EXPERIENCES, PSYCHOSOCIAL CHALLENGES AND SOCIAL INTEGRATION OF WOMEN WITH OBSTETRIC FISTULA IN SELECTED HOSPITALS IN CENTRAL AND WESTERN UGANDA

BY

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DECLARATION

DECLARATION BY THE CANDIDATE:

I ARYEIJA WARREN hereby declare that this thesis titled **"Experiences, Psychosocial Challenges and Social integration of Women with Obstetric Fistula in Selected Hospitals in Central and Western Uganda"** is my own original work except where references and citations have been made and acknowledged. This piece of work has not been presented for examination leading to a certification for a degree or any other qualification in a University or Institution. No part of this thesis may be produced without prior permission from the author.

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DEDICATION

Dedicated to my parents Frederick Bitarabeho (RIP) and Winfreda Bitarabeho.

ABSTRACT

Obstetric fistula is a worldwide public health challenge affecting more than two million women and girls worldwide. According to Uganda Health Demographic Survey report of 2011 it was reported that 2.6% of women of reproductive age in Uganda have experienced fistula. Women with fistula live with physical and psycho social challenges because most do not get appropriate health and social care. The study objectives were to; establish experiences faced by women during pregnancy, delivery, and post delivery for the pregnancy that caused fistula, identify psycho social challenges experienced by women wih fistula, establish coping mechanisms and identify factors that enhance integration of women affected by fistula in the community. A cross sectional descriptive design was used for the study. Quantitative data was gathered using a questionnaire while Focus Group discussions, Indepth and Key Informant Interviews were used to collect the qualitative data. Two hundred four women were purposively selected and interviewed from Mulago national referral hospital located in central Uganda and two district private hospitals, that is, Kagando in western Uganda, and Kitovu in central Uganda. The key findings of the study were; the majority of women with fistula were in age range of 15-20 years (28.4%), and most had low levels of education whereby 22.5% never attended school, and (55.8%), attained primary levels of education. Majority got fistula on first order of delivery 116 (56.8%), 111 (54.4%) delivered by caesarean section for the delivery that caused fistula after prolonged labour. A significant number had separted from husband because of fistula (29.5%). The psycho social challenges included; isolation, feelings of sadness, shame, worthlessness, self dislike, reduced self esteem, concentration difficulties and experiences of suicidal thoughts. Fistula victims coped through keeping proper hygiene, use of pampers and pieces of cloths as pads to reduce leakage of urine and feaces, isolation from the public, prayer, family support and care and some practicing sexual abstinence. Integration of women with fistula requires community sensitization and education, counselling for fistula survivors and family, financial support to enable them engage in income generating work. The study recommended facilitation of hospitals to offer appropriate fistula repair services, capacity building for health personnel to provide the required services, community education on prevention and care for fistula. The study concludes that women who give birth at young age, with low levels of education and from poor families have a high risk of getting fistula and sufer for a long time.

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LIST OF ABBREVIATIONS/ACRONYMS

AIDS	-	Acquired Immune Deficiency Syndrome
CMR	-	Child Mortality Rate
FDGs	-	Focus Discussions Groups
FGDs	-	Focus Group Discussion
FGM	-	Female Genital Mutilation
HIV	-	Human Immune Virus
IMR	-	Infant Mortality Rate
IRB	-	Institutional Review Board
KII	-	Key Informants
MDGs	-	Millennium Development Goals
MMR	-	Maternal Mortality Ratio
MoH	-	Ministry of Health
NGO	-	Non Governmental Organisation
RVF	-	Recto-Vaginal Fistula
SDS	-	Seventh Day Adventist Church
SPSS	-	Statistical Package for Social Scientists
UBOS	-	Uganda Bureau of Statistics
UDHS	-	Uganda Demographic Health Survey
UN	-	United Nations

UNFPA	-	United Nations Population Fund
UNICEF	-	United Nations Children Fund
US$	-	United States Dollars – One US Dollar equivalent to Uganda Shillings 2,580 by June 2013
VVF	-	Vesico-Vaginal Fistula
WHO	-	World Health Organisation

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DEFINITION OF TERMS

Youths	-	Female or male person aged between 18years – 35 yrs in Uganda.
“Engozi:	-	Kind of stretcher which is traditionally made from a straws with two big sticks on two sides. It is long to accommodate a human being and is used to carry a very sick person who is unable to walk by himself/herself. Usually used by people in Western and South Western Uganda to carry patients to health facilities. Two (2) men or four (4) carry the patient on shoulders its used in areas where there is no road access.

