

**ACHIEVING INTEGRATED APPROACH: MOVING FROM REPAIR TO
COMPREHENSIVE REINTEGRATION OF OBSTETRIC FISTULA SURVIVORS IN
KISII COUNTY**

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DECLARATION

This project paper is my own original work and has not been submitted for a degree in any other university.

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This project paper has been submitted for examination with my approval as the university supervisor.

Signature Date

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DEDICATION

This study is dedicated to my late mother, Naomi Wanjiru Kamau. She passed on during the course of my study. Her love and cheerful encouragement in personal development motivated my pursuit for higher education.

The study is also dedicated to the obstetric fistula survivors for their resilience and courage to brave the difficult reproductive health condition that deprived them of their dignity as women and subjected them to unbearable suffering. These women now live to prove that obstetric fistula is a treatable condition and that reintegration services are paramount in holistic healing and restoration of their dignity.

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ABSTRACT

This study explored the availability and access to comprehensive reintegration support services for obstetric fistula survivors in Kisii County. It was a phenomenological qualitative study. Data was collected using in-depth interviews and case narratives with obstetric fistula survivors and key informant interviews. The study was guided by the general systems theory. Survivors were recruited through the Kisii Teaching and Referral Hospital and interviewed in their places of preference including residence. The findings show that although there is support in treatment (repair) there are no formal support structures for reintegration of obstetric fistula survivors. Survivors have formed informal networks, including groups of fistula survivors. Further, the survivors rely on family and neighbours for support. Survivors face stigma and isolation and financial challenges in the reintegration process. These challenges can be addressed through support groups, sensitization and creating awareness, as well as economic empowerment and capacity building. The study concludes that treatment and repair of fistula is not matched with proper reintegration for comprehensive fistula management. Therefore, the study recommends appropriate ways of responding to the barriers to reintegration of obstetric fistula survivors that should be adopted and reinforced with willingness and deliberate actions from key stakeholders involved in fistula response management.

LIST OF ABBREVIATIONS AND ACRONYMS

AMREF	African Medical Research Foundation
CSOs	Civil Society Organizations
FGM/C	Female Genital Mutilation Cutting
IDI	In-depth Interview
KII	Key Informant Interview
KDHS	Kenya Demographic Health Survey
KNBS	Kenya National Bureau of Statistics
KNH/UON ERC	Kenyatta National Hospital/University of Nairobi Ethical Review Committee
KTRH	Kisii Teaching and Referral Hospital
MOH	Ministry of Health
NACOSTI	National Council for Science, Technology and Innovation
SID	Society for International Development
TBA	Traditional Birth Attendant
UNFPA	United Nations Populations Fund
UoN	University of Nairobi
WHO	World Health Organization

CHAPTER ONE

BACKGROUND TO THE STUDY

1.1 Introduction

Obstetric fistula is a hole in the birth canal between the bladder, rectum, urethra or uterus that is caused by obstructed labour. Obstructed and prolonged labour leads to necrosis creating a hole—or fistula—between the vagina and the bladder (vesicovaginal fistula) and/or rectum (rectovaginal fistula). Obstetric fistula is not only a health problem but has social and economic implications for women before and after treatment (UNFPA and Engender Health, 2013).

Although obstetric fistula is a global problem, it exerts much weight in the developing world. Estimations show that more than 2 million women have obstetric fistula but exclusively in sub-Saharan African and Asia (UNFPA and Engender Health, 2003). This is particularly because of the low income status and traditional harmful practices such as early marriage and female genital mutilation.

In Kenya, obstetric fistula remains a major maternal health concern. Annually there is an estimated 3,000 new fistula cases but only 7.5% are reported and treated. The problem of obstetric fistula is more pronounced in the pastoral regions of West Pokot, Turkana and Garissa, and in South Nyanza (UNFPA and MOH Kenya, 2004). According to the 2016 Fistula Camp report by the Kenya Fistula Foundation, Kisii Teaching Referral Hospital (KTRH) has hosted fistula camps for the last eight years. In 2016 KTRH recorded a total of 463 fistula cases treated since 2009 and Kisii County was over-represented in fistula cases operated on (Freedom from Fistula Foundation, 2016).

Interventions from the government, non-governmental organizations and development partners have targeted treatment and prevention of fistula. Consequently, fistula centres and

camps have been established in various hospitals across the country including Kisii Teaching and Referral Hospital. Although prevention and treatment of obstetric fistula has shown progress, there remains a major gap in the reintegration of survivors into their communities (UN General Assembly Resolution 69/148, 2015).

Obstetric fistula often leads to social, physical, emotional and economic decline and it leaves women with few opportunities for meaningful social and economic participation (Khisa, 2010). Fistula patients and survivors are shunned, secluded and experience intense feeling of shame, self-loathing and depression. This disconnects them from social and economic processes. It is therefore important to focus on social reintegration programmes and interventions to help fistula survivors reintegrate into their communities and connect with their families (UNFPA and Engender Health, 2003).

Reintegration is the process of helping women affected by obstetric fistula return to the life they had before they developed obstetric fistula (Khisa, 2010). This addresses how women adjust and reconnect to livelihood: employment, families, communities, and social life in order to restore their lost dignity and respect and to boost their self-esteem (Mselle *et al.*, 2011). The study was conducted in Kisii County to explore the availability and access to comprehensive reintegration support services for obstetric fistula survivors.

1.2 Statement of the Problem

Obstetric fistula is a debilitating medical condition affecting women especially in low-income settings. The condition is not only medical but has significant individual and social ramifications (Khisa, 2010). Obstetric fistula leaves women unable to control urine or faeces. This is associated with a lot of shame and stigma from the society. On the one hand, the women feel embarrassed, struggle with shame and may isolate themselves from others due to humiliation that comes with the smell of urine (Were, 2015). This renders them incapable of

meaningfully engaging in social and economic activities and become disconnected from both social and human capital as they do not mingle with others. This may create or perpetuate the vicious cycle of poverty.

On the other hand, the social stigma from the community aggravates the feeling of shame. The affected women may be ostracized from the community, abandoned or divorced (Khisa, 2010; Were, 2015). This isolation elevates the woman's self-imposed belief of disgrace and unworthiness. With dwindling social and family support, women with obstetric fistula stay alone and remain disconnected from mainstream society.

Treatment for obstetric fistula is often surgical and the healing takes time. In the process the women lose touch with the community. When they come back, they continue facing stigma and struggle to fit in as normal persons. With the feeling of shame, stigma and social rejection, women fistula survivors find it hard to reintegrate into society.

The Kisii Teaching and Referral Hospital has been holding annual obstetric fistula camps since 2009 as a response to the high prevalence of obstetric fistula in the region. During the 2016 free fistula medical camp, it was noted that Kisii County has high prevalence of obstetric fistula compared to other counties in the region. The County accounted for 58% of all fistula cases handled during the 2016 free fistula camp at KTRH (Freedom from Fistula Foundation, 2016). Although the women were treated, the need for reintegration remains high. This study, therefore, sought to explore the availability and access to comprehensive reintegration support services for obstetric fistula survivors in Kisii County and answered the following research questions: What reintegration services are available for women fistula survivors in Kisii County?, What are the reintegration challenges experienced by these women and how can these challenges be addressed?

1.3 Objectives of the Study

1.3.1 General Objective

To explore the availability and access to comprehensive reintegration support services for obstetric fistula survivors in Kisii County.

1.3.2 Specific Objectives

1. To determine the reintegration services available for women fistula survivors in Kisii County.
2. To identify reintegration challenges experienced by these women.
3. To establish how these challenges can be addressed

1.4 Assumptions of the Study

1. Kisii County has reintegration services for women fistula survivors.
2. Women fistula survivors in Kisii County experience some challenges in family and community reintegration.
3. The challenges experienced by women fistula survivors in Kisii County can be addressed.

1.5 Justification of the Study

Rehabilitation and social reintegration of fistula survivors back into their families and community after medical treatment is an area that has not received much focus in terms of research especially in Kisii County. The study on social reintegration is essential in achieving an integrated approach in obstetric fistula response. Availability of reintegration services and support of fistula survivors is a great need in Kenya, especially due the increased fistula camps hosted in the country in an effort to reach out to obstetric fistula patients suffering in the rural areas. The study has generated a body of knowledge that can contribute to formulation of reintegration programmes and services easily available to fistula survivors for holistic healing. Therefore, the study should add value to decision-making at policy level.

The study has also provided information on post-repair factors influencing comprehensive reintegration of fistula survivors into the community. This should help relevant stakeholders in reintegration including health care workers, civil society organizations, care givers and donors to support post-repair factors with positive influence and create strategies to mitigate factors with negative influence. This way, the study has provided evidence-based best practices for comprehensive reintegration of fistula survivors that can be applied in other communities depending on cultural orientation. Finally, the study findings have built on the literature in reintegration of fistula survivors and therefore can be used as a reference by future researchers.

1.6 Scope and Limitations of the Study

The study was conducted in Kisii County and focused on the availability and access to comprehensive reintegration support services for obstetric fistula survivors. It focused on the reintegration services provided, the challenges and experiences on reintegration that women fistula survivors face. The study was guided by systems theory, and was cross-sectional and exploratory in nature. This had the potential of limiting the generalizability of the findings, but the study has yielded rich qualitative data which can be used by other researchers to replicate the study in other counties. In addition, the study focused on a very sensitive area of reproductive health and so some respondents would not to open up, thereby limiting full disclosure. However, the researcher mitigated this limitation by ensuring the privacy of the interview settings and assuring the respondents of confidentiality. The researcher also asked the rather sensitive questions in a friendly and less emotive way to avoid respondent discomfort or drop-out.

1.7 Definitions of Key Terms

Obstetric fistula: Hole between the vagina and rectum or bladder, caused by prolonged and obstructed labour, leaving a woman with urine and/or faeces incontinence.

