because her repair was unsuccessful:

Until now, the operation didn't assist me as am still leaking urine. It is still a challenge. The societal perception about my foul smell is distressing. They think

am cursed, am not supposed to get near people. (Chepengat, a 17 year old obstetric fistula survivor)

Another survivor whose surgery was unsuccessful described her family's blame on her;

I believed I would be healed and be reintegrated back to the society. But in my case I didn't heal. They asked me 'why have you come back with the same problem? We thought you said you will be healed! (Cheptios, a 17 year old obstetric fistula survivor)

4.3 REINTEGRATING OBSTETRIC FISTULA SURVIVORS

Obstetric fistula survivors mentioned several factors that helped or prevented their reintegration after surgery. Some of these were corroborated by key informants who also added a few others that they had observed during their interaction with obstetric fistula survivors. These factors that influence the reintegration of fistula survivors are discussed in the first section, while the second part highlights findings on proposed avenues for reintegrating obstetric fistula survivors. Most of the proposed avenues were reported by both the survivors and key informants.

4.3.1 Factors influencing social reintegration of obstetric fistula survivors

4.3.1.1 Surgery outcomes

Survivors who have gone through the surgeries program have found the medical assistance helpful. They feel this was pivotal to their return to normal life. Although the study and questions posed were about factors that affected the survivors' reintegration after surgery, the survivors quickly pointed back to the surgery itself as a lifeline, a starting point for their reintegration.

Operation is the only solution. As long as an operation is not forthcoming you [survivor] are still abandoned and discriminated. (Chepengat, a 17 year old obstetric fistula survivor)

Key informants felt that surgery and its outcome is a factor that plays an important role in the social reintegration of fistula survivors. After surgery the survivors feel more accepted by others and their social life becomes better. Socially they are accepted back and can have friends and relatives and feel as part of a community. The survivor is likely to be accepted by her husband after she has been surgery than before. However this

acceptance may easily be mistaken by the general acceptance a community may give to a survivor as in the Pokot culture a wife belongs to the community. The survivor is also more psychologically settled and happier. A social worker commented:

I can say there are two things. One is psychologically. When a patient has been done a successful operation her psychology can settle. We can talk of physically. You know she has been waking up, walking with a lot of urine or the stool, but once they have a successful operation you find that those wastes are no longer there. So physically they feel better. And socially you they are always segregated and being put at a distance. So once all these things are not there they are accepted back. And they can be with friends, relatives and feels at least she is part of the community. And again, you know after that operation those ones who are married they no longer go back to their husbands. When they have fistula but once they now have the successful operation the husband always asks her to come back as his wife or wives.

Unsuccessful repair is one of the factors that hinder reintegration of fistula survivors. In this case the survivors face isolation and stigma. It seems the survivors' lives stay on hold depending on the possibility of a successful repair. As long as it is not forthcoming then they still have to contend with stigma and isolation. This further makes them to lose hope and get depressed. One survivor says of such; "One major barring factor to my reintegration was my unsuccessful repair. Nothing was as big as that!" (Katiraya, a 26 year old obstetric fistula survivor)

Key informants observed that the outcome of the surgical operation determines whether the survivors will be accepted back in their community or not. The successful repairs integrate more easily especially if the survivors did not live long with the fistula. In case the survivor had lived with a fistula for a long time they are so stigmatized even if they are repaired they take a while to go back to their normal lives. According to a key informant if the timing of the repair is before a year even the husband is hopeful that the woman will come back. For unsuccessful repairs the woman is still isolated and is not allowed to cook or milk for she is taken to be still unclean. She may also continue shying away from the community and will not fit in.

4.3.1.2 Family support

Survivors also cited family support as one of the factors that played a great role in their reintegration. In cases where the family supported the survivors, they settled down better and were able to live normal lives, get children and do business. One survivor who had been accepted back and supported by her husband and the rest of the family returned to her marital home and even conceived the second child (Cheptoo; 24 years; obstetric fistula survivor). Another feels her problems ended when her husband who had initially abandoned her after surgery returned home. In her words:

Life got better. Even myself, I got better health. When I was sick I didn't know water, I had no soap to shower as I was fending for myself. A day would pass without food. But now life is better, he could bring sugar and it lasts a whole week. But when I was alone, I would buy sugar, flour, what not! That is a heavy burden. (Tingoyi, a 30 year old obstetric fistula survivor)

Other survivors who had been taken back by their parents and were taken care of. They say this has helped them. One survivor was taken in by her parents. They sponsored her to do a tailoring course at Kapenguria polytechnic. Her clan and community members also empathised with her. In her words;

They told me, we will help you where possible and they did. They took it as their problem. They helped me and were happy. I didn't see anything bad. They didn't backbite [talk badly about] me. (Chepkiror, a 24 year old obstetric fistula survivor)

However, not every woman who had undergone repair was able to get back and receive support from their families. Some, like Cheptios (17 year old obstetric fistula survivor) were chased away from their homes and left on their own. They reported experiencing a lot of problems due to little or no family support

4.3.1.3 Skill training and employment

Obstetric fistula survivors who received skill training like tailoring said it was among the things that helped their reintegration. They reported learning a meaningful trade to occupy their minds. The training also provided them with a sense of security in the future especially with prospects of getting employment. Other survivors who were running a form of business said this was very instrumental to their reintegration. One survivor commented;

It's important because even you when you're taught it will help you. The work of your hands is blessed and can help you. I would say if I had a job I wouldn't suffer the way I did. Like now I have gone for tailoring and it has helped me. If I had someone else to donate money to start my clothes business I would be very happy. (Chepengat, a 24 year old obstetric fistula survivor)

According to key informants interviewed, poverty is another factor influencing the reintegration of fistula survivors in West Pokot. It poses a challenge in that women who have undergone surgery often go back home dependent on their husbands. It is worth noting that in this community women fend for themselves, something they cannot do in convalescence. They therefore are often helpless, abandoned by their husbands and even go without food. They either have to go back to their parents, be fed by well wishers or depend on world food programme for their survival. (Surgeon, key informant)