CHAPTER ONE

INTRODUCTION

1.1.0. Background to the Study

Maternal mortality and morbidity until today remains one of the daunting reproductive health problems in developing countries and reduction of maternal mortality and morbidity is number five of the Millennium Development Goals (MDGs) (Mavalankar and Rosenfield 2005). This goal will not be met unless all countries create national maternal and child health services with universal access. Pregnancy and child birth are still the leading causes of death and disease in women of reproductive age in developing countries. Improving maternal health is inextricably linked with the promotion of gender equality and women's empowerment (MDG-3) (Shetty and Tandria 2006). This can be achieved through policies and programmes which build women's capability, improve their access, economic and political opportunity and guarantee their safety. Long term and sustained improvements in women's health require retrification of the inequality and disadvantages that girls and women face in education and economic opportunity. Gender equity and social transformation are likely to be achieved when men recognise that lives of men and women are interdependent and that the empowerment of women benefits everyone. Therefore MDGs that promote gender equality and empower women and MGDs that improve maternal health ought to be promoted side by side (Shaw, D., 2006).

Globally, over half a million women die each year from complications of pregnancy and child birth and an estimate of 10 million experience injuries, infections, diseases or disability that cause lifelong suffering – almost half of these women are from Sub-

Saharan Africa. Most maternal deaths occur during child birth yet the presence of trained medical staff could greatly reduce this number (UNICEF 2008). Maternal health services have a potentially critical role in the improvement of sexual and reproductive health. The use of health services is related to the availability, quality and cost of services as well as social structures, health benefits and personal characteristics of users (Chakraborty, *et al*: 2003).

Women are frequently reluctant to seek health services for sexual and reproductive health because of many barriers among which are, poverty, restrictive laws and policies, equipment, materials and private work place, and lack of training for and in understanding of adolescent reproductive needs (Bearinger *et al*, 2007).

Obstructed labour, although largely preventable, continuous to be the leading cause of maternal disability and death resulting in an estimated eight percent of the approximately half million maternal deaths worldwide. Fistula results from prolonged and obstructed labour, when the head of the baby cannot pass through the birth canal. The constant pressure of the baby's head forces a hole between the bladder and the vagina (Vesico-vaginal fistula) or the rectum and the vagina (recto-vaginal fistula). This leaves the girl or woman incontinent of urine, faeces or both. The constant wetness and odour often lead to social and biological consequences, like divorce, abandonment and enormous shame and suffering.

Obstetric fistula affects primarily poor rural women and teenage mothers living in remote areas of developing countries where the health services are limited. Studies by (Cook *et al* 2004, UNFPA 2002, WHO 2000) have revealed that there are multiple

factors associated with fistula. These include cultural beliefs, limited decision making, illiteracy, low status of women, gender relations and inequality, decision making power, malnutrition and the lack of emergency obstetric care.

Obstetric fistula is a worldwide public health challenge. Empirical studies point out that there are more than 2 million girls and women worldwide living with the problem of Obstetric fistula, the vast majority of whom are in Africa and Asia (Suellen, Felicia, Monique and Beth, 2005). In the developed world however, the advert of modern obstetric care and it s accessibility has led to the eradication of obstetric fistula in nearly every country.

The WHO Global Burden of Diseases report pointed out that, because women may live for many years with fistula, the burden borne by these women measured in quality-adjusted life years is immense (Wall, 2006). The capacity to repair obstetric fistula does not match with the incidence of fistula in developing countries. This, the number of women with fistula is steadily increasing, with the majority of these unfortunate women left in a state of desperation. It is widely known that there are physical problems and co morbidities associated with fistula. One of the causes of obstructed prolonged labour, which is estimated to be the cause of at least 8% of maternal deaths worldwide (Donnay & Romsey, 2006) and other causes which are the effects of the fistula itself.

These include foetal demise, damage to the cervix or pelvic bones, neurological conditions such as foot-drop, leakage of urine and/or faeces into the vagina, genitor urinary infections, ammaria dermatitis, genital lacerations (Women Dignity Project &

Engender Health, 2006), Kidney infections and amenorrhoea (Suellen *et al*, 2005). Surgical treatment which is successful in 80 – 90 percent (women Dignity Project & Engender Health, 2006), can help restore women's health and return them to a life in dignity. However, women often suffer for many years, because fistula repair services, are not readily available, and even when available women are unaware that fistula can be repaired (WHO 2000) and or they lack resources to enable them get treatment. In review of the literature (Suellen *et al*, 2005, Wall, 2006) pointed that fistula is a major problem in Africa, however, very few countries have the capacity and expertise to manage fistulas. It should be noted that fistula is debilitating, dehumanising, and disfiguring condition affecting women that has not received appropriate attention by the health policy and health services. In addition how the quality of life of the women with fistulas could be restored, rehabilitated and preserved is left in limbo.