Reintegration: Process of integrating fistula survivors back into the society, community or family after fistula repair to fit in, regain their dignity and productivity.

Rehabilitation: The action/process of restoring fistula survivors to normal life through vocational training, economic empowerment and counselling.

Holistic healing: Healing beyond the physical form of healing that considers the whole person's body, mind, spirit and emotions.

Obstetric fistula survivor: An individual in the reproductive age who has gone through the condition of fistula and has repair done at a facility, with or without success.

Community: A group of individuals who share particular common characteristics.

Stigma: Feeling of shame and negative attitudes by obstetric fistula women survivors and discrimination against them by community members due to the condition.

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

This chapter reviews the literature relevant to the research problem. The literature is reviewed using the following subheadings: obstetric fistula, challenges faces by fistula survivors, corrective surgery outcomes and reintegration pathways and services. The chapter ends with a discussion of the theory that guided the study.

2.2 Literature Review

2.2.1 Obstetric Fistula

Obstetric fistula is a medical condition caused by an abnormal opening between the bladder and the vagina (vesicovaginal fistula) or between the rectum and the vagina (rectovaginal fistula) or both (Browning and Menber, 2008). The opening leads to incontinence in which the patients lack the capacity to control leakage of urine and/or faecal matter. The underlying cause of obstetric fistula is prolonged and unattended labour (Khisa, 2010). During prolonged labour, the baby's head pushes constantly against the mother's pelvic bone and cuts off the blood flow to the soft tissue (Wall, 2006). Eventually, this leads to necrosis creating a hole—or fistula—between the vagina and the bladder.

Obstetric fistula remains one of the leading maternal health concerns and this is attributable mainly to disregard of human, and particularly women rights (Cook *et al.*, 2004) Further, it is not only a medical condition but also has psychosocial and economic ramifications. Due to the inability to control urine or faecal matter, patients experience foul smell and are unable to participate in social and economic activities. The offensive smell leads to isolation and marginalization of the women with fistula by their families and communities (Ashford, 2002; Bangser, 2006; Semere and Nour, 2008). The patients are unable to participate in various social and religious activities. The psychological aspect of fistula is characterized by

psychological dissonance, distress, depression, shame and embarrassment as well as disappointment (Wall *et al.*, 2005). These may lead to suicide in some instances (Nielsen *et al.*, 2009).

Although the major cause of obstetric fistula is prolonged labour, this can be a consequence of various factors that singly, collectively and in various combinations lead to risk of obstetric fistula. The general breakdown of maternal and public health characterized by poor access to comprehensive maternal care and skilled delivery contribute significantly to the risk of obstetric fistula (Donnay and Ramsey, 2006). The gender inequalities that produce health differences between men and women and the general disregard and abuse of women are also cited as contributing factors. In this line of thought, harmful traditional practices such as female genital mutilation and child marriage form part of the predisposing factors to obstetric fistula.

According to Khisa and Nyamongo (2012), most women with obstetric fistula have undergone FGM. Child marriage and early pregnancy cause prolonged labour and other complications related to obstetric fistula since the young girls' reproductive organs are not mature enough to handle the child birth process (Donnay and Ramsey, 2006). Reliance on unskilled birth attendants (traditional birth attendants or TBAs) is also a contributing factor leading to development of obstetric fistula among many women (Cook *et al.*, 2004). These women may be in a cultural matrix that puts emphasis on the deliveries attended by TBAs, have poor access to health facilities due to distance, or poverty that hinders comprehensive emergency obstetric care (Tebeu *et al.*, 2011).

Although obstetric fistula has been managed successfully in high-income or developed countries, it remains a pressing maternal health problem in low-income and developing countries in Africa and Asia, with high prevalence and incidence levels. Worldwide, early

this century, more than 2 million women lived with the problem of obstetric fistula and most are in Africa and Asia, with an additional 50,000-100,000 new cases being experienced each year (WHO, 2005). According to Bangser (2006) and Wall (2006) the incidence rate was 50,000-130,000 per year. However, sub-Saharan Africa and South Asia have most cases of obstetric fistula affecting poor and marginalized women especially in settings with weak health systems and limited resources (Bangser, 2006). In the sub-Saharan region, there is a high-risk area called the “fistula belt” where 33,000 new cases develop each year (Tebeu *et al.*, 2011:387).

In Kenya, data on obstetric fistula prevalence and incidences remain scanty and unknown (UNFPA and MOH Kenya, 2004). In high-risk areas such as Western and North Rift Kenya, estimations show that 1 in every 1,000 women develop obstetric fistula (Mabeya, 2003). According to WHO (2005), these statistics could even be higher.

2.2.2 Challenges Faced by Fistula Survivors and affect Reintegration

2.2.2.1 Stigma, Psychological Trauma, and Low Self-esteem

Studies have shown that although fistula patients experience discrete challenges before surgery or treatment, certain challenges are transferred to the post-treatment (Nielsen *et al.*, 2009; Mabeya, 2003; Donnay and Ramsey, 2006). Obstetric fistula is a stigmatizing condition and the patients experience stigma from the society and family. The condition lowers the quality of life for the patients as they experience low self-esteem and are marginalized, ostracized, labelled, and discriminated against (Ashford, 2002). They may be hidden away and fail to participate in important social and economic functions as feelings of shame and embarrassment for themselves and for families and communities persist. Stigma also persists among the survivors after treatment (Nielsen *et al.*, 2009). Women survivors are worried as to whether they will be accepted back into their families or not.

According to Khisa and Nyamongo (2012), even after corrective surgery, women are subjected to blatant discrimination and isolation. Apparently, families and the community isolate the survivors and do not allow them to participate fully in household chores. Such survivors are constantly reminded of their previous condition through negative comments and are not accepted (Ashford, 2002; Khisa and Nyamongo, 2012). In certain instances, the stigma associated with fistula is expressed in subtle forms.

However, in other cases it is expressed explicitly, with unconcealed discrimination as the norm. Although the women may be invited to social events such as weddings, they may not be allowed to participate in food preparation or meeting guests. They are described as spoiled, are discredited as women and their social status devalued. In other cases, the survivors are believed to be cursed, providing the reason for isolation and in case of unsuccessful repair, the women may be chased away from home or divorced (Wall *et al.*, 2005).

The experience of stigma is associated with detrimental psychological effects for the survivors. There is long-term psychological trauma when the women are labelled and described using derogatory terms that drain the little self-esteem left (Ashford, 2002). Even after surgery, fistula survivors have doubt and fear regarding whether they will be accepted. They are not confident and doubt their self-worth even when they may not be isolated by the family or community. The feeling of being unwanted and isolated reminds them of the undesirable past experience of incontinence. The survivors feel embarrassed, lose meaning of life and this may lead to suicide ideation (Cook *et al.*, 2004). The inclusive loss associated with fistula may have long-term social and psychological effects for the survivors. In some cases, the women lose their babies and long after surgery, they mourn the loss and face social ridicule linked to not having a baby (Khisa and Nyamongo, 2012).

Thus, stigma and the consequent psychological dissonance affect reintegration of fistula survivors in the family and in the community. Stigma may also be the cause of lack of proper integration but, at first, it inhibits proper integration and social engagement. The survivors lose the social ties and networks they had before fistula (Semere and Nour, 2008). Upon return and compounded by stigma, they may not be accepted back or be treated differently because of their condition. Due to stigma and psychological trauma, the survivors lose networks that would otherwise support their full integration.

2.2.2.2 Fertility, Separation and Divorce

Meaningful reintegration of fistula survivors suffers a significant setback under the patronage of separation and divorce. After corrective surgery, fistula survivors are not accepted back in their families and are often separated from husbands or spouses (Semere and Nour, 2008). This has detrimental effects not only on their marriages but also on future marriage prospects (Khisra and Nyamongo, 2012). On the other hand, after the corrective surgery, the survivors are instructed to abstain from sexual intercourse for a period of time and delay the next child birth (Semere and Nour, 2008). Husbands may not understand this and they often abandon their wives and move on with other women. In other circumstances, the women survivors themselves may move to stay with their parents until healing to reduce the risk of sexual contact and/or pregnancy which is higher when they live with the husbands (Khisra and Nyamongo, 2012). The separation leaves the survivors with no meaningful social and material support, thereby frustrating significant reintegration (Lewis and WHO, 2006).

In addition, the survivors may have experienced multiple losses after developing fistula. They may not only lose their babies but also lose the uterus (Zacharin, 2012). The fertility concerns are evident for both single and married fistula survivors. This fundamentally damages their future marriage prospects as they are devalued and not seen as women in the

society. This is especially true when the measure of a woman is her ability to give birth and attract a huge bride wealth for the family. When the survivors do not meet these social expectations, they do not only suffer from stigma but also lose support for reintegration.

2.2.2.3 Surgery Outcomes

Surgery remains a key treatment option for fistula (Browning and Menber, 2008). The possibilities and chances of successful reintegration are highly dependent on the surgery outcomes. According to Khisa and Nyamongo (2012), fistula survivors who benefit from corrective surgery find the treatment helpful. For the survivors, surgery is an important turning point to normal life. In this perspective, undergoing medical treatment and surgery is the point of departure for reintegration. The idea is that the surgery has the capacity to restore the confidence and alleviate the embarrassment and discomfort that comes with fistula. Therefore, women who have undergone successful surgery have an upper hand in terms of reintegration than those who have unsuccessful surgery (Lewis and WHO, 2006).

Studies have also shown that individuals and communities believe that the only solution to obstetric fistula is surgery and that without it, patients continue to be discriminated and abandoned. Surgery provides an important milestone to social reintegration as the survivors feel more accepted, can have friends and be part of the community (Lewis and WHO, 2006). After successful surgery, the survivor is also likely to be accepted back by the husband and receive material, emotional and inclusive social support if she has managed to heal emotionally.