4.3.1.4 Social stigma

This was seen as influencing the reintegration of obstetric fistula survivors. The informants agree that there is not a hundred percent eradication of stigma after surgery, the remaining bit of it poses a challenge to the social reintegration of fistula survivors. They suggested many ways of overcoming this stigma, as it not only hinders the reintegration of fistula survivors but also delays those who are suffering from seeking medical attention. A social worker explained the effect of stigma in this excerpt:

Imagine yourself you are not accepted by the community. Or neither you husband accepts you. So you that's bad actually. You know how it is. Secondly you find that as a result of that stigma, somebody might just decide that these [survivors'] family members are not accepting me and even the community. Then what next? Committing suicide. Is it the better option? Yes some of them contemplate on it but by chance we always get them in time. So you find that others are constructed for a hut some distance away from the home so she can go and stay there because of the family feel it is a shame to have such a person in the homestead. They don't know how the other people will say about her so they have to construct a hut somewhere. But she eats on her own, sleeps on her own. She lives on her own. After surgery it will be just like that but is not very big as earlier.

4.3.1.5 Cultural beliefs

Cultural beliefs are a great challenge to the reintegration of obstetric fistula survivors. This is seen in cases whereby the community does not believe that it is possibly Female genital mutilation or early forced marriage that may have contributed to the formation of

a fistula but rather they believe the girl or woman is cursed or bewitched. Besides there is no known cure for this curse or witchcraft and the survivor is left without a hope. The community continues looking at her and treating her in this stigmatizing sense and in such cases the woman will be depressed. The community acceptance that is meant to be part of reintegration is lost further slowing the process altogether. The depression is also contributed to by repeated unsuccessful surgeries. Examples were given of cases where the survivors felt they may never be healed and gave up. Some left or ran away from hospital; others started talking to themselves herself because of the psychological torture the condition put them through.

4.3.2 Avenues for social reintegration of obstetric fistula survivors

Fistula survivors mentioned several avenues which fostered their fast reintegration. Key informants in the study also corroborated some of these as being useful avenues that the survivors had been using. The next part of the report highlights the avenues that were perceived as key to survivors' reintegration. It is worth noting that both obstetric fistula survivors and key informants pointed to an apparent lack of any clear cut programs or services available to reintegrate obstetric fistula survivors in West Pokot. In the interviews several services were mentioned as being important towards reintegration. They include successful surgery, counselling, income generating activities, vocational training, family and community support, community mobilization and prevention of obstetric fistula.

4.3.2.1 Successful repair and healing

A survivor felt that once a person is healed physically they can be able to fend for themselves. Also the social stigma only lessens when one is healed. The survivors stressed the importance of surgical repair and healing, bringing mentioning it in the same breath they mentioned other reintegration services. In the interviews, it appeared as though successful repair and healing signalled the end of illness and the return to normalcy, a time when they could be bargain with the community for reacceptance. Quoting some survivors sentiments:

When someone is better, [healed] they can plant maize and sell. There is no otherwise until they're assisted and come up to manage on their own. (Katiraya, a 26 year old obstetric fistula survivor)

Operation is the only solution. As long as an operation is not forthcoming you are still abandoned and discriminated! (Chepengat, a 24 year old obstetric fistula survivor)

Key informants observed that surgery is the first step in reintegrating fistula survivor. This was said to cost about ten thousand Kenya shillings. The surgeries are sponsored by two NGOs; AMREF and Sentinelles. However there were calls for a free surgical repair clinics held by government or other organizations as there are many more women suffering from obstetric fistula. Close follow up is needed after surgery. This is done by a nurse, a social worker and a volunteer advocacy member to ensure the survivor is counselled and her physical health assessed. Her family and community are invited to take care of her and her need for financial assistance is also assessed. This follow up is essential for her healing and social reintegration, as left on her own means it will be difficult. It was argued that a comprehensive surgery program must be coupled with follow up, counselling and other reintegration services.

4.3.2.2 Income generating activities

Most survivors who had received a form of help or business capital felt that this was a very important and had helped in their reintegration. Similarly, those who hadn't received financial help felt that having an income generating activity would have been useful. The income generating activities afford the survivors food and other material needs, as well as an avenue to self fulfilment. Other survivors felt that if they had money it would make it difficult for people to look down upon them. There was a direct plea for help from the government towards supporting income generating activities. For instance, a survivor suggested that; "The government could look at the state of the household, money, food; depending on what she needs she should be helped." (Chepkiror, a 24 year old obstetric fistula survivor)

Key informants observed that income generating activities play a vital role in the reintegration of fistula survivors. Toward their reintegration the survivors are given a goat or a little cash as business capital by an NGO. This has enabled many women and girls to cater for their material needs and improve their reintegration. The participatory approach was seen to be working well amongst survivors who were supported financially to start a business. The survivor contributes to the establishment of the IGA in terms of labour and will pay back the business capital once the profit is ploughed back enough to support the business. The ones who are given a goat to rear will eventually give back a kid to help the next survivor who needs similar help. The participatory approach is seen as key in sustaining the IGA as the survivor assumes some responsibility in the success of project. It was also felt that an income generating activity is better than giving the survivors cash money as they may not be able to handle the money well because of the low levels of education held by some survivors.

4.3.2.3 Formal education and Vocational/ Skill training

It was suggested that skill and vocational training would be of help towards reintegrating obstetric fistula survivors. At the time of study, survivors who were enrolled in polytechnic reported feeling more optimistic about the future in terms of getting a job and had less worry or thoughts. Other survivors expressed their interest in going back to school. A survivor who was in training at the time of interview explained:

For me my training is important. Education comes first, I want to finish the course am doing. Another thing is if I got a small salary. My job would prevent me from having many thoughts, of thinking I need this or that. Or if one opened a business for me, would I have thoughts? Capital for business would help me; it shortens thoughts, because if something is far, you think, how can I help these people who have been assisting me?" (Chepkiror, a 24 year old obstetric fistula survivor)

Similarly, key informants proposed formal schooling as another way of social reintegration for fistula survivors. This is because the survivors' age(s) range from 13 years to 20 years of age and this is an age that can easily gain literacy and numeracy skills. Furthermore, most of the survivors dropped out of primary school at levels of class

two to five. Another argument to support this strategy was that they are no longer useful to their communities, especially the ones who had lost the uterus and cannot give birth. They are not valued at all and taking them back to school or giving them a trade to focus on may help them have meaning in life and help in their social reintegration. Currently there are a few obstetric fistula survivors in primary school and in youth polytechnics, though they are sponsored by well wishers there being no clear cut plan for supporting those who want to go back to school. The schools in West Pokot are sparse and lack teachers posing a challenge to those who want to access the free primary education program.