It is estimated that 2.6% of women of reproductive age in Uganda have experienced obstetric fistula (UBOS 2007). Based on the population data from the most recent census, this equates to a national prevalence of over 142,000 women. Although fistula first presents itself as a medical condition, its condition is deeply rooted in women's social vulnerability that aggravates its widespread incidence, prevalence and management (maternal deaths and disabilities) and these can only be understood in the context of women's acute socio-economic vulnerability in developing countries which denies them access to timely and appropriate health care including decision making.

Underlying fistula's medical presentation are its true determinants: the powerlessness of women to control their sexual and reproductive lives and to decide on their own

health care, a lack of education on pregnancy and childbirth, poverty that denies families the means to afford health services, the severe shortage of qualified health workers, and adequately equipped health facilities and the lack of transport and roads to reach health facilities quickly when maternal emergencies arise.

The prohibitive costs of transport and health services and the low expectations of the care they deserve compound the seriousness of the problem. For the same socio-economic reasons many women with fistula are unaware that the surgical treatment is available, or cannot access or afford the treatment. As a result they often live with the condition for years or until death. In addition the basic repair health services are unavailable in most developing countries where the capacity to treat fistula cannot meet the demand for services (UNFPA and Engender Health 2003, Women's Dignity Project 2002, Wall, 2006). With no treatment, girls and women with fistula not only suffer psychosocial health but they are also economically incapacitated in families and community due to the constant leaking and odour (Wall, Karshimia, Kurschner, Arrowsmith, and Polan 2004).

The short term and long term impacts of women with fistula that are manifested in experiencial,psychosocial and psychological challenges required a scientific study of this magnititude.The ways of coping when faced with unresolved challenges equally deserved systematic investigation and societal or community integration of women with fistula also required scientific investigation which this study ably provided justice.

1.2.0. Statement of the Problem

The Uganda Demographic Health Survey 2011 shows that 2.6% of women in Uganda have experienced fistula.Noted also is that there are few specialists who can repair fistulas in the country.The problem is made more difficult in a situation where the country has few health facilities with the capacity to manage fistula.This situation has left most women who get fistula live and suffer long period with the problem of fistula. Those women experience several psychological,psychosocial and economic challenges.The challenges the women with fistula face, the coping mechanisms and how they have been intrgrated in the community were never been systematically investigated and that formed the basis of the researcher to carry out this study.

This study therefore investigated and established experiences, psychosocial challenges, issues and factors that enhance re-integration of woman living with fistula.

1.3.0. Research Questions

1. How did women experience the pregnancy, delivery and after delivery that caused fistula?
2. What are the psychosocial challenges of women affected by obstetric fistula?
3. What are the needs required to enhance reintegration of women living with obstetric fistula into their families and communities?
4. How do women cope with challenges of living with obstetric fistula?

1.4.0 Objectives of the Study

1.4.1 General Objective

The main aim of the study was to explore experiences, psychosocial challenges and reintegration needs of women affected by obstetric fistula.

1.4.2 Specific Objectives of the Study

1. To establish experiences faced by women during the pregnancy, delivery and post delivery that caused Obstetric Fistula.
2. To identify psychosocial challenges experienced by women affected by obstetric fistula.
3. To establish the coping ways used by women with obstetric fistula.
4. To identify factors that enhance community reintegration of women affected by obstetric fistula.

1.5.0. Scope of the Study

The study ‘s major focus was on the lived experiences and challenges women with fistula endure specifically the psychosocial challenges and what it takes/it would take to overcome these problems and ultimately be reintegrated into their families/communities like any other human being. The study will target women affected by fistula found at Mulago National Referral hospital, Kagando and Kitovu hospitals. Data collection started in January 2012 up to February 2013.

1.6.0. Significance of the Study

Obstetric fistula affects many girls and women and has rendered them physically disabled, it has made them outcasts and hopeless members in the society. The problem of fistula is preventable, treatable and manageable but few people support and care for the women affected by the condition. The public sphere does not clearly understand the problem. There is limited knowledge on the experiences, psychosocial challenges and the factors that enhance reintegration of women with fistula in the communities. A clear understanding of lived experiences of women devastated by fistula is required in order to inform policy and highlight the motivation factors that restore hope to fistula survivors and their families. The premise of this study was to elucidate the social vulnerabilities individual experiences and psychosocial and how hope can be restored to fistula victims.