However, according to Khisa and Nyamongo (2012), unsuccessful surgical repairs leave the patients worse off than before. They are considered as a bad omen and alienated further. The family and community expect that after surgery or repair the women are healed and continue

with normal life. In the event that the repair is not successful, the women are blamed and isolated for this failure, which is seen as theirs. Therefore, the extent to which survivors are integrated and accepted back in the community is dependent highly on the surgical repair outcome.

2.2.2.4 Economic Challenges

Economic challenges pose a significant threat for fistula survivors in relation to their integration in the society (Khisa, 2010). Fistula can be said to be a cause and consequence of poverty. On the one hand, it is more prevalent in low income settings with breakdowns in healthcare systems. On the other hand, it disconnects the women from their income generating activities as they remain no longer capable of performing various duties (Dworkin *et al.*, 2007). Fistula survivors may also abandon their previously established business ventures or other income generating activities. They thus remain dependent on their husbands or other people.

In addition, due to economic gender inequalities and economic disempowerment of women, the survivors lack capital and the physical strength to work. They are also immersed in negative labelling by the community and prospective employers may look down upon such women and view them as unproductive (Lewis and WHO, 2006). Consequently, the survivors do not only lose economic and employment opportunities but are also disconnected from the means to generate income. Full and meaningful reintegration is thus negatively affected as the women become dependent and lack capacity to participate in and fulfil their economic lives.

2.2.3 Reintegration Pathways and Services

Although substantial breakthrough has been realized in the prevention and treatment of fistula, there remains a need to address the issue of reintegration. It is evident that obstetric

fistula is stigmatizing even after repair and there is need for elimination of stigma, through community sensitization and mobilization. A needs assessment carried out by UNFPA and MOH Kenya (2004) showed that much attention is directed at prevention and treatment while reintegration of the survivors receives little attention.

Civil society organizations, community-based organizations (CBOs), faith-based organizations (FBOs) and non-governmental organizations (NGOs), have provided concerted efforts and played a key role in community sensitization on obstetric fistula, recruitment and referral of fistula clients for repair and social reintegration (UNFPA and MOH Kenya, (2004). The idea is that addressing and eliminating fistula is not only a function of prevention and treatment (surgical repair) but also integrating the survivors back into their communities and families as well as ensuring holistic healing. This is the true definition of comprehensive and integrated approach to fistula response, prevention, medical/surgical treatment, and reintegration. Reintegration ensures that the survivors continue with their normal lives and that their image and community participation is not affected by the fistula condition. According to UNFPA and MOH Kenya (2004), the context within which fistula occurs transcends the health sector.

This means that fistula is not only a health problem but has social dimensions that require social-based approaches. Partnership with relevant government departments, private sector, donor agencies, NGOs and CBOs is essential in addressing the issue of reintegration of fistula survivors. Social reintegration strategies are largely dependent on the elimination of social stigma and mobilizing society and family to provide support to survivors. Some of the reintegration strategies and services that are needed by obstetric fistula survivors include income generating activities, vocational and skill training, counselling, fertility treatment and

family planning, fistula prevention, family and community support, shelter homes and rescue centres and survivor support groups (Khisa, 2010:59).

2.2.4 Theoretical Framework

2.2.4.1 General Systems Theory

This study was guided by general systems theory (GST) as proposed by Ludwig Bertalanffy and as applied in social sciences. Systems theory has its roots in the 1950s in a variety of sources such as cybernetics, engineering, and epidemiology (Rodin *et al.*, 1978). It also developed in Western and Marxist social contexts. GST is a multidisciplinary approach to systems analysis and views systems to have components (Bertalanffy, 1971). The components must work harmoniously for the functioning of the whole system.

In the social sciences, systems theory came to offer tools that can be used to model multivariate interactions although the models in social sciences are more complicated than those in the physical sciences (Rodin *et al.*, 1978). Systems theory emphasizes the interconnectedness or interrelatedness of social phenomena. Anthropologist Gregory Bateson was the first to apply general systems theory in the social sciences in the 1940s. Bateson describes the application of systems theory in human societies. For him, a system is a unit with feedback structure (Bateson, 2000). A system, in a social science perspective, is thus a viewpoint on the relationship of persons with their social environment.

General systems theory, as a multidisciplinary approach of systems analysis, has the concept of non-representational and non-referential. This means that instead of having mental concepts, it is important to trace the network of things. According to Bateson, tracing mental images bring in sight material reality that has been obscured under the universalization of concepts (Bateson, 2000).

The other concept in systems theory is non-Cartesian. The Cartesian subject imposes mental concepts on things to control nature or what exists outside the mind. The subject-centred view has reduced the complex nature of the universe. Systems theory comes in handy to displace the Cartesian subject and assert the idea that human beings are not a supreme entity. Rather, they are part of the universe and this makes social sciences move away from a subject-centred view of the world (Bateson, 2000).

In order to move away from a subject-centred view of the world, an open system (and not closed one) is required. An open system allows interactions between its internal elements and the environment. Open systems are well described by Bateson who argues that “ecological systems, social systems, and the individual organism plus the environment with which it interacts is itself a system in this technical sense” (Bateson, 2000:260).

In setting out the general rule of systems theory, Bateson argues that:

The basic rule of systems theory is that, if you want to understand some phenomenon or appearance, you must consider that phenomenon within the context of all completed circuits which are relevant to it. The emphasis is on the concept of the completed communicational circuit and implicit in the theory is the expectation that all units containing completed circuits will show mental characteristics. The mind, in other words, is immanent in the circuitry. We are accustomed to thinking of the mind as somehow contained within the skin of an organism, but the circuitry is not contained within the skin (Bateson, 2000:260).

Thus, systems theory views social phenomena in their holistic terms including the components that make up the systems. The underlying idea is that each part of the system must function well for the functioning of the whole system.

2.2.4.2 Relevance of the Theory to the Study

Systems theory was relevant because of its connectedness to this study and the objectives. The study views treatment of obstetric fistula as a continuum or as a system with different components. In the comprehensive treatment of obstetric fistula, surgery is a part (or

component) of treatment. Reintegration of the survivors back into the community is another component and must be addressed. In regard to the theory, a phenomenon must be considered within the context of all components. In the social phenomenon in the study, reintegration of the survivors must be considered if the whole system (comprehensive) treatment has to work well.

In addition, obstetric fistula treatment and recovery does not occur in a vacuum. Rather, it is a system connecting the individuals, community, healthcare providers and other stakeholders. All the components in the system must play their role for the functioning of the whole system. The theory informed the study that the existing gap in comprehensive treatment for fistula is a result of the non-performance of the components such as the community which might affect the system through stigma. This provided information about the challenges in the reintegration of the obstetric fistula survivors, hence addressing the second and third study objectives (Fig.2.1).

Independent Variables

- Reintegration services**
 - Civic education
 - Community Sensitization
 - Community mobilization
 - Dealing with rejection and stigma



- Individual empowerment**
 - Fertility treatment and family planning
 - Individual Counseling
 - Entrepreneurship skills
 - Vocational skills
 - Income generating activities

Dependent Variable

- Reintegration of Obstetric Fistula Survivors**
 - Social reintegration
 - Economic reintegration
 - Psychological integration

- Intervening Variables**
 - Family (husband) support
 - Support from women groups
 - Community support

Figure 2.1: Conceptual Framework

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter describes the methods used in the study. It describes the research site, study design, study population and unit of analysis, sample population and sampling procedure, data collection methods and data processing and analysis procedures. It also discusses the ethical issues that were taken into consideration.

3.2 Research Site

This study was carried out at Kisii Teaching and Referral Hospital (KTRH) located in Kisii County. KTRH provides health services including obstetric fistula treatment and holds annual medical camps for sensitization and treatment of obstetric fistula.

Kisii County (Fig.3:1) borders Nyamira County to the North East, Narok County to the South and Homa Bay and Migori Counties to the West, and covers an area of 1,317.5 km² (KNBS, 2015). Based on the 2009 Population and Housing Census, Kisii County's population was 1,152,282 comprising 550,464 males and 601,818 females. The Kisii County Government (2013) projected that this population would increase to 1,367,049 (660,810 males and 706,239 females) by 2017.

During the Free fistula medical camp held at the KTRH in 2016, 58% of fistula cases came from Kisii County (Free from Fistula Foundation, 2016). Thus, the County has high prevalence of obstetric fistula compared to the other counties in the region. This high prevalence of obstetric fistula in Kisii County is partly explained by the high prevalence of predisposing factors such as female genital mutilation (FGM) where the rate is more than 84.4%. (KNBS, 2014:333-334).