There are three polytechnics in West Pokot: Sigor, Kacheliba and Kapenguria. However it was noted that while some survivors have adequate literacy and basic formal education to train in tailoring, some have little basic education. Furthermore their advanced age and spouse reluctance may hinder them from accessing such training. It was proposed that they may be supported in making handicrafts like mats and gourds. Towards this a survivor will need support in terms of sourcing for raw materials and marketing of her products.

4.3.2.4 Counselling

This emerged as another strategy that is needed by the fistula survivors to be reintegrated. Most survivors observed that they did not know of any place where they could get such a service when they needed it. Others reported having had emotional trauma, describing the situation as that of having many thoughts. Such survivors would have benefitted from counselling. Others reported having had to content with only the counselling session they had in hospital and felt they would have benefitted if the sessions continued even after discharge. The survivors had this to say about counselling:

I could not get any counselling after discharge; it was only in the hospital that they counselled me. I could have benefitted if they continued counselling and exercises after I went home. (Cheptiros, a 24 year old obstetric fistula survivor)

According to the key informants interviewed counselling services are needed by the obstetric fistula survivors even after surgery. This is long term counselling which

depending on the individuals other coping skills may go up to three years. The spouse to the survivor also needs counselling to accept the survivor and to know the importance of cooperating with the after surgery restrictions on sexual intercourse and childbirth.

The counselling that is available in hospital is amorphous in that there are no specialized counsellors to handle crises such as communicating and managing devastating information like when a woman will never be able to give birth again. This is an area where the administrators of medical services need to look into with an aim of helping fistula survivors.

Counselling is one of the major activities involved in by one NGO that sponsors the surgery of fistula survivors. The organisation has to cover a great expanse of terrain and the most frequent they can visit a survivor is once in two months. However the counselling is done alongside other activities like social work and assessment of financial need. Moreover there are still no specialized counsellors and the number of nurses and social workers are much fewer than the work to be done. In this light there is an identified gap in terms of funds to employ more counsellors or other sectors in government to boost this organizations work. As it is the survivors need long term counselling which is not sufficiently available to them.

4.3.2.5 Support groups

Survivors felt there is need for fistula survivors to support each other. However this was suggested by a survivor and later introduced in the focus discussion group for the survivors. It was seen as a very good idea for people of the same problem namely fistula survivors to support each other so that they can get support. A key informant particularly suggested a form of social network whereby the survivors could support each other.

Specific settings to allow networking of fistula survivors and to allow them to share experience and form survivor Saccos should be encouraged. (Surgeon; obstetric fistula programme)

4.3.2.6 Family planning and fertility treatment

While some survivors cited the need for family planning as their reintegration need, others were more worried about the need for fertility treatment and their inability to

conceive. The latter reported having been ridiculed for lack of a child. Some survivors had no functional physiological signs of fertility like menstruation while others were just worried about their future ability to have children. Some reported to have sought help to restore their fertility after surgery. The survivors felt that if they could be helped for their fertility to be restored they would settle back into the society in a better way.

4.3.2.7 Family and community support

Survivors said that they needed love and support from their families so that they may be accepted back and lead normal lives. This view was shared by key informants as demonstrated in the excerpt below:

Help in reintegrating the fistula survivor through supporting in education, income generating activities. They can also help in getting the patient to the hospital for repair and follow-up. They should accept the fistula survivor in view that most survivors are ostracized and neglected. For the husband to actually accept her [after surgery], it is not easy for them. So we have to counsel the husband. (Surgeon; obstetric fistula repair programme)

From the community, the survivors need acceptance and involvement in the normal activities like women's merry-go-round. However the community's role goes beyond acceptance to recognise their role in formation of obstetric fistula, and the effect of their beliefs towards stigmatising the survivors. A survivor commented on this:

The FGM should stop. It is the cause of fistula [obstetric] in West Pokot. The parents should be told the truth. But they are hard headed. They say "are you dreaming?" Some say I was bewitched, but if it was true I could be dead by now. The girls are not physically forced but the women push them by words so they can get many cows when the girls get married. (Cheptios, a 17 year old obstetric fistula survivor)

Family and community support was also suggested by key informants and further explained. The family has a big role to play in supporting a fistula survivor. Acceptance and taking care of her nutritional and hygiene needs is important. They provide the social form of interaction for her and if they do this without humiliation it will help her feel accepted. The husband and co-wives reception of a survivor also determines her reintegration back to a normal life. It was seen that the survivors who were accepted and supported by their families had a better quality of life after surgery, while ones who were

shunned and chased away live with little hope for life. This was intertwined with the community's role in preventing obstetric fistula. A key informant captured these issues in her explanation:

The community also is accepting the fistula survivors but it is more of being aware of the contributing factors to its forming so that they can help each other because labour and childbirth is a community thing among the Pokot. So if they could insist for good care during that time. So that they know the traditional birth attendants have their place but there is a time when they have to make a decision to take the mother to hospital. Not just to think that it is heroic for her to suffer because they have to deliver with a birth attendant who is not skilled. So the community needs to be aware because these are, the TBAs are culturally health stakeholders in the community. So the community to give them their place that this you will do but this you won't do. As much as we say they shouldn't do deliveries, but the community keeps giving them people. Because one amongst ten, let's say, gets the problem. So the community to safeguard the other nine and to see the one is also saved. (Surgeon, obstetric fistula repair programme)

It was felt that community acceptance of a fistula survivor is also important. However it was also pointed out that members of the community have a much bigger role to play in terms of being aware of contributing factor to its formation. This way they will harbour less stigma towards a fistula survivor. This is because childbirth is a community affair amongst the Pokot. The community members are responsible for deciding when to take an expectant woman to deliver in hospital and not to delay her at the hands of an unskilled birth attendant/ TBA, nor engage in rituals to appease the child to come out. They also have a role in the prevention of obstetric fistula through learning from the experiences of girls who have undergone FGM and EFM.