The information generated by this study contributes to the body of knowledge on the experiences and magnitude of the problem. This is hoped to give precursor in designing appropriate programs and policies to prevent, care and support obstetric fistula victims. The findings of this study may be used to reduce maternal morbidity and mortality caused by fistula. Evidence based information on the socio-economic and cultural contexts within which mothers are left severely disabled without the prospect of care and support is required to inform policy on reducing maternal mortality and morbidity including infant morbidity and this forms the wider menu of this study.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1.0. Introduction.

Literature on obstetric fistula, women's experiences, coping mechanisms reintegration of fistula victims in community, including critical methodological and content issues surrounding this subject are discussed in this chapter.

2.1.1. Women's Reproductive Health Situation in Uganda

One of the goals of the Uganda Health Sector Strategic Plan (HSSP II 2005/06 – 2009/10) is to contribute towards the reduction of maternal and under five mortality. This is in line with the achievements of the HSSP 1, the unmet need for family planning stands at 40.6 percent and 3.8% for adolescents 15–19 years**.** The unmet need for emergency obstetric care is 86% 944. Only 41.1 percent of births take place in a health facility (public and private sector) and 42.1 percent deliveries occur supervised by skilled providers. The percentage of adolescent pregnancies has reduced from 44 percent to 22 percent during about 15 years but this is still unacceptably high (Table 1.1). The total fertility rate remains high at 6.7 (Donny, and Ramsey, 2006).

2.1.2. Girls and Women's Health Seeking Behaviour

Health seeking behaviour (HSB) refers to any activity undertaken by individuals, who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy (UBOS 2006. 2007). This is, therefore, a sequence of remedial actions that individuals undertake to rectify perceived illness. It starts with symptom definition upon which a strategy for treatment is devised. Teenage girls tend to shy

away from seeking health services when pregnant. For instance it is documented that teenage girls book late for antenatal care (in the second or third trimester) or attend only at once, thereby limiting the potential impact of the quality of antenatal care. (Filippi, Rosmans, Campbel, Graham, Mills 2006). The causes of this are financial barriers, embarrassment and attempts to hide the pregnancy. There is also dissatisfaction with provider practices, such as clinic waiting times, lack of privacy and unfriendly attitudes among care givers. Although there are adolescents who are glad to be pregnant (e.g. married adolescents) many of them are embarrassed and do not know what to do. A number of factors like knowledge of role of ANC, perceived health needs, nurse-patient relationship, economics and transport influenced attendance at ANC (Abouzahir, 2003; UBOS, 2006: 2007).

Delivery services especially emergency obstetric are critical for pregnant women if they experience pregnancy related complications such as obstructed labour, pregnancy induced hypertension, eclampsia – or severe untreated anaemia. Each year, nearly 70,000 adolescent girls aged 15-19 die from pregnancy related complications, which are responsible for most of the mortality in this group. Younger adolescents and prime gravida adult women appear to be at especially high risk for obstructed or prolonged labour which causes higher morbidity and mortality in these mothers. Fistula results from prolonged and obstructed labour, when the head of the baby cannot pass through the birth canal. The constant pressure of the baby's head forces a hole between the bladder and the vagina or the rectum and the vagina. This leaves the girl or the woman incontinent of urine, faeces or both. The constant wetness, odour often lead to social consequences like divorce, abandonment and ostracisation by the community. (UNICEF, 2008).

The main reason why women get fistula is that the pelvic bones and birth canal of younger adolescents are not fully developed, due to young age, and, sometimes, poor nutrition status. In Uganda overall, only 41 percent of births occurred in health facilities and 58 percent took place elsewhere. For instance 49 percent of births to adolescents took place in health facilities compared 32 percent for mothers aged 35 – 59 years. Antenatal care and place of child birth are related to each other. In Uganda, births to women who made four or more ANC visits were nearly four times more likely to occur in a health facility than women who did not attend ANC (56 percent versus 16 percent) (Donny and Ramsey, 2006).

Post-partum care is important for the mother and the baby to treat complications arising from the delivery as well as to provide the mother with information about herself and the baby. In Uganda a big proportion (over 70%) of mothers, including adolescents, do not receive any post partum services at all. It has been observed that first-time mothers returned home feeling unprepared to take care of themselves and their babies. They felt overwhelmed due to increased responsibility and vulnerability. This situation propelled them to seek information on motherhood, which they often got inconsistently, and in fragments. (Donny, and Ramsey, 2006).