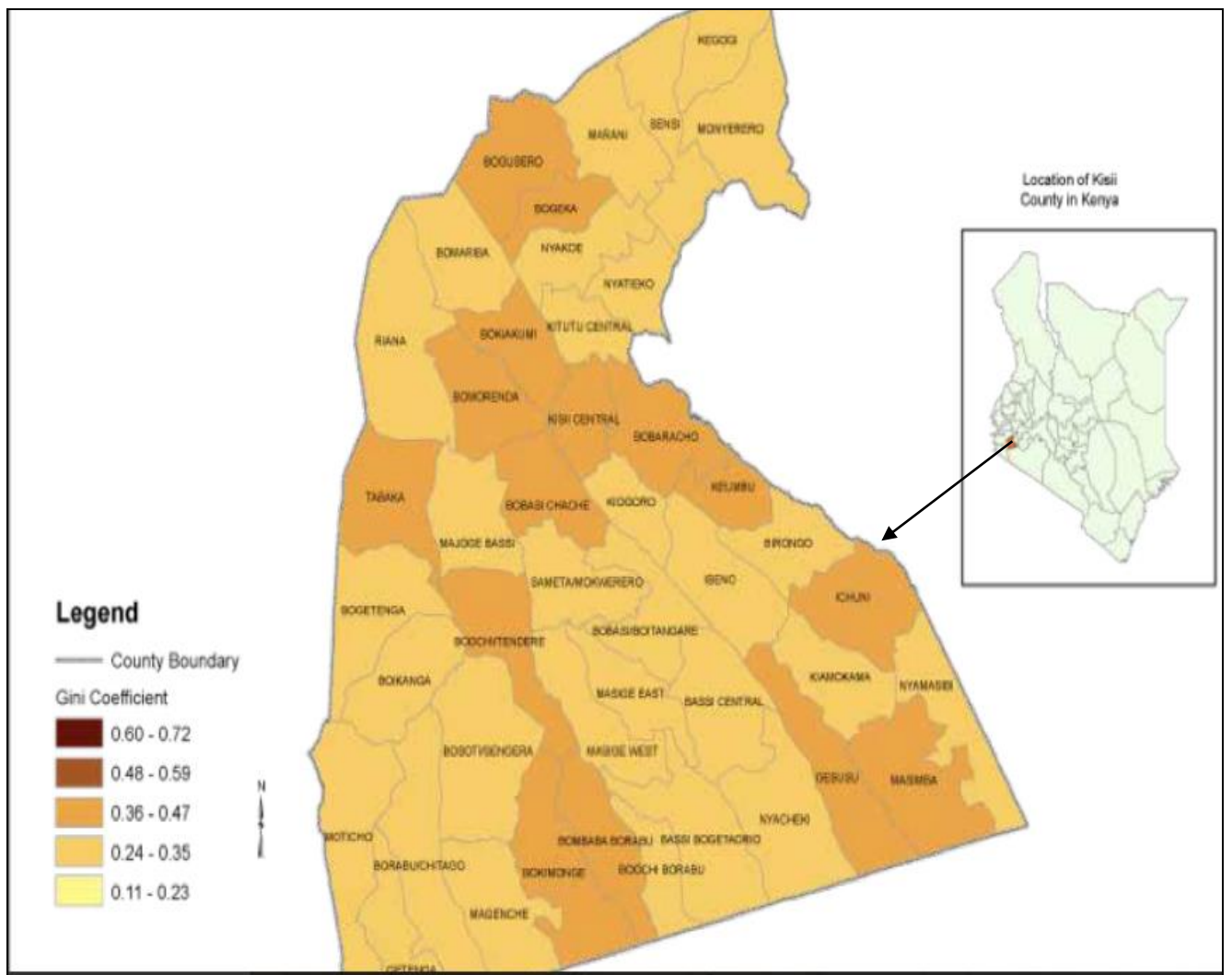


Figure 3.1: Map of Kisii County (Source: KNBS and SID, 2013).

3.3 Research Design

According to Burns and Grove (2003), a research design is an outline for conducting a study with maximum control over factors that may interfere with the validity of the findings. This study used a phenomenological research design employing qualitative research method. Individual lived experiences were examined through in-depth interviews. Case narratives were used to augment qualitative data obtained from in-depth interviews. Additional information was obtained through key informant interviews. Data were analysed using Nvivo software. Key themes were developed focusing on the three study objectives.

The findings are presented using key themes and relevant quotes to present the voices of the respondents.

3.4 Study Population and Unit of Analysis

The study population consisted of women fistula survivors living in Kisii County and above 18 years age. The unit of analysis was the individual woman fistula survivor treated at Kisii Teaching and Referral Hospital and has had surgical repair for fistula in the previous two years.

3.5 Sample Population and Sampling Procedure

The study originally planned to have a sample size of 30 respondents. However, the study only managed to recruit 22 respondents.

The Kisii Teaching and Referral Hospital was purposively selected as the recruitment centre. The final sample size was selected from the hospital register, which was the sample frame. The researcher created contacts with the selected women fistula survivors with the support of both clinical officers and community health workers/volunteers (CHWs or CHVs) at the centre. This established the initial contact point from where the researcher, with assistance of CHVs, located or arranged to meet the respondents in their homes or at an agreed point of meeting. Any respondent who agreed to participate in the study and met the criteria of inclusion, was recruited for the study.

3.6 Data Collection Methods

3.6.1 In-depth Interviews

In-depth interviews were the main data collection method. These interviews were conducted among obstetric fistula survivors treated at Kisii Teaching and Referral Hospital. The method was used to collect data on the challenges experienced in reintegration of obstetric fistula survivors and identifying ways of addressing these challenges. An in-depth interview

schedule (Appendix 2) was used to collect the data. With the respondents' consent, a digital recorder was used to record the interviews for further processing.

3.6.2 Case Narratives

The study targeted 5 case narratives from the women fistula survivors who were selected purposively from the list of respondents. The method targeted such women to obtain information covering a long period of time with integration. A case narrative guide (Appendix 3) was used to focus on key themes and aspects relating to the challenges as well as reintegration services.

3.6.3 Key Informant Interviews (KIIs)

The study sought to obtain the key information from focal persons involved in fistula management. Three key informants were purposively selected. The key informants were health care workers and nurses who attended to the fistula patients at the research site. A key informant interview guide (Appendix 5) was used.

3.6.4 Secondary Sources

In order to address the research questions, secondary data were collected through desk review, through content analysis of information from government and non-governmental organizations reports, journal articles, the internet, and books. This information was continually used throughout the study.

3.7 Data Processing and Analysis

The audio-taped data from the in-depth interviews, case narratives, and key informant interviews was transcribed verbatim in English. A code book was developed to help generate codes and themes through qualitative content analysis and thematic analysis. Detailed analysis involved identifying recurring and significant themes of the text coded within and

across transcripts using Nvivo data analysis software. Key themes were developed focusing on the three study objectives.

3.8 Ethical Considerations

Aspects related to ethical considerations were taken into account to ensure that the study was conducted in line with sound research principles and regulations. The study applied and obtained a research permit from the National Commission for Science, Technology and Innovation (NACOSTI). Further Ethical approval for the study was sought and obtained from the Kenyatta National Hospital/University of Nairobi Ethical Review Committee (KNH/UON ERC) and Research Committee of the Kisii Teaching and Referral Hospital. Verbal and written informed consent was sought from the respondents by the researcher.

Furthermore, the purpose of the study was explained to the respondents and an informed consent form was read and signed by each respondent (Appendix 1). The informed consent entailed voluntary participation of the study where the respondents were free to withdraw at any stage of the study. The aims and procedure of the study were explained to them. Other aspects of ethical consideration included confidentiality and anonymity where the participants were assured that the information they gave would be held with utmost confidentiality and their identity would not be revealed in reporting.

3.9 Problems Faced and their Solutions

Obstetric fistula is a potentially stigmatizing condition and a sensitive area of discussion especially with the survivors. The researcher had anticipated non-disclosure or refusal to participate in the study. However, the researcher liaised with the health facility management and Community Health Volunteers (CHVs) to find the patients and create rapport with them since the survivors were quite familiar with the CHVs. The respondents were further assured

of confidentiality and anonymity and this encouraged their disclosure. This also helped locate the homes of the survivors.

CHAPTER FOUR

REINTEGRATION OF OBSTETRIC FISTULA SURVIVORS

4.1 Introduction

This chapter presents the study findings on the integrated approach in obstetric fistula management. The integrated approach encompasses the complete rehabilitation and reintegration of obstetric fistula survivors after treatment and their accommodation back into the society as well as regaining their lost dignity. The chapter has two broad sections. The first section presents the socio-demographic characteristics of the respondents. On the other hand, the second section presents the findings in relation to the study objectives. In the specific objectives, the study sought to determine the availability of reintegration service or programme and the challenges that the survivors face after repair and getting back into the community and livelihoods. Further, the study sought to establish how the challenges can be addressed.

4.2 Socio-Demographic Characteristics of the Respondents

The following socio-demographic characteristics were measured: Age, level of education, marital status, religion, and occupation. Occupation, religion, education, and marital status were measured based on their relevance and influence on the study topic. Essentially, the experience of obstetric fistula including stigma, support, isolation, and economic challenges, are fundamentally influenced by education, religion, occupation (income), and marital status. These are illustrated in Table 4.1 below.

Table 4.1. Social-demographic characteristics of respondents

Characteristic	N (%) N=22
Age	
18-29	2(9.0%)
30-39	4(18.1%)
40-49	6(27.2%)
50 and above	10(45.4%)
Education	
Not Attend School	3(13.6%)
Primary Not Completed	5(22.7%)
Primary Completed	5(22.7%)
Secondary Not Completed	4(18.1%)
Secondary Completed	4(18.1%)
Technical Training	1(4.5%)
Marital Status	
Married	9(40.9%)
Separated	11(50%)
Widowed	2(9%)
Religion	
Catholic	12(54.5%)
Protestant	10(45.4%)
Occupation	
Informal	11(50%)
Business	6(27.2%)
Jobless	5(22.7%)

4.2.1 Age

The study findings show that 48.6% of the fistula survivors were in the reproductive age of between 30 and 49 years. The reproductive age of between 18 and 29 accounted for 11.4%, while those aged 50 and above accounted for 40%.

4.2.2 Level of Educational

The findings indicate that 13% of the respondents had not attended school, 22.7% had primary education level but did not complete, 22.7% had completed primary education, 18.1% had secondary education but did not complete, 18.1% had completed secondary education, while 4.5% had technical training education. The study findings indicate that the majority of the respondents had some level of education, hence they understood the subject under consideration. However, they might have been limited in terms of understanding their health rights due to the level of education.

4.2.3 Marital Status

In regard to marital status, 40.9% of the respondents were married, 50% were separated, while 9% were widows. It was important to know the marital status of the respondents to establish whether their condition had contributed to couple separation or not. Indeed, the research findings reveal that a half of the respondents were separated. Others, though married had co-wives, in polygamous unions, meaning they lived in separate homes with their husbands. The respondents living in polygamous families indicated that it was very difficult to relate with the other members of the family. The findings suggest that stigma and isolation still existed after repair.