4.3.2.8 Awareness and sensitization

Publicity is another strategy mentioned as being crucial in eliminating stigma towards fistula survivors. In informant views, when people know about a condition they destigmatise it. An example of HIV/AIDS was given, that owing to the public campaigns the condition attracts less stigma as every member of the public is aware of the facts. There was fear that some women with obstetric fistula could be suffering quietly and with good publicity those who have been suffering for many years may come for help and not

only the fresh ones. If the members of the community know that it is a condition that may be helped then they will reduce the stigma towards the survivor.

4.3.2.9 Community mobilization

The community can be mobilized to reduce stigma resulting from obstetric fistula using awareness campaigns. Seminars can be held where the community members are taught on the facts about the causes of obstetric fistula. Advocacy can also be done through members of the community, the chiefs, the village elders and even church leaders. The village elders however were seen as the most culturally appropriate people through whom advocacy meetings can be held and conducted. The village elders who also act as prophets have the authority to stop FGM through their prophecies since the community respects and will listen to them.

4.4 PREVENTION

Prevention of obstetric fistula was suggested as the ultimate goal of all reintegration programs. Informants felt that performing fistula correction surgery is like fire fighting. There is need to initiate community based/ oriented safe motherhood initiatives, as they were lauded as the possible prevention against obstetric fistula. A surgeon described obstetric fistula as a public health concern. In tandem with this approach is the communities need to know their rights to good care and demand for the same. Equally, empowerment in terms of knowing that obstetric fistula can be treated is important for the survivors.

I think we should not be having that number of fistulas. There are so many and I think being in the hospital to wait to prevent the fistulas is fire fighting. It is a public health thing. We should just be there to prevent bad ones from happening but it should be in the community [prevention]. (Surgeon; obstetric fistula repair programme)

A community verbal autopsy or post-mortem was suggested. This is whereby, following a bad obstetric event like obstetric fistula, the community is engaged in a discussion about the possible causes of such an event and the community's role in its occurrence. In this way they own the problem and the community helps to find a solution. In the words of an informant "even if we make everything ready but the community does not move on

we will not be helping them. The community once it has understood its role in the formation of a fistula will be able to participate in preventing it from occurring again or to other women and girls.’’

According to a nurse caring for fistula survivors, the young men in Pokot community should be involved in preventing obstetric fistula. It was suggested that since FGM is a contributing factor, they may be persuaded to only marry girls who have not undergone FGM. This in turn would force the women to stop forcing their daughters to be mutilated so as to be eligible for marriage. However, the young men would only be part of such strategies if the harmful practices contributing to obstetric fistula are included in school curriculum in form of social studies and biology. The ultimate should however be the empowerment of women and girls in this region to stop participating in FGM.

Shelter homes were recommended for those survivors who have serious crisis. For example the ones who continue leaking urine. Also the ones who have undergone urinary diversion and need more frequent hospital check up. An example was given of Ethiopia whereby the rescue villages also provide a place where the survivors can be taught how to take care of themselves when they go back home. In West Pokot there is a shelter home run by an NGO to rescue girls escaping from early forced marriages and female genital mutilation. Since these two practices were perceived as contributing factors to fistula, it was felt that there is need for a government run shelter home as part of the government’s show of commitment to prevent obstetric fistula in this region.

There is an emerging overall necessity to execute new reintegration strategies and expand the coverage of other existing ones. This also includes prevention of obstetric fistula through primary healthcare and safe motherhood initiatives. All strategies proposed need human resource, logistical preparation and equipment. These strategies also need to be sustained for long periods of time for the desired effects to be realized. Funds are therefore needed to execute and sustain these strategies. A key informant explained the need for funding in this excerpt:

Funding? All those need funding – the publicity, the *Kirors*, they all need funding. What the government is trying to do is the level one to make the primary healthcare to pick up. Maybe they should continue doing that. Because they have been concentrating on the curative but now they are going to primary healthcare.”
(Surgeon, obstetric fistula repair programme)

CHAPTER FIVE: DISCUSSION AND RECOMENDATIONS

5.1 The challenges

Women living with obstetric fistula in West Pokot experience various challenges which include social stigma, reduced sense of worth; physical illness and economic loss due to fistula among others. These challenges have been reported in other studies (WHO 2006; Cook *et al.*, 2004; FIGO, 2006; Holtz and Ahmed, 2007). Social stigma is the greatest that the women living with fistula have to face in their interactions with the community. This further challenges their well being as they are isolated, abandoned and left to fend for themselves.

Donnay and Ramsey (2006) established that stigma, shame and misperceptions exist after surgery for obstetric fistula survivors. Another study done by Engender Health (2006) in Tanzania established that obstetric fistula survivors experience stigma after surgery; although the extent of the stigma and its forms were not reported. This study has established that social stigma continued even after surgery, and highlighted the forms of stigma that obstetric fistula survivors face in West Pokot. Social stigma was manifest in subtle forms in some cases and in others, blatant discrimination. In all cases, however, the survivors were labelled as spoilt. Consequently, potential marriage suitors shied off and were reluctant to discuss their bride price. They were discredited as women, their social status questioned and devalued. The survivors were separated from mainstream society either by total isolation or being partially accepted at social events. In cases where the surgery was unsuccessful the survivors were blatantly discriminated against and at times chased away from home. This study demonstrates that after surgery the survivors experience psychological trauma as though they still have a fistula even though they may be physically healed. Often, physical healing is not sufficient for fistula survivors and there is need to address social stigma that continues after surgery. Therefore there is need for long term counselling for survivors and community sensitisation to counteract the effects of stigma.