Table 1.1: Trends in selected demographic, health and social-economic indicators

Characteristics/Indicators	Years			
Population	**1991**	**1995**	**2002**	**2007**
Population (millions)	16.7	19.3	24.4	29.6[*1]
Population growth rate	2.5	2.5		
Health Indicators	**1991**	**1995**	**2001**	**2006**
Infant mortality rate (IMR) (%) per 1000	122	81	88	76
Child mortality rate (CMR) per 1000	203	147	152	137
Maternal mortality ratio (MMR) per 100,000	527	506	505	435
Adolescent pregnancy rate (%)	44	41	31	25
Total fertility rate (%)	7.1	6.9	6.9	6.7
Contraceptive prevalence rate (%)	5.0	15.0	22.8	24.4
Antenatal attendance at least once (%)	-	-	91	94
Supervised deliveries (%)	38	38	38	41
Full immunisation (%)	28	47	38	46
HIV prevalence (%)	30.0	15.0	6.1	6.4
Social indicators	**1991**	**2000**	**2004**	**2006**
Literacy rate (%)	54	65	-	69
Literacy rate men (%)	-	-	-	76
Literacy rate women (%)	-	-	-	63
Households with access to safe water (%)	44	54	61	68
Life expectancy	48.1	46.0	51.4[*2]	51.0
Economic indicators	**1991**	**2002**	**2004**	**2006**
Population below poverty line (under US$) %	56	35	38	31
Government expenditure on health as % of GDP	2.1	2.1	2.2	-

Source: WHO: 2006 and UBOS: 2006/07

2.2.0. Obstetric Fistula and its Causes

2.2.1 Biomedical factors influencing development of obstetric fistula

Nearly half million women will die of pregnancy or child birth, and a further 1.4 million will barely survive life threatening complications (Filippi *et al*, 2006). Haemorrhage, sepsis, hypertensive disorders of pregnancy, unsafe abortion, and obstructed labour are the five main causes of maternal deaths. Obstructed labour is principally responsible for obstetric fistula, a devastating injury sustained by women

during child birth. Over 80 percent of fistulas in developing countries result from neglected obstructed labour (Hilton, 2003). Data in hospital settings show that fistula can also be got through accidental injury to the vaginal wall during difficult operative deliveries, or through surgical incompetence and negligence (Wall, 2007).

As many as one hundred thirty thousand new cases of fistula are occurring annually, and up to 3.5 million women may be living with the condition. The majority of these women live in resource poor countries. All these injuries could be prevented if timely and appropriate obstetric care was available, accessible and affordable. (Wall, 2007).
According to the 2011 Demographic and Health Survey in Uganda, an estimated 2.6% of women of reproductive age (15-49 years) had experienced obstetric fistula. Based on the population of reproductive age from the most recent census, this equates to a national prevalence of over 142,000 women The population of women of childbearing age – 15-49 years was at 5,476,435 (UBOS, 2002). During prolonged obstructed labour, the presenting part of the foetus, usually the head, compresses the soft tissues of the mother's vagina, bladder, and rectum against the maternal pelvic bones.
Without proper intervention – typically, a caesarean section to relieve the obstruction – the foetus is asphyxiated and the impacted tissues of the mother's vaginal wall sustain pressure necrosis, slough off, and leave a hole (or abnormal communication) between the vagina and the bladder (vesico-vaginal fistula) or between the vagina and the rectum (recto-vaginal fistula).

As a result, the girl or woman is left with uncontrollable leaking of urine and or faeces from her vagina, and constant and humiliating odour and wetness. Compounding this catastrophic physical trauma, in almost all cases, the woman suffers the loss of her

baby. Without treatment women are frequently ostracised or withdraw from their communities out of shame. Some are rejected or abandoned by husbands and families. Many are unable to work to earn a living, driving them deeper into poverty.

2.2.2 Social- cultural factors that lead to occurrence of fistula

The high rates of obstetric fistula in several developing countries may not only be due to poverty, but also due to the impact of socio-cultural practices on women's status, health and well being. In Uganda a number of cultures entertain early marriages. In Uganda, 25 percent of adolescents 13-19 years have began child bearing and 19 percent of them already have a child (Donny, and Ramsey, 2006).

Although adolescent pregnancy in Uganda has been steadily declining (41% in 1995, 31% in 2000, 25% in 2006), it is still high (Donny, and Ramsey, 2006). This poses a challenge to health service providers to understand how adolescents cope with pregnancy and early motherhood. Adolescent pregnancy is singled out because of its association with higher morbidity and mortality including fistula for the mother and child as well as the psycho-social consequences involved (Women Dignity Project 2006; Murphy, 1981; Cron, 2003)).