4.2.4 Religion

The study sought to establish the religious background of the respondents. The findings reveal that all respondents were either Catholic or Protestant, 54.5% were Catholic while 45.4% were Protestants. Religious background was important in understanding beliefs and ideologies in relation to the obstetric fistula condition. It also offered social support from faith forums. Findings reveal that obstetric fistula within the community had super-structural and religious aspects that influence reintegration. This was reveal by (Respondent 15, aged

23 years) who stated that she feared telling people about her problem because they thought she was bewitched and that even after treatment they did not believe that she was healed.

4.2.5 Occupation

As regards occupation, 50% were engaged in the informal sector, 27.2% were in business, while 22.7% were without employment. Occupation is an important variable in fostering the social integration of a fistula survivor. An obstetric fistula survivor with employment is most likely to quickly recover and reintegrate back to the community more than the one without employment.

4.3 From Repair to Comprehensive Reintegration

4.3.1 Services Available for Reintegration of Fistula Survivors

The study sought to determine the reintegration services available to obstetric fistula survivors. It focused on women fistula survivors who have been repaired, discharged from hospital and reintegrating back into the community. Since there are programmes to facilitate the surgery and repair of obstetric fistula, the study investigated the availability of reintegration services for a comprehensive obstetric fistula management. The study findings show that the reintegration process is significant as it acts as a bridge and provides continuity where the obstetric fistula survivors are rehabilitated and fit back in the community. The development and treatment of the condition detaches patients from their normal socio-economic lives, hence the need to reintegrate them back into the society.

4.3.2 Formal Reintegration Services for Obstetric Fistula Survivors

The development and treatment of fistula separates patients from their normal socio-economic lives, hence the need to reintegrate them back into the society. The study findings

confirm that after receiving treatment, the reintegration process is significant for holistic healing and restoration to normal life in the family and community.

The study sought to establish the availability of formal reintegration services for fistula survivors in Kisii County. The views from respondents below indicate that reintegration services are not available although the services were very important for holistic healing after repair.

*There was none [reintegration service] in the hospital; there was no one to help me. I did not get any help after operation. The only help one gets is treatment from the doctors and the counselling they give us, that is all. You leave the hospital without knowing where you are going or how and where you will start life (**Respondent 20, aged 40 years**).*

*After surgery, I only received a lesa to tie around my waste just in case I spoiled my clothes and a container for water. I did not receive anything else (reintegration service). I left the hospital and did not know where to go, where to start life. I feared going back to people who did not like me (**Respondent 13, aged 40 years**).*

When asked whether she had received any help after repair, respondent number three answered that she had not received any help. According to her, the only help she had received was about repair treatment and counselling offered at the hospital.

The findings show that there are no elaborate deliberate and formal social reintegration services for the fistula survivors after repair. While concerted efforts for treatment and repair are demonstrated by the free medical camps and sponsorships for surgery, lack of formal structured support mechanisms for social reintegration of fistula survivors into normal life reveal gaps in achieving comprehensive approach to fistula management.

The findings demonstrate that after repair services at the hospital during treatment, there is usually no follow-up and provision of social reintegration services for the survivors as further confirmed by a nurse handling obstetric fistula patients and survivors.

They [reintegration services] are not there, as nurses, we asked ourselves, 'now that we have this job, if a visitor comes and asks us whether we can get fistula survivors we can call even if it is on one trip to be seen or supported as survivors, will we have any'? We do not have any formal support from the hospital. The other nurse asked me what are we going to do about this, since we see the fistula survivors suffer so much in the community? I told her that when those women will be coming for a re-visit, we should give them some ideas. We can start a small women group for social support (Key Informant 2, Nurse).

Although the above finding reveals lack of formal reintegration services from public and community health programming, there are informal and personal reintegration services on an ad hoc basis.

The study established that despite the concerted efforts to hold an annual free medical camps to treat the fistula patients in KTRH on annual basis, the hospital has not put in place formal structures to offer social reintegration services to follow up on fistula survivors and support their integration into the community after repair. This explains why obstetric fistula survivors still face psychological, social and economic challenges after repair and upon returning home. However, there exist some informal or private networks or services that play an essential role in supporting the reintegration of fistula survivors in the community. These informal services or networks are discussed in the following section.

4.3.3 Informal Reintegration Services that Support Fistula Survivors

Study findings reveal that there are no formal reintegration services to continue supporting the social reintegration of fistula survivors into the community after repair. However, it was evident from the respondents that there exist alternative informal ways to receiving support from within the family and community. According to one respondent:

*When I returned home, I continued farming bananas in a small portion of land little by little and my friends from church helped me to find market. I continued planting bananas and tea as this was the only thing I could do. My brother living across the other side of home had given me a cow and allowed me to farm in the family farm, although, I did not own the land, only to cultivate (**Respondent 5, aged 39 years**).*

This was further confirmed by another respondent as indicated below:

*After repair, I could not do a hard job, my body was still weak. I still needed support. My family helped me with food and money for whatever I needed. However, I was uncomfortable with being fed all my life. I felt helpless although I had already been treated. I wanted to take care of myself and feel worthy again but I appreciated since I could not yet go out to earn a living (**Respondent 1, aged 60 years**).*

Another respondent also expressed availability of family support as stated below:

*My husband has always supported me (pointing at her husband). He is a leader in church and encourages men to support their wives. He has always been there for me, he was sad and very affected when I was sick. When we heard through the radio about free medical treatment for this condition, he took me to the hospital. After repair he stayed home taking care of me as I could not do much for myself. He is a very good man (laughter) (**Respondent 10, aged 45 years**).*

Community and family support was also illustrated in a case narrative confirming availability of informal support as follows:

*I have a kiosk here in town. My brothers who own a business in town gave me a place to stay and I put a kiosk next to them. They still support me in taking care of my children. I sell everything there and I am able to buy my medication. I go home on Saturdays to see my children then I come back on Sunday. I stay here in town (**Case narrative 4**).*

The study findings cited above indicate that individual and family support continues to play essential role in supporting social reintegration of fistula survivors in Kisii County. Besides individual and family support, fistula survivors also receive support from community groups.

This was illustrated by one the respondent as cited below:

We have a small group where we help each other, visiting each other and sharing whatever we have. If one of our friends is sick, we contribute and visit and provide food or make sure she has medication. In case of any challenge at least you have some people who understand you and will not judge you for who you are. We feel comfortable and appreciated in the group (Respondent 22, aged 53 years).

In case narrative 2, a fistula survivor continued receiving support from her group to help her settle back in the family and community. She noted that: “This group, we meet at KTRH. We visit each person at her home. We are remaining with one person. When that is over, we shall come back here then decide what we shall do next” (Case narrative 2).

Another informal reintegration service involves holding of free medical fistula camps, where fistula survivors are involved in encouraging the patients scheduled for repair. Respondent thirteen elaborated on this explaining that:

You know, when there is a fistula treatment camp, nurses call us, those who are able (fistula survivors) to come and comfort those who have come for treatment as we share our story with them. We share our experiences and listen to their stories. There at home there is no group offering any support. But when we come to the hospital, we feel better to see we are not the only ones who suffered this problem. When we come, we share our story with the patients and contribute something small if you have, sometimes we do not have anything (Respondent 13, aged 40 years).

In explaining another type of informal reintegration service that is available, key informant one stated that:

We also teach them how to make pesticide for killing cockroaches. It is not hospital arrangement but as nurses we feel for them. We want them to come and make table clothes and bags. When there is another fistula camp, they can sell to the visitors. That way, they make some little money. We started contributing one hundred shillings recently. We are thinking of buying a piece of land and put a structure so that women can benefit from the income. We have tried with other groups and it seems they never understood the importance (Key Informant 1, Nurse).

The findings above indicate that informal services play a very important role in terms of supporting the social and economic reintegration of fistula survivors in Kisii County. Essentially they support the fistula survivors reintegrate back into the community and recover to normal life. The informal networks that survivors have or build are important in their reintegration as they focus on strengthening livelihoods and enhancing acceptance back into the community. The networks are significant for socio-economic empowerment as well as a pathway for regaining the previously compromised self-esteem and dignity.

In conclusion, the study findings responded to the first research question and established that there are no formal reintegration services in place in Kisii County to support smooth social reintegration of obstetric fistula survivors back into the family and community. It was evident that after undergoing repair, there was no structured reintegration service in place to follow up on the social and economic reintegration of fistula survivors, yet they continue to face immense social and economic challenges coupled with psychological challenges. The study established that informal or private social services such as support from individuals, families and social groups played an essential role in supporting reintegration of fistula survivors into the community.

4.4 Reintegration Challenges Faced by Fistula Survivors

The social reintegration process of fistula survivors is riddled with various challenges. In the absence of concerted structural and programme efforts for providing social reintegration services, obstetric fistula survivors face similar or heightened challenges as experienced in the pre-repair period. Development of obstetric fistula renders the patients incapable of meaningfully participation in social and economic lives. Fistula patients face rejection, discrimination and isolation in the community that robs their dignity and wellbeing. As a

result, they are separated from their economic activities and social networks that would otherwise offer support after repair. Respondents narrated this detachment and stigma vividly as discussed below.