The survivors reported felt stigma in many different ways, yet the community focused group discussants reported enacting little if any stigma. It could be the things the

survivors perceived as stigmatising were not perceived in the same light as the community members. It is also worth noting that at times the survivors did not necessarily mention stigma but rather its components. Any research on the condition and policy measures emanating from it should therefore take the survivors view as ultimate. This also directly applies to any community awareness and education messages that may be formulated. Follow up after surgery should include accompanying women to their homes to do health education sessions and counselling to their families. This strategy has been employed and found to work in West Pokot as seen by the work of an NGO; and other settings in Africa (Holtz and Ahmed, 2007).

An earlier study by MOH and UNFPA (2004) highlighted that whilst there is obstetric fistula in other parts of Kenya, the women living with the condition in West Pokot were more likely to experience social stigma than their counterparts in other regions. This study established that the stigma experienced here is related to the cultural beliefs and practices of the Pokot community. Here the value of a woman is determined by her ability to give birth to children. This affords her social status and worth especially in marriage and in the community in general. However, when she fails to or delays to give birth then her social worth is questioned and her social status threatened. Obstetric fistula is perceived as an incurable curse; a bad omen for the marriage and/ or a result of witchcraft. Its occurrence means that the survivor is unclean hence not fit to interact with other community members. She is isolated and even after surgery she is not fully accepted back. The challenge of social stigma is unique in that it is deeply rooted in the cultural beliefs and practices; its eradication will depend on culturally appropriate ways of demystifying obstetric fistula. The community needs to beware of the contribution of cultural beliefs to stigma, which immensely challenges the reintegration of obstetric fistula survivors. In this way they will be able to support the survivors in their reintegration. However, in designing interventions towards this, one needs to be aware of ethnocentric ideology and avoid such in dispensation of community sensitisation.

The social stigma elicited in this study is consistent with Erving Goffman's (1963) definition of stigma and the various components of stigma as conceptualised by Link and

Phelan (2001). Although the latter's components of stigma – labelling, stereotyping, separation, status loss and discrimination - appeared intertwined in most cases, they occurred singly in other cases. Other internal processes such as a reduced sense of worth, low self esteem, overwhelming helplessness and self isolation were also elicited from the survivors. It appears as though these individual processes interact with enacted stigma to further contribute to felt stigma by the survivors. The survivors reduced sense of worth could be resulting from the survivors having heard so many times how of little value they are as women after having had a fistula. Their awareness of the community's negative perception to their condition causes further self doubt even in situations where they are accepted by their families. The survivors end up questioning their normalcy as women and feel less of women after surgery.

Holtz and Ahmed (2007) reiterated that social reintegration is imperative for obstetric fistula survivors. In their argument, the survivors' social and economic life changes forever unless they are aided to return to normalcy. This study confirms these findings further; socially obstetric fistula survivors undergo challenges in marriage and also face economic challenges. The survivors' marriages are jeopardised two fold, first because they may separate temporarily to allow for six months healing before sexual intimacy, and secondly because the husbands take the illness as a bad omen to the marriage and abandon their wives. In both cases, it seems as though women who develop obstetric fistula are certain that their marriages will be negatively affected. For some survivors who get abandoned the husband claims back the bride price. In cases where the survivors' clans cannot refund the bride price then she is taken back to cook for the husband even though she may no longer be able to give birth as her uterus is removed. In a community where a woman's worth is gauged on her ability to fetch many cows as bride price for her clan; and her ability to give birth to children to her husband's clan, the survivors often finds themselves of little value to both sides. Even after surgery their reintegration is difficult. It is not clear to which side they belong. In the cases where the survivors parents took them back they got some sense of belonging and were able to settle better. The dire lack of a survivor's family support is detrimental. In this case

reintegration has little chance since it cannot happen in a vacuum. Furthermore, this challenges their livelihood as they are left to fend for themselves when they are still ill.

The economic challenges to the survivors occur due to their illness, after surgery restrictions and inability to carry on with their businesses as usual. However, other times it is the stigma that is associated with the condition that keeps customers at bay. The survivors then are left with no economic empowerment and depend on other people for food. It is important to empower obstetric fistula survivors as it affords them material needs, psychological satisfaction of intervening in their own situations and gives them productive activities with which to engage in with other people. The last aspect is a vital part of reintegration, one which if omitted banishes a survivor to her lonely fate.

Another challenge for fistula survivors is their infertility. Immediately after surgery they have difficulty coping with instructions, especially of getting a child after two years. This is because of their own desire to get a child sooner and also the social pressure. These coupled with absent signs of normal physiological function like menstrual periods are devastating to survivors. Many seek assistance about their fertility, contrary to expected belief that they would seek family planning instead. Therefore planned reintegration programmes need to anticipate this need by the survivors and cater for it. In cases where the survivors' uteruses were removed, with no future prospects of getting other children, their reintegration is severely compromised.

5.2 Reintegration efforts

Several studies acknowledge that corrective surgery must be followed by help to reintegrate into families and communities depending on the survivors needs (Mohammad, 2007; Bangser, 2007 and Diallo, 2009). Some of the studies also reported the effectiveness of selected reintegration avenues. This study discerned factors that positively aided the reintegration process of obstetric fistula survivors. They include successful outcomes after surgery; family and community support; having a form of income generating activity and undergoing a form of skill training. These factors were noted to have a positive effect on the survivors' psychological well being as well as

providing them with material needs like food and clothes. The presence of such factors greatly enhanced the reintegration of obstetric fistula survivors. The reintegration needs of fistula survivors varied at individual levels, with some survivors needing counselling, formal education or even support to generate income. Therefore reintegration efforts must be preceded by a needs assessment on individual women living with fistula before corrective surgery. It is also worth noting that while fistula survivor may be abandoned by family and their spouses, other parents take back their daughters and support them. This tendency of unconditional positive regard by parents should be built on and encouraged as it is a form of family support that fistula survivors may fall back to.