The breakdown of traditional sexuality and reproductive information channels are socio-cultural factors thought to facilitate early sexuality among female adolescents (Lugoe, 1996). Early sexual activity is attributed to some extent the loss of moral values and familial control that prepare young people for adulthood roles and responsibilities (Silberschmidt & Rasch, 2001). Because adolescent girls become pregnant at an early age, or engage in unprotected sexual intercourse when their

pelvises are not mature enough to allow passage of the baby, and with unskilled delivery attendants, they end up with prolonged obstructed labour that results into fistula.

Traditional practices such as female genital mutilation (FGM), the surgical removal of clitoris and or labia to restrict sexual pleasure and temptation increases the risk of fistula. A quantitative study conducted in Kenya by (Mabeya, 2004:2) revealed that 80% of the girls and women admitted in a rural hospital in West Pokot, had undergone severe female genital mutilation. Complications associated with female genital mutilation are mostly evident during childbirth, as a result of reduced elasticity of the vagina caused by scar tissue formed as a result of the FGM practice (Kabir, Iliyasu, Abubakar, and Umar, 2003: 56). Elasticity of the vagina allows more room for foetal passage during labour. To compensate for the reduced vaginal on fice elasticity during child birth, minute tears develop around the vagina, these however are too small to be repaired - thus provokes formation of fistula.

The provision of a woman in labour with water to drink to facilitate the birth of a baby is another malpractice. A full bladder during labour makes it difficult for uterus to contract efficiently and prevents the descent of the baby. Therefore full bladder increases the risk of prolonged labour and fistula as well (Cook *et al* 2004: 73).

Gender relations that manifests in subordination of women in several ways and at different fronts lowers the status of women and are interrelated to the some of the causes of obstetric fistula. The woman lack power to make decisions about their reproductive health concerns. Decisions on when to start bearing children, seek

medical care and where to go in times of illness and child birth are often made by male partners or male relatives thus affects both adult and adolescent mothers. Other social cultural factors like the desire to have many children, desire to have preferred sex, produce many children and increase the number for family/clan make women deliver many children that puts them at risk of getting fistula (Mirembe *et al*, 2009).

The woman encounter problems of delays to seek health services, there are several determinants of delay in the Uganda context which affects delivery health seeking that results into maternal morbidity and mortality including fistula – These are availability – which is the degree of fit between the existing resources like drugs and clients needs. Accessibility – which expresses the extent to which the geographical location of the health services is related to the clients who seek for the services. Affordability – which shows the degree to which the cost of the services are within reach of the clients ability to pay. Accommodation – which shows the extent to which services meet the expectations of the clients like the opening hours matching the schedules of the clients work.

Acceptability – which expresses the extent to which the clients are satisfied with the characteristics of the services like the quality of care (Obrist *et al* 2007, Richetts and Goldsmith 2005). A mixture of these factor s limit health seeking patterns for women and results into cases of fistula for some women (Women's Dignity Project and Engender Health 2007).

According to (Wall *et al* 2004) malnutrition is cited as a cause of fistula. People become malnourished if their diet does not provide adequate calories and protein for growth and maintenance. Malnutrition causes stunted pelvis, a small structure and

small pelvis that may not permit vaginal delivery, in addition malnutrition impairs the healing process of bruises that occur during labour and wounds after fistula repair. Therefore, women's nutritional status during growth, pregnancy, and after delivery has greater implication to the formation of fistula. Other factors responsible for causing fistula are low social status of women; poor, limited social and economic infrastructure. In summary, fistula is a manifestation of inequity in access to care and the linkages between poverty, poor reproductive health and traditions (Bangaser 2007).

2.2.3 Psychosocial Challenges faced by Girls and Women with Fistula

The psychosocial impact of women with fistula has been discussed in Women Dignity and Project and Engender Health 2007. However this study was qualitative only, few empirical studies have nevertheless investigated this issue.

A study done in Uganda found that nearly all the women with fistula experienced isolation (Women Dignity Project and Engender Health 2007), either they isolated themselves due to feelings of shame or were cut off from normal participation in their communities as a result of stigma surrounding the condition. They lacked self confidence to participate in public activities such as funerals, weddings, community meetings and church services – for fear of wetting themselves and smelling badly in public, or they were not welcome to attend. They live a life of social outcasts, and some fall into deeper physical and emotional decline in addition are severely stressed and women with such feelings may resort to suicide (Women's Dignity Project and Engender Health 2006 and 2007).

Fistula leaves women with few opportunities to earn a living, their ability to work, or to work to their capacity, access to jobs, is limited and this increases their dependence on others (UNFPA, 2006). Denied family support, their poverty and malnutrition are frustrating. They may earn through begging and comparable stigmatising employment (Cook *et al*, 2004).