4.4.1 Psychological Challenges

The initial development of obstetric fistula is associated with psychological challenges. Depression, fear, rejection and trauma challenges are transferred to the post-treatment period as fistula survivors struggle to overcome past experiences even after repair. Obstetric fistula survivors go through traumatic experiences of rejection and isolation by their families and communities that hinder them from participating fully in household chores or social activities. The study findings reveal that even after treatment, fistula survivors continue to face such challenges when they return home to the same community which isolated them and still not educated on fistula condition. The detachment process is also linked to stigma and discrimination as illustrated by this respondent:

*It does not matter that you have been treated, you are rejected when you are sick and even after you have received treatment. People still see you as if you are still sick and even if you explain that you got well, they think that your condition will come back. That is the reason why I still keep distance, they do not want you around them. It is very sad to be rejected by other people, it is very lonely (**Respondent 2, aged 35 years**).*

Another respondent expressed the same frustration and disappointment thus:

*Before I was sick, I was planting vegetables and selling them at the market. When I fell sick, I did not have a place to sell as I could not go to the market any more. Other traders isolated me and also incite customers not to buy from someone smelling. I felt very bad. I am already treated, I am not smelling anymore but they do not believe that Why did God make me like this? (**Respondent 12, aged 56 years**).*

In case narrative one that involved women fistula survivor, psychological trauma and stigma were caused by closed relatives and her husband. In her case, she explained that:

Isolation continues even after healing. When I was at the hospital he (husband) thought I was HIV positive and because of that he refused to support me during my treatment. He did not chase me from home. We are together but we do not sleep in one bed, we live in separate rooms (Case narrative 1).

The study confirms that fistula survivors face psychological challenges that range from stigmatization, depression, grief, to anxiety before and after repair. Thus, psychological challenges continue to hinder and undermine proper social reintegration for obstetric fistula survivors. There is need to eliminate stigma by creating community awareness on the social reintegration of fistula survivors.

4.4.2 Social Challenges

Besides psychological challenges, obstetric fistula survivors face many other social challenges that hinder their social reintegration into the family and community. Fistula survivors experience social segregation from family members and the community. This was evidence from one of the respondents who explained the effects of rejection by her husband:

*As a result of my situation, my husband resorted to marrying another wife. It was like adding an insult to injury. This was a very big problem to me, as I did not know what to do or where to go. I cried a lot and wished I could die instead of being humiliated. The rejection was even extended to my children; he refused to look after me and my children. I could not go back to my parents because I was already married and there is nothing for me at my parents' home. I had to stay under oppression (**Respondent 17, aged 53 years**).*

Respondent number 16 explained how her family members rejected her to the extent of dividing amongst themselves the family piece of land leaving her out without any place to settle.

When I fell sick my husband chased me out of our matrimonial home. I went back to my parents where we are now. My brothers have shared all this land among themselves. The piece of land where we are sitting right now belongs to the last born. That one is for the other brother, up there

near that avocado tree is for the oldest brother who passed on, and there is nothing left for me. This is because of my condition (Respondent 16, aged 43 years).

Socially, fistula survivors lose social networks and relationships as a result of their fistula condition which otherwise would support them reintegrate back into the community. This was expressed by one respondent cited below:

With this fistula problem, you cannot visit other people at their places. The fistula condition does not allow you to move around. The smell is too bad, people cover their noses when you are around them. When they visit the family, you hide. As soon as you notice that visitors are coming to your home you run and hide you have to hide because you are ashamed of yourself and feeling of shame due to the smell. You have to go behind the house until visitors leave without meeting you and reappear when they are gone. After treatment I could not face them, I was still ashamed of myself (Respondent 2, aged 35 years).

Another respondent expressed the same feeling by explaining that when she got sick, she became lonely. She stated that she would only receive support from my mum. All her friends wanted was just to greet her and leave quickly: they did not believe she was healed (Respondent 7, aged 35 years).

The social exclusion of fistula survivors from community and family is a devastating experience that undermines the reintegration process of fistula survivors and makes it more difficult to attain holistic healing and restoration of dignity as one respondent put it:

One of the respondents expounded that:

When you are suffering with this sickness (fistula) you cannot visit other people in their places. How do you even approach their home? And if you are in the house and you hear a visitor, you hide inside until they leave. You can even go behind the house until they go so that they do not see you. After treatment you do not know how to

relate with the people because you have been hiding. They are all like strangers. You feel nobody understands what you are going through (Respondent 4, aged 32 years).

One of the case narrative on the social challenges, the narrator explained that:

I had lost all my friends. They were not aware that it was a disease, a condition that could be treated. Even after receiving treatment, I have not reached out to them, because I do not know how they would react (Case narrative 1).

The study findings indicate that social challenges cause immense suffering to fistula survivors even after repair if the social reintegration services are not available to help them reconnect with family and community.

This was further confirmed by Key informant 2 who pointed out that many women who were married are now are divorced. They were divorced during that time of sickness. Fistula is regarded as witchcraft and therefore relatives see fistula patients as outcasts, and do not want to associate with them (Key Informant 2, Nurse).

Key informant 3 who is a social worker, confirmed that fistula survivors continued to face social challenges even after repair by explaining that:

They were rejected when they were sick and even after they are repaired, the community still isolates them, not believing they are healed. They say that their condition will come back again. This is the reason why they are still kept away from the rest of the community (KII 3, Social Worker).

Although fistula survivors would try to amend and revive the relationships and networks, the community's knowledge about the condition and the religious influence hinder proper reintegration. This is by permeating stigma and limiting support.

However, findings reveal an exception where, after receiving treatment, a woman fistula survivor did not go through social challenges. She indicated that since she got well, her

interaction with the neighbours had changed. They visit each other and they also invite her when they have a safari. They go back together. She continued to explain that “they received me very well. Even my husband received me well” (**Respondent 1, aged 60 years**).

In case narrative 1 the narrator explained that her reintegration was fairly smooth as shown below:

They were happy. I had lost all my friends. I would tell them that I no longer smell. I was treated. I reconfirmed to them again it was not witchcraft, it was a disease. Though I lost many of my friends now we are together again, we are well. There is only one who has refused to understand me, I will keep reaching out to her. I want her to know that I have no problem with her (Case narrative 1).

The study findings show that while the majority of fistula survivors go through social/community stigma even after repair, there exist some few exceptions where fistula survivors do not face social challenges, their integration is facilitated by family members' acceptance of their return home. Nevertheless, in general, social stigma still continues to be a significant barrier to social reintegration as society denies survivors supportive structures to fit back and continue with their lives. Psychological and social challenges exacerbate the economic situation of fistula survivors. The next section discusses economic challenges facing fistula survivors in Kisii County.

4.4.3 Economic Challenges

Economic factors pose enormous threat to smooth social reintegration of obstetric fistula survivors. In the development of the condition, survivors were detached and separated from their income generation activities and find it difficult to reconnect with economic activities after repair. The following statements from respondents illustrate the economic constraints experienced by obstetric fistula survivors.

I was plaiting hair and I was forced to stop plaiting hair because of my condition. I was smelling and customers thought I was a very dirty woman. Nobody came to my salon. I had to close it since I could not pay the rent. This affected my life as I could not afford anything, even food, I had nothing. After repair I had no money to re-open the salon again. (Respondent 10, aged 30 years).

On the other hand, respondent 12 stated challenges she continued to face by relying on family members for feeding. She explained that:

Getting food is a problem as I continue to rely on my brother and his wife. This seemed to be a big problem to him and family. The wife gives me little food like a child. I cannot complain because I cannot afford it. I accept whatever she gives me. I wish I could get some little money to start a business and earn myself some money (Respondent 12, aged 56 years).

Due to isolation during the development and treatment period, fistula women are unable to engage in any economic activities in the community after repair which worsens their vulnerability.

One of the respondents narrated her ordeal explaining that “I used to do farming but now I cannot. I just stay at home. May be washing the utensils. I stay with my mother. I do not go out to work. With the kidney problem, I cannot do any hard work” (Respondent 14, aged 55 years).

In narrating her case, a 44 year old respondent confirmed how social stigmatization and exclusion led to her economic challenges. She narrated that:

I could not go to the market anymore. How can you go? Community members were inciting customers not to buy my vegetables saying that I was handling the vegetables with urine and nobody was willing to buy from me. This is the reason why I decided to stop going to the market again. My business ended there (Case Narrative 2).

In explaining economic challenges facing fistula survivors, a nurse who was one of the key informant, revealed that some women opened up to her and informed that they did not either have a home to go back to, or the ability to start off life again (**Key Informant 2, Nurse**)

The findings clearly indicate that the situation of women fistula survivors in Kisii County is not different from that of West Pokot. According to Khisa (2010:63) fistula survivors in West Pokot often failed to participate in economic activities as they used to, either because of lack of capital or physical strength or the negative label the community attached to them. Additionally, economic challenges due to lack of economic empowerment was a big challenge after surgery as the women found themselves dependent on their spouses and other relatives. The situation in Kisii County shows that after treatment and detachment from previous economic activities, survivors find difficulties in integrating back into the community and engaging in economic activities.

These findings fully corroborate with a study carried out by Keya *et al.* (2018) in Uganda and Nigeria where it was also noted that after developing fistula, fistula survivors describe an inability to continue with their enterprises because of physical limitations, including loss of farm ownership, often as result of social separation or divorce because of their fistula condition. This loss of income represents significant opportunity costs for living with fistula.

To respond to the second research question, the study established that the reintegration process of fistula survivors is riddled with various challenges including psychological, social and economic. These challenges are intertwined, social challenges lead to psychological challenges which culminate in economic challenges. Community and family rejection leads to stigma and trauma, which in return lead to isolation which makes women fistula survivors unable to get involved in any income generating activities. The United Nations General

Assembly Resolution 69/148 (2015) confirmed that women living with or recovering from fistula are often “invisible”, neglected and stigmatized.

4.5 Remedy to the Reintegration Challenges

The third and last objective of the study sought to establish strategies for responding to challenges that fistula survivors do face in reintegrating back into their socio-economic life upon receiving treatment. The study concludes that fistula survivors do face a lot of psychological challenges especially due to stigma and social/community rejection as well as economic challenges. However, there are no formal reintegration services in place to follow up on fistula survivors. The question is therefore to know what remedy should be put in place for a sustainable reintegration of fistula survivors into the community.