However the presence of some factors was seen as slowing down the reintegration process or preventing it altogether. They included social stigma, unsuccessful repair, negative cultural beliefs, poverty and general lack of economic empowerment. The negative factors interplayed in many cases and must all be eliminated if reintegration process is to bear fruit. For example, the survivors who were stigmatised found it hard to interact with other community members and shied off. This further jeopardised their chances at social and economic activities, leading to poverty, helplessness and psychological trauma. Social stigma is the greatest of these challenges and must be eliminated for the survivors to lead a meaningful life. Most of these factors are dependent on the community. Therefore their elimination depends on the community's action, albeit with external support.

There is an apparent lack of comprehensive reintegration services for obstetric fistula survivors in West Pokot. There is effort by an NGO (Sentinelles) to support fistula survivors after sponsoring their surgery by doing counselling, medical follow up and starting income generating activities for some survivors. Another NGO (AMREF) sponsors the surgery for fistula survivors. However the surgeries performed are only few, and the reintegration process is also challenged in terms of capacity. There was admitted need for more help on the avenues for reintegration that are already ongoing and others not yet started but much needed by fistula survivors. It was also apparent that there is no government effort that targets obstetric fistula survivors. As has been established, mass

treatment campaigns may draw national and international attention; create awareness and reduce backlog of women awaiting treatment (Ramsey *et al.*, 2007). The government should sponsor such mass campaigns as a way of clearing the backlog of cases in West Pokot, as well as creating community sensitisation and awareness amongst the community.

Some of the reintegration services that are needed by obstetric fistula survivors in West Pokot include counselling, income generating activities, fertility treatment and family planning, education and training, family and community support, shelter homes and rescue centres and survivor support groups. Of these a unique need to the region is in terms of need for shelter homes and rescue centres for the survivors who are in crisis. The shelter homes may double up as waiting homes for women who are expectant to stay in as they await delivery in a hospital. This has been practiced in other countries like Ethiopia with great success

The survivors need long term counselling which, depending on the individuals coping skills, could go on for a few months up to many years. Often, the survivor undergoes serious crisis which must be addressed by a professional counsellor. This was one of the needs stressed on with a general admittance by both survivors and key informants as to be on a low key and more needs to be done in terms of getting more counsellors to cover the large number of survivors and given the expanse of the region. There is also need to carry out couple counselling at the time before during and after surgery. This would help the husbands to the survivors to understand better the after surgery restrictions. It would also encourage them to accept the survivor and support them hence lessening her psychological burden and speeding up her social reintegration. Couple counselling has been practiced in other reintegration programs and proven to work (Wegner *et al.*, 2007) for instance, in Nambya Mission Hospital in Uganda. Couple counselling is done to ensure six months sexual abstinence by the survivors after surgery. This ensures better coping with after surgery instructions for the survivors.

Obstetric fistula survivors need formal education and training so as to lead a meaningful life after surgery. Indeed the few who were undergoing this process seemed to have settled down much better than their counterparts and had greater hopes for the future. However it is worth noting that the prospects of educating and or vocational/ skill training of obstetric fistula survivors depend on many factors. Formal education is possible for survivors who are not married and of a young age. Vocational training is possible if the survivor has sufficient basic education and is not married or her husband permits. In cases where the survivors are well advanced in age without sufficient basic education then they may benefit from skill training like making gourds, mats baskets but in this case they will need support in terms sourcing for materials and marketing for their products.

5.3

Recommendations

5.3.1 Community mobilisation

Stigma is a barrier to the reintegration of obstetric fistula survivors and must be eliminated alongside other factors that hinder reintegration. Stigma is a social construct whose occurrence depends on the society. In this sense, family and community support to obstetric fistula survivors after surgery is critical. The community should be mobilised in culturally appropriate ways so as to eradicate stigma towards obstetric fistula survivors. The community should also be engaged in dialogue on the contributing factors to the occurrence of obstetric fistula in the region. The community is important in eliminating other contributing factors to obstetric fistula; early forced marriage and female genital mutilation and regulating the role of the traditional birth attendants. They also play a big role in the reintegration of fistula survivors as they provide social interaction to the survivors. Family support is pivotal in the reintegration of survivors. Therefore the family must be counselled and sensitised on the needs of a fistula survivor to better prepare in supporting her after surgery. Community members can best be involved through their participation in developing schemes towards obstetric fistula prevention, care of women living with obstetric fistula and reintegration of survivors after surgery.

5.3.2 Couple counselling

Obstetric fistula survivors need long term counselling to cope with reintegration after surgery. Towards this need, professional counsellors need to be deployed to cater for the needs of the survivors. Counselling services should be situated at accessible points for the survivors and should be an integral part of the reintegration efforts. There is also need for couple counselling before and after surgery to help the survivors' husbands support them in their reintegration.

5.3.3 Income Generating Activities, Education and Training

These offer a new avenue for reintegration and should be pursued. After surgery, the individual needs of every survivor should also be assessed before any of these are set to be done. To enable good planning, the needs assessment for an individual survivor may be done before the surgery by social workers. While some survivors may benefit from capital to run an income generating activity after surgery, the majority of survivors need skill training. Furthermore, the survivors who have adequate basic education can benefit from vocational training at the polytechnics. Some survivors who are still in the school going age should be supported to attain basic education as it is the first step towards their empowerment.

5.3.4 Surgery

Surgery and its outcomes are clearly the turning point for the survivors. Therefore every effort should be made to ensure that the repairs are successful as this helps the reintegration of fistula survivors. There ought to be put in place mechanisms for capacity building; to expand surgical facilities, increase personnel numbers at the surgical facilities and train more obstetric fistula repair surgeons in the region. There is need to clear the backlog of fistula cases by sponsoring free repair camps for all existing women living with fistula in West Pokot.