The grief of losing a child and becoming disabled exacerbates the pain, and further, they may have to spend many years with no hope of getting surgical repair since few hospitals and surgeons are able to provide treatment. For many women, the social isolation they face is worse than the physical agony. The girls and women pregnancy and delivery experiences critically needs light onto policies and interventions to decrease maternal morbidity and mortality, as well as improve their health and well being. (Bangser, 2006)

2.2.4 Biological/Physical challenges

A number of challenges facing girls and women go far beyond the physical disability and child loss. Problems like secondary infertility, vaginal stenosis, amenorrhea, foot drop, infection and skin excoriation are very common for women affected by the condition. The wetness cause skin excoriation and subsequent infections (Cook *et al*, 2004).

The cleaning up is regular, and the pain or discomfort may be continuous as well. Moreover, several studies reported that following obstetric fistula, women complains of secondary amenorrhea Amenorrhea results from dysfunction of hypothalamus and

intrauterine scaring wall. Paralysis or foot drop results from extreme nerve damage to the women's lower limbs following traumatic labour. (WDP, 2006. Browning, 2004, Ezegwui Nwogu-Ikojo).

2.2.5 Integration of Women after Fistula Repair/No Repair (Whether successful or unsuccessful)

Women who are affected by fistulas live with the condition for many years without any biomedical solution. Constant urine and faecal incontinence results into their families and communities view them as disabled and defective, and this in most cases results into separation and rejection by their partners/families. Some women get successful fistula repairs but they may not go back to their communities especially if they were ostracized. Some of those who fail to get fistula repair live in misery and isolation. In Uganda there is limited information available on women's experience with reintegration particularly for those who are affected by fistula. There are some documented evidence however by Women's Dignity Project and Engender Health (2007) which reveals that following successful fistula repair women resume normal lives and are able to work freely with their families and communities.

After fistula repair women could take up active economic and social activities. However as observed some women even after successful surgery still face stigma. People in the community could not believe that they have been healed. The stigma and isolation is more vivid when the fistula repair is unsuccessful or where health services have not been sought at all. Recognising the importance of reintegration of women affected with fistula is important and factors that facilitate reintegration and

needs required for reintegration into the communities and families should be identified, this is one of the basic premises of this study.

In summary fistula causes social, economic, physical (medical problems) and psychological problems. These problems also lead to other problems that result in social isolation of the individual. From the community point of view the individual withdraws from social-economic activities and this leads to loss of employment resulting into poverty. The psychological problems for example, feelings of being useless – once these are not addressed they can lead to mental illness and suicide – or withdrawal from the community.

Society needs these women to lead healthy lives (we want them to live a productive and less painful life) and from the expert point of view something can be done – This person can live and therefore this person who has obstetric fistula needs help to overcome these problems. If she is a well to do person (rich woman / from a rich family) she can overcome these problems on her own. But if it is somebody who have a weakness (poor, illiterate, with no support), she will need those who have knowledge and the ability to overcome those problems.

2.3.0 Theoretical Framework

This study was guided by critical and critical discourse analysis theories. Discourse is socially constitutive as well as socially conditioned- it constitutes situations, objects of knowledge, and social identities of and relationships between people and social groups of people. It is constitutive both in the sense that it helps to sustain and reproduce the social status quo, and in the sense that it contributes to transforming it.

Since discourse is so socially consequential, it gives rise to important issues of power. Discursive practices may have major ideological effects-that is, they can keep, produce and reproduce unequal power relations between (for-instance) social classes, women and men and ethnic/cultural majorities and minorities through the ways in which they represent things and position people (Fairclough, 1997). The theory make visible the interconnectedness of things, critical theories under which critical discourse analysis is classified also want to produce and convey critical knowledge that enables human beings to emancipate themselves from forms of domination through self reflection, so they are aimed at producing enlightenment and emancipation.

Critical theory further seeks to create awareness in agents of their own needs and interests. Critical theory regularly aims at revealing structures of power and unmasking ideologies. Ideologies are representations of aspects of the world within which human beings contribute to establishing and maintaining relations of power, domination and exploitation. Those individuals in power are responsible for the existence of inequalities (Craigcalhourn, 1995). Critical Discourse Analysis aims to investigate critically social inequality as it is expressed, constituted, legitimized, and so on by language use (or in discourse). Critical theory exists in a variety of forms, It is based on the following three assumptions: First, groups and societies are characterized by shared values *and* conflicts of interest, Second, social life involves continuous processes of negotiation, compromise, and coercion because agreements about values and social organization are never permanent, and third, that values and social organization change over time and from one situation to another as there are shifts in the power balance between groups of people in society. Forms of critical