4.5.1 Community Sensitization on the Fistula Condition

The need for community sensitization on the fistula condition is fundamental and strategic intervention in reducing stigma and social exclusion of fistula survivors in Kisii County. One respondent argued that the community should be educated about fistula (**Respondent 22, aged 53 years**). This was supported by a key informant who explained that community sensitization is of great importance in achieving social reintegration.

That is why we even get many patients. We also go to churches like when we are having a camp. We go to chiefs and community leaders and churches, we go to any baraza. We even go to schools. We talk about fistula. These days are not like the first time we had a camp. Those patients had a problem. These days the patients are brought to the hospital. So in the community we need to create more awareness. Since we started creating awareness there is a difference. Fistula patients do not suffer for a long time. The community needs awareness about fistula more and more. Talking to them and telling them that they are not outcasts, they are people like them who developed a disease. You know others think it was a curse. Others mistake this fistula for witchcraft.. They even think these ladies who had fistula were prostitutes. They do

not see them as normal women or as if an accident happened (**Key Informant 2, Nurse**).

Another respondent substantiated on the same indicating that “people should be educated about fistula so that even those who are hiding can seek treatment” (**Respondent 13, aged 40 years**). In a case narrative 2, a fistula survivor maintained that the church should play the role of sensitizing members in reintegration of fistula survivors back into the community because many are members in these churches. According to her, if possible at the church people should be taught about fistula. Maybe they set aside a day for that. Those doing the sensitization should be motivated so as to keep educating the community.

Furthermore, sensitization should also engage key stakeholders from the public and private sectors. The view was shared by a key informant saying:

I think if people are given proper education about fistula and the survivors, the community, the chiefs, DO, DC and Governor, will know their role. Where they started and where they are now, they should open for them something like an NGO. Something that can make them feel that they are worthy. They are not mentioned anywhere. We are only heard when there is a camp and they advertise in the radio. Now in the county, if they start looking for them, they do not have that role. The Ministry of Health should know these people are there. Their office should be established (**Key Informant 1, Nurse**).

Finally, another respondent was of the view that sensitization should also target men and husbands to support their women who develop obstetric fistula. According to her:

They [men/husbands] should be told that they took these women when they were smart, they impregnated them and when they are giving birth they get the problem. They should not run away to other women. They should love them just as they loved them when they were girls (**Respondent 12, aged 56 years**).

The study findings suggest that sensitization on fistula should be considered multi-stakeholders’ engagement. This means that all stakeholders should be fully involved in the process of understanding the fistula condition in Kisii County, including the community at

large, key stakeholders from public and private sector, above all, family members and husbands in particular should be informed and sensitized to eliminate misconceptions about obstetric fistula, to stop attributing the condition to curses, cultural spirits or considering the condition as a curse from gods. The condition is also associated with sexual transmitted disease, having sex during menstrual periods or misuse of family planning methods. Such misconceptions of obstetric fistula should be demystified through sensitization.

Turan *et al* (2007) observed that awareness of obstetric fistula is still low in many developing countries where it is prevalent. Sensitization of community and key stakeholders is therefore expected to reduce the stigma and social exclusion of fistula patients and survivors.

4.5.2 Economic Empowerment of Fistula Survivors

The study established that fistula survivors do face economic challenges before and after recovery due to psychological and social challenges. According to the respondents, the solution to addressing economic challenges facing fistula survivors is about empowering them economically at individual level as well as at group level to help them come up with income-generating activities. This solution was supported by different respondents and key informant. According to the key informant:

If they can be given little money, they start businesses because they have nothing. That time they were isolated, there was no place they could do business to even get 10 shillings. You cannot even go wash clothes for people. Now that they are well, they can do that work and with the little money one can buy some tomatoes then sell (Key Informant 3, Social Worker).

Additionally, formation of support groups was cited as another way of addressing reintegration challenges. The groups would ease the financial challenges.

One of the respondents explained that:

If we come together in a group, we can discuss and exchange ideas. We can even lease land, plant grass and sell. We will get money for our personal use. When we are in the group, we can make school sweaters and sell if we get sewing machines. That will help us. (Respondent 14, aged 55 years).

In a case narrative three, a fistula survivor rejected the idea of being given money. She rather supported the idea of forming groups by explaining the following:

As an individual, I do not think if given money it is going to help. But if a group can be assisted to get a plot and get a room that will remind someone that she had a problem and she was assisted. The room will be a source of income as it will be rented out (Case narrative 3).

Capacity building was identified as a solution to empowering survivors and improving their economic status. This was supported by one respondent who explained that:

If schools are open for fistula discussion, fistula survivors can be empowered to share in schools to educate their children. If churches and religious places would allow, we would also talk to people about fistula to reduce hatred and rejection in homes and the community, and especially market place (Respondent 4, aged 32 years).

A key informant supported this idea of capacity building and noted that:

These women, if they can be talked to and trained, I think they can do better. Some of them are somehow learned and others are not learned. According to my observation, some of them were in college/school and others had businesses. Because of this condition, they could not associate with people. After they are healed, I think it is good if they are given like a seminar or training. Then they will choose what to do (Key Informant 2, Nurse).

Study findings show that reintegration challenges can be addressed through community sensitization and education, with the central aim of increasing acceptance of fistula survivors. Sensitization would also draw the attention of key players in the civil society and in the

government. The challenges can also be addressed through formation of support groups that would be the structures to accommodate and support survivors economically. Finally, the challenges can be addressed through direct economic empowerment and capacity-building programme including appropriate training.

The study identified two main interconnected strategies to support reintegration of fistula survivors, namely, sensitization of the community and all key stakeholders on fistula condition and empowerment of fistula survivors. Sensitization should be comprehensive in terms of understanding prevention, causes, consequences and treatment of the fistula condition with the aim of enhancing smooth reintegration survivors into the family and community. This would reduce stigma and the social challenges that obstetric fistula survivors have been facing. Empowerment, on the other hand, can take different forms, including financial, capacity building or economic.

The findings support the application of general system theory which considers treatment of obstetric fistula as a continuum or as a system with different components. In the comprehensive treatment of obstetric fistula, surgery is part (or component) of treatment. Reintegration of the survivors back into the community is another component and must be addressed. In regard to the theory, a phenomenon must be considered within the context of all components. In the social phenomenon in the study, reintegration of the obstetric fistula survivors must be incorporated in the system (comprehensive) for fistula treatment to achieve holistic healing.

CHAPTER FIVE

DISCUSSION, CONCLUSIONS, RECOMMENDATIONS

5.1 Introduction

This chapter discusses the study findings. The discussion centres on the study objectives and synthesizes the findings, linking them to findings in other studies on the topic. Other sections in the chapter are the conclusions that details the study's deductions and the recommendations drawn from the study.

5.1 From Repair to Reintegration

The United Nations General Assembly Resolution 69/148 (2015) on intensifying efforts to end obstetric fistula highlighted that a major gap exists in the social reintegration of fistula survivors. An integrated approach to obstetric fistula management should incorporate social reintegration to achieve holistic healing. It involves enabling the obstetric fistula survivors to fit back into the community, family and livelihoods. This rests on the assumption that the fistula patients are detached from their physical and life worlds, especially during hospitalization. The condition is also associated with limited mobility and activity, which might further prohibit the patients from their normal social and economic activities. For example, the exemption of fistula patients in social activities is a salient example of such alienation. The inability to participate meaningfully in socio-economic activities among fistula patients and survivors is well demonstrated (Mwangi and Warren, 2008).

Post-repair reintegration is as important as the repair itself. The seamless transition in the development of the condition, repair and reintegration is the true reflection of the integrated approach (Khisa and Nyamongo, 2012). The approach acknowledges that both repair and reintegration are significant for comprehensive fistula management. According to Jarvis *et al.* (2017), there are several unanticipated physical, emotional and economic challenges that

survivors and their families have to contend with. There is thus the need for enhancing the reintegration process to provide adequate care and support.

Reintegrating fistula survivors back into their social and economic lives is important and inevitable if comprehensive fistula management and restoration of womanhood dignity is to be achieved. This is because the reintegration process is the other component of the integrated approach, apart from surgery and repair. The study findings indicate that there are no reintegration programmes within the public health domain. Khisa (2010) reported similar findings in West Pokot, Kenya, where fistula survivors experience reintegration challenges. Apparently, there is no comprehensive reintegration programmes for the obstetric fistula survivors.

In contrast, in settings where there are programmes to reintegrate fistula survivors, there is faster healing and the programmes target vital components of survivors' lives. For example, according to Mohammad (2007), reintegration programmes in Nigeria have targeted economic aspect as a need for the survivors. Consequently, the programmes have succeeded in reintegrating survivors back into the community and their previous livelihoods.

Factors and challenges such as stigma remain even after surgery and can hinder reintegration hence the need to have support structures to receive the survivors back into the community. This study also found stigma and isolation, economic constraints, and cultural beliefs as key barriers to reintegration of fistula survivors. For Khisa (2010), stigma might arise because of cultural beliefs and folk knowledge related to the condition including association with witchcraft and continues even after surgery.

Economic challenges also pose a barrier to reintegration of obstetric fistula survivors because survivors were disconnected with their income generating activities during the development of the condition and repair. They thus face financial challenges which create an obstacle to

proper accommodation and reintegration. Therefore, a comprehensive reintegration package should involve addressing stigma and reconnecting the survivors with their previous social and economic activities. It is important to address the challenges since they might “reverse gains and hopes of re-integrating into their relationships and community” (Khisa and Nyamongo, 2012:64).