5.3.5 Integrated approach

Elimination of social stigma towards obstetric fistula survivors is beyond the scope of the health service providers alone. An integrated approach must be adopted, both in the reintegration of survivors and prevention of future cases, a deliberate effort to involve

every stakeholder. This needs government commitment and coordination amongst its various sectors. Further, there is need to coordinate effort amongst government sectors, NGOs, and the local community. Safe motherhood initiatives therefore must cater for the community's need to prevent obstetric fistula against the backdrop of infrastructural and socioeconomic challenges that women in this region face. International resolve and efforts to support the eradication of obstetric fistula in developing countries should be coordinated with local effort.

5.3.6 Male advocacy

Men should be involved as stakeholders in the health of women to ensure they too support efforts to prevent obstetric fistula. This is because men play an important role, both in the family and at the community level on matters of decision making and control of resources towards health in this community. Therefore they need to make these decisions considering the needs of a fistula survivor. They also have a role to play in eradicating FGM which is a contributing factor to the formation of obstetric fistula.

5.3.7 Research

Further research areas on the topic include the prevalence of obstetric fistula in West Pokot; the intersection of culture and reproductive health risks among the Pokot community; reintegration outcomes of selected reintegration avenues; effect of FGM on formation of obstetric fistula; long term prognosis following surgery; impact of obstetric fistula on survivors' families.

5.3.8 Prevention

The ultimate goal of any obstetric fistula reintegration programme should be to prevent obstetric fistula from occurring in future in this region. Women's right to sexual and reproductive health, as outlined in the CEDAW, ECOSOC and our national reproductive health policy must be respected. Strategies to prevent obstetric fistula should therefore be incorporated in the current safe motherhood initiatives (SMI). These strategies must take into consideration the unique needs of women in this region during pregnancy and childbirth. Prevention will also largely depend on women's empowerment. This may be

done by ensuring female equity in access to healthcare; implementation of the primary healthcare with emphasis on women's reproductive health needs in the region; education and training of women and girls; income generating activities and autonomous decision making by women and girls concerning FGM, marriage, family planning and childbirth.

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APPENDICES

APPENDIX A: INDEPTH INTERVIEW SCHEDULE

My name is Anne Khisa, a student at the University of Nairobi. I am conducting a study on the social stigma and reintegration of obstetric fistula survivors in West Pokot. I would be grateful if you could spare some time to answer some questions. The information obtained will be used for academic purposes only and will be treated confidentially.

1. Describe your experience when living with obstetric fistula? *Probe role of family and community in this experience*
2. You have undergone corrective obstetric fistula surgery. Kindly explain how you got selected to undergo this surgery?
What information did you receive from the healthcare provider?
3. What were the changes in your life and identity as a woman after surgery? *Probe in terms of roles, gender relations and socioeconomic status*
4. What reaction did you expect from your family after surgery?
After surgery what was your family's reaction on your return home?
What reaction did you expect from the community after surgery?
What was your community's reaction on your return after surgery?
5. What meaning do you attach to your previous illness? *Probe on chances of getting married, employed, acceptance at social events*
6. In your opinion what is the best way to reintegrate a person back to the society?
Individually, what kind of support do you need to reintegrate back to the society?
7. How is the obstetric fistula perceived in this community? *Probe explanation within the context of birth culture and beliefs and taboos.*

APPENDIX B: KEY INFORMANT INTERVIEW SCHEDULE

My name is Anne Khisa, a student at the University of Nairobi. I am conducting a study on the social stigma and reintegration of obstetric fistula survivors in West Pokot. I would be grateful if you could spare some time to answer some questions. The information obtained will be used for academic purposes only and will be treated confidentially.

1. What is the magnitude of obstetric fistula in West Pokot?
2. What interaction do you have with obstetric fistula survivors and how often do you interact?
3. What factors contribute to the formation of obstetric fistula in this community?
4. What are the changes in the women's lives and identity after surgery? *Probe in terms of roles, gender relations and socioeconomic status*
5. What is the degree to which women with successful and unsuccessful repair reintegrate back into their families and communities?
6. What is the effect of stigma on the overall reintegration process of survivors?
7. What services are available to reintegrate fistula survivors into the community?
8. What services do fistula survivors need in the long term for reintegration? *Probe for counselling, skill training, business capital, social immersion.*
9. In your opinion what is the role of the following in supporting fistula survivors:
 - a) The family?
 - b) The community?
 - c) The government?
10. How is obstetric fistula perceived in this community? *Probe explanation within the context of birth culture and beliefs and taboos.*
11. How best can this community be mobilized to address stigma resulting from Obstetric fistula? *Probe for culturally appropriate channels*

APPENDIX C: FOCUS GROUP DISCUSSION GUIDE

My name is Anne Khisa, a student at the University of Nairobi. I am conducting a study on the social stigma and reintegration of obstetric fistula survivors in West Pokot. I would be grateful if you could spare some time to answer some questions. The information obtained will be used for academic purposes only and will be treated confidentially.

1. How is obstetric fistula perceived in this community? *Probe explanation within the context of birth culture and beliefs and taboos.*
2. How does this community interact with obstetric fistula survivors? *Probe for acceptance, isolation, discrimination*
3. What are the changes in the lives and identity of the women before and after surgery? *Probe in terms of their role, gender relations and socio-economic status*
4. What is the degree to which women with successful and unsuccessful repair reintegrate back into their families and communities?
5. What is the role of stigma in their reintegration process?
6. What is the perception of the obstetric fistula survivors on reintegrating themselves back into their families and community?
7. In your opinion what is the role of the following in supporting fistula survivors:
 - a. The family?
 - b. The community?
 - c. The government?
8. How best can this community be mobilized to address stigma resulting from Obstetric fistula? *Probe for culturally appropriate channels*
9. What kind of support would you benefit from after surgery to help in your reintegration process? *Probe for counselling, skill training, business capital, and social immersion.*

APPENDIX D: NARRATIVE GUIDE

My name is Anne Khisa, a student at the University of Nairobi. I am conducting a study on the social stigma and reintegration of obstetric fistula survivors in West Pokot. I would be grateful if you could spare some time to answer some questions. The information obtained will be used for academic purposes only and will be treated confidentially.

1. Describe your experience growing up as a child? *Probe for nutrition, number of siblings and their gender, any illnesses, schooling, immunization*
2. What initiation rites have you undergone? *Probe for FGM and a description of what was done*
3. Describe your experience surrounding marriage? *Probe for age at marriage, consent, bride price*
4. Describe your experience when living with obstetric fistula? *Probe for the challenges, stigma, and residence during illness, role of family and community in this experience, changes in life and identity.*
5. You have undergone corrective obstetric fistula surgery. Kindly describe the experience you went through? *Probe for explanation on how she got selected to undergo this surgery, information she received from the healthcare provider, any other help she was accorded.*
6. What were the changes in your life and identity as a woman after surgery? *Probe in terms of stigma and reintegration, roles, gender relations and socioeconomic status.*
7. What is the role of stigma in your reintegration process? *Probe for perception of the obstetric fistula survivor on reintegrating themselves back into their families and community.*
8. Kindly describe the meaning of your previous illness on your future life? *Probe for life chances economically, physical health, marital life, friendships, spiritual life.*
9. Kindly explain how this community can be mobilized to eradicate stigma for fistula survivors?

10. In your opinion what is the role of the following in supporting fistula survivors:
- a. The family?
 - b. The community?
 - c. The government?
11. Given the experience you have described so far, what is your resolve towards helping fistula survivors in this community? *Probe for sharing information, moral support and advocacy to authorities.*
12. What message would you like to give to all people about obstetric fistula? *Probe to convey a mutual feeling of the survivor.*

APPENDIX E: SURVIVOR'S PROFILES²

Code No. OF/FSI/01 – Cheptoo

This survivor is 23 years old. She is married but has no children. She has had two pregnancies before and had a stillbirth on both occasions due to prolonged labour. She developed obstetric fistula on both occasions. She had been surgically repaired the first fistula and lived for four years before returning to her husband. During the second pregnancy she was followed up and went to hospital to deliver. However her caesarean section was delayed and she developed a fistula while delivering normally. This interview takes place at a time when she has just been discharged from the second surgery. She underwent FGM type III (infibulation) in her teenage.

Code No. OF/FSI/02 - Chepengat

This survivor is about 17 years of age. She is single and lives with her mother. The whereabouts of her father is not clear. She has no other children as the fistula was caused by her first pregnancy. She had an infibulations (Type III FGM) done in her teenage. In the pregnancy that caused this fistula she laboured for 48 hours. She had been attended to by the traditional birth attendant during labour then referred to hospital. The interview takes place after the fourth vesicovaginal fistula repair.

Code No. OF/FSI/03 - Chepkiror

The survivor was done for FGM type III (infibulation) as described by her, at 15 years of age. She is now 24 years and reports having lived with a fistula for three years. She separated from the husband and has no child. She lives with her parents, who also have sponsored her tailoring course. The interview takes place a year after her second surgical repair. She has healed and is enrolled in a polytechnic studying tailoring.

² The names used in these survivors' profiles are fictitious to ensure anonymity and to protect the survivors' dignity.

Code No. OF /FSI/O4 - Chebet

She is about seventeen years of age but is not sure. The survivor resides in Kolowo, East Pokot. Records indicate that she was done for fistula repair at OMH under the sponsorship of Sentinelles NGO. When we find her she says she never had a fistula, and then later admits that she had a fistula but she healed on her own (without repair). We have a general chat with her during which she narrates part of her experience. We note that the survivor is too overwhelmed by the memories of living with fistula. We make a note for the social workers to follow her up through Sentinelles. She is now living at her husband's compound, having separated during the time she had a fistula. At the time of interview her husband has migrated to Uganda in search of pasture for cattle. Her father in-law is present and he is advised to ensure she comes to the Sentinelles offices for help; as she also has not been able to conceive.

Code No. OF/FSI/05 - Cheptiros

This survivor is aged 20 years. She was married but her husband abandoned her when she got a fistula delivering her first child. She lives on her own though she has both parents alive. She resides in Chemulingot, East Pokot. She runs a groceries business at Laudo market where we find her for this interview. She was done for VVF repair which was successful and is now healed. This survivor was done for FGM Type III at thirteen years of age.

Code No. OF/FSI/06 - Cheptios

The survivor is seventeen years old. She got pregnant while at her parent's home at thirteen years of age. When she was six months into the pregnancy she underwent FGM type III. During childbirth she laboured for over two days while being attended to by a traditional birth attendant. Then she was taken to OMH where she was assisted to deliver, though the baby was dead on delivery. She developed both vesicovaginal and rectovaginal fistulas. The RVF was repaired but the VVF has been attempted repair thrice without success. At the time, she is scheduled for another repair later on in the Moi Teaching and referral Hospital in a better equipped theatre. Her mother passed away and

she was chased away from her stepfather's home by her stepbrother. At the time of the interview she is living at the Sentinelles office premises in Makutano. She sells vegetables, an income generating activity that was sponsored by Sentinelles NGO.

Code No. OF /FSI/07 - Tingoyi

She is approximately aged 30 years. The survivor is married with 4 children. She developed a rectovaginal fistula during delivery of her third child. It was a home delivery which by description was preceded by precipitate labour. The baby survived and is alive and well. She was surgically repaired in two days but remained incontinent of stool for a year. A second surgery was done which was successful and she was healed. After surgery she was abandoned by her husband who went to live with the other wife but now they are living together. At the time of interview she reports being of good health and leading a normal life with her husband. She went on to deliver another child by caesarean section; the child is alive and well. She does maize farming, rears goats and runs a groceries kiosk in her compound for income. The interview took place in her home.

Code No. OF/FSI/08 - Katiraya

This survivor is 26 year old. They separated with the husband though he lives in the same compound with her. She says he didn't marry again as he is poor. The survivor had other children prior to the pregnancy that caused the fistula. The survivor underwent the first vesicovaginal fistula repair which was unsuccessful. At the time of interview she is still leaking urine and is scheduled for a second operation soon. She has come to Sentinelles office where the interview took place.