Although formal reintegration programmes are not available for the reintegration of fistula survivors, the community and family provide support and facilitate reintegration. In this study, survivors who reported support from family and friends showed seamless transition in the fistula experience. Such survivors resumed social and economic activities. In their study, Pope *et al.* (2011) found that women survivors with families at the core of support were able to resume to their economic activities with ease. In the absence of formal reintegration programmes and services, the community, family and friends constitute the support structures for accommodation and reintegration of obstetric fistula survivors. The study established that most survivors rely on relatives, friends, spouses and the general community. Khisa (2010) found that the community and family, in the absence of other reintegration services, are instrumental in reintegrating fistula survivors. According to Donnelly *et al.* (2015), women fistula survivors regain the life they had before development of the condition mainly because of the family support.

Apart from the family, other networks within the social environment are important in addressing the reintegration challenges and achieving comprehensive reintegration. In this study, the idea of welfare groups for fistula survivors came up. This not only addresses the issue of stigma and belonging, but also easing economic challenges faced by the survivors and which create an obstacle to reintegration. The welfare groups expand the networks within which reintegration of fistula survivors takes place.

Capacity building, economic empowerment and self-reliance avenues can also be explored to address reintegration challenges and ensure community incorporation of the survivors. In the study, survivors cited vocational training and courses as an important way of empowering them and easing financial challenges. Similarly, Khisa (2010) found that counselling, training and government support are desired ways of both addressing reintegration challenges and improving the reintegration welfare of the survivors.

Community sensitization and education were identified as one way of addressing reintegration challenges and help achieve comprehensive reintegration. This invokes the stigma issue where the community would be informed about and made sensitive to obstetric fistula. It calls for community support as a key player to produce and sustain reintegration.

5.2 Conclusion

Obstetric fistula condition is recognized as a medical condition in Kisii County and one of the maternal complications, that require immediate attention, hence the opening of an obstetric fistula section at KTRH that deals with creating awareness and organizing fistula medical camps. Although such maternal complications as obstetric fistula are associated with especially financial challenges, the health care system in KTRH is keen to meet the corrective surgery and repair needs for the fistula patients. The annual fistula camps recognize that fistula repair is costly and complex and women in low-income settings might not afford. Thus, surgeries are organized and conducted free of charge. This has helped offset the financial burden and challenge towards treatment.

However, there are no programmes for reintegrating the survivors back into the community. There is a gap in fistula management as attention is directed to treatment while the reintegration component is ignored despite its demonstrated importance. Consequently, survivors are taken back to the communities that stigmatized them and in the setting where

survivors had previously been disconnected with social and economic lives. Owing to social (stigma) and economic challenges, many survivors find it difficult to be accommodated and accepted back into the community even after repair.

Comprehensive fistula management and reintegration calls for inter-related services. Apart from surgery, survivors require psychosocial and economic support for full recovery. From treatment, survivors require social support and acceptance, counselling, and family support. Further, the survivors need to be connected to social and welfare groups to increase acceptance (reduce stigma) and improve their economic lives. Government support is also imperative to help survivors in training and skill development.

Reintegration of fistula survivors is an important component that reinforces repair to achieve holistic healing and recovery of dignity. The system is holistic and brings together family, community, government, civil society, and other stakeholders. Based on this conclusion, the study provides the following recommendations.

5.3 Recommendations

1. Policy makers and stakeholders should embrace integrated approach to include the aspect of reintegration of fistula survivors in strategic response to fistula treatment in order to achieve holistic healing.
2. KTRH in Kisii County should consider incorporating reintegration services in the health facility to ensure restoration of dignity of fistula survivors after repair.
3. Community leaders should mobilize the community in creating social awareness on social reintegration support services to fistula survivors to reduce stigma, discrimination and isolation.

5.4 Areas for Further Research

Research to explore the significance and feasibility of actively involving men as key players in reintegration of obstetric fistula survivors back into the community and family.

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Appendix 1: Informed Consent Form

Investigator: Dorcas Muthengi

Introduction

I am Dorcas Muthengi from the Institute of Anthropology, Gender and African Studies, University of Nairobi. I am conducting a study on:

ACHIEVING INTEGRATED APPROACH: MOVING FROM REPAIR TO COMPREHENSIVE REINTEGRATION OF OBSTETRIC FISTULA SURVIVORS IN KISII COUNTY

Purpose

The study seeks to explore the availability and access to comprehensive reintegration support services for obstetric fistula survivors in Kisii County.

Procedure

If you agree to participate in the study, you will be asked various questions related to the study. Although you will be asked certain specific questions, you will be free to provide more information that is relevant to the themes being addressed.

Risks/Discomfort

There are no risks in participating in this study. However, you may experience discomfort or psychological distress because of the personal nature of some of the questions asked. However, you are free to decline to answer the questions that you are uncomfortable with. Further, the questions will be asked in a non-emotive and friendly way. In case of any psychological distress or discomfort, I have liaised with the hospital management so that you get help immediately.

Benefits

Although there will be no direct or immediate benefit for participating in the study, the investigator will assist in answering questions that you may have. Further, the study aims at exploring the availability and access to comprehensive reintegration support services for obstetric fistula survivors in Kisii County and the findings of this study will be of benefit to the individual survivors and the community.

Confidentiality and Anonymity

Your confidentiality will be maintained at all times during the study. The information provided will not be used for any other purpose than the one stated. The names or identifiers of participants will not be used in the report or publications which may arise from the study. True identification of participants will be concealed at all times.

Compensation

There will be no direct compensation for your participation in the study although you will be reimbursed your transport expenses.

Voluntariness

Participation in the study is voluntary. You will be free to withdraw at any stage of the study and doing so will not attract any penalties or discrimination whatsoever. However, I humbly request for your cooperation, which will be highly appreciated.

Persons to contact

If you have any questions regarding the study, you can contact Dorcas Muthengi through telephone number 0721425959.

You may also contact the Prof. M. L. Chindia, the Secretary to KNH/UoN/ERC Committee, Telephone Number (254-020)2726300 Extension 44355, Email: uonknh_erc@uonbi.ac.ke, or Prof. Simiyu Wandibba, University of Nairobi, Mobile No. 0722552391, Email:swandibba@yahoo.com.

I would like to know whether you have a question to ask now. If no, would you like to participate in the study? If yes, please sign the space below.

I _____ hereby voluntarily consent to participate in the study. I acknowledge that a thorough explanation of the nature of the study has been given to me by Mr./Ms._____. I clearly understand that my participation is voluntary.

Signature_____Date_____

Signature of Researcher _____Date_____

Appendix 2: In-depth Interview Schedule

1. Demographic Information

a) Age

18 -29 30 – 39 40 - 49 50 and above

b) Marital Status

Single Married Separated Widowed

c) Level of Education

Primary Secondary Tertiary University

d) Occupation

Formal Employment Informal Employment Business Jobless

e) Religion

Catholic Protestant Muslim Other (specify).....

2. For how long did you suffer from obstetric fistula and how did you obtain treatment?
3. Whom did you inform about your condition and why? How did they react?
4. Did you go through any challenges? Describe them.
5. What happened after treatment and you were discharged?
6. Did you receive any support to settle back in the family and community? Explain how? If no, why? Were you satisfied with the support?
7. In your own view/opinion, what other forms of support can be provided to help you settle back in family and community?

Appendix 3: Case Narrative Guide

1. Please describe your experience as a fistula survivor and how you fitted back in the society and family after treatment.
2. Please narrate any challenges you faced as you settled back into your family/community after treatment.

Appendix 4: Key Informant Interview Guide

1. What is the role of reintegration in the holistic healing of fistula survivors in Kisii County?
2. What is your general observation on the transition trends between treatment and reintegration?
3. What types of reintegration services are available for women fistula survivors?
4. What are the barriers to and enablers for reintegration for obstetric fistula survivors?
5. From your experience, what are the best practices for reintegrating obstetric fistula survivors in the community?

Appendix 5: KNH/UON ERC Ethical Approval



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Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

Ref: KNH-ERC/A/239

Dorcas Muthengi
Reg. No. N69/73401/2014
Dept. of Gender and Development Studies
Institute of Anthropology, Gender and African Studies
University of Nairobi



June 13, 2018

Dear Dorcas

RESEARCH PROPOSAL – ACHIEVING INTEGRATED APPROACH; MOVING FROM REPAIR TO COMPREHENSIVE REINTEGRATION OF OBSTETRIC FISTULA SURVIVORS IN KISII COUNTY (P212/04/2018)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is from 13th June 2018 – 12th June 2019.

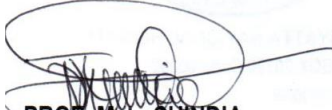
This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH-UoN ERC before implementation.
- Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal.*)
- Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Yours sincerely,



PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

- c.c. The Principal, College of Health Sciences, UoN
The Deputy Director, CS, KNH
The Chairperson, KNH-UON ERC
The Assistant Director, Health Information, KNH
The Director, Institute of Anthropology, Gender and African Studies, UON
The Chair, Dept. of Gender and Development Studies, UON
Supervisor: Prof. Simiyu Wandibba, Institute of Anthropology, Gender and African Studies

Protect to discover

Appendix 6: NACOSTI Research Permit

THIS IS TO CERTIFY THAT:
MS. DORCAS WAIRIMU MUTHENGI
of **UNIVERSITY OF NAIROBI, 30218-100**
NAIROBI, has been permitted to conduct
research in **Kisii County**

Permit No : NACOSTI/P/18/56196/22323
Date Of Issue : 25th April, 2018
Fee Received :Ksh 1000

on the topic: **ACHIEVING INTEGRATED**
APPROACH: MOVING FROM REPAIR TO
COMPREHENSIVE REINTEGRATION OF
OBSTETRIC FISTULA SURVIVORS IN KISII
COUNTY

for the period ending:
23rd April, 2019





Applicant's
Signature



Director General
National Commission for Science,
Technology & Innovation

CONDITIONS

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