theory were developed as people realized that societies are too messy, complex, and fluid to be described as “systems” and that it is instead of focusing on society as a whole, critical theory focuses on the diversity, complexity, contradictions, and changes that characterize social life as it is lived and experienced by people who interact with one another and struggle over how to organize their lives together. Although critical theory comes in many forms, it focuses primarily on the following topics: (1) the processes through which culture is produced, reproduced, and changed, (2) the ways that power and social inequalities are involved in processes of cultural production, reproduction, and change, and (3) the ideologies that people use as they make sense of the world, form identities, interact with others, and transform the conditions of their lives. Critical theory also encourages action and political involvement. It has been developed by scholars dedicated to identifying issues and problems for the sake of eliminating oppression and seeking justice and equity in social life. Critical theory is a valuable tool when identifying and studying specific social problems. People who use it assume that social relationships are grounded in political struggles over how social life should be defined and organized.

Guided by critical and critical discourse analysis theories the women in this study and indeed in most developing countries find themselves in complex, patriarchal dominated and most exploited by men through cultural institutions and male dominated made polices that may not provide equity to men and women. The importance of gender in the dynamics of sexual relationships, health seeking and decision making have been highlighted in most contemporary gender debates. Gender is used to describe those characteristics of women and men, which are socially constructed, while the concept “sex” refers to those, which are biologically determined. People are born female or male but learn to be girls and boys who grow

into women and men. This learned and socialisation behaviour makes up gender identity and determines gender roles, expectations and locates a person to a cultural social status. Gender identification includes understanding the roles, values, duties, beliefs and responsibilities of being a man or woman (WHO, 1998).

The critical theory addresses the wider social environmental issues surrounding women and men, such as the distribution of power and authority, effective influences and gender specific norms within heterosexual relationships. Programmes using critical discourse analysis theory provide an interpretation and the impact of structurally determined gender differences on interpersonal sexual relationships (perceptions of socially prescribed gender relations), reproduction and sexual reproductive rights and health seeking.

Division of labour and the sexual division of power are recognized as salient factors that partially explain gender relations including the emotional components of relationships. The structures are maintained within the institutions' social mechanisms such as unequal pay for comparable work, discriminatory practices at school and the workplace, the imbalance of control within relationships and workplace, less emphasis of women's health concerns by national budgets thus negatively impacting on related health provision, the stereotypical and/or degrading images of women portrayed in the media. These and other social mechanisms limit women's way of life by producing gender-based expectations of women's roles in society. Based on this theory, it is the gender-based inequalities and inconsistencies in expectations that produce the exposures or risk factors that adversely influence women's health.

Various researchers have used the theory to investigate the role of gender and gender roles in sexual behaviour choices, reproductive rights, health seeking and decision making. Using this theory it can guide interventions and equitable development with women in heterosexual relationships and male dominated policy making systems. This can help investigate how a woman's commitment to a relationship and lack of power can influence her risk reduction. The critical theory can be applied to examine womens' exposure to fistula, risk factors and intervention programmes for women. The researcher contends that the sexual division of labour which refers to assigning women and men certain occupations. This in turn affects women, since the nature and organisation of women's work limit their economic potential and restricts their career paths. The theory further elucidates the sexual division of power. Power refers to having power over others and exists at the interpersonal level and occasionally at the institutional level. Women in relationships where there is an imbalance of power are inclined to depend on their male partner, as men are often the ones who bring more financial assets (such as money, status) into the relationship at a social level. The social division of power results in negative health outcomes for women, such as not deciding where to go for appropriate health services during pregnancy, delivery and after delivery, being vulnerable to divorce/ separation when with fistula, and health policies and budgets not being sensitive to womens' health and welfare among others. .

Furthermore attachments to social norms determines appropriate sexual behaviour for women and is characterised by the emotional and sexual attachments that women have with men. The structures at family, community and societal levels limit the expectations that society has about women concerning their sexuality and health. This in turn shapes the perceptions that women have of themselves and others and this

limits womens' experience of reality. This structure also explains the link between women's sexuality and other concerns related to impurity and immorality. On an institutional level, this structure is maintained by social mechanisms such as sexual stereotyping of women. These biases produce cultural norms, the enforcement of strict gender roles and stereotypical beliefs such as the belief that women should have sex only for procreation, creating taboos for female sexuality which eventually objectifies the female body.

Attitudes and experience of sexuality become "gendered" in that the cultural expression of sexuality is directly associated with the appropriate performance of gender. Therefore, ideals of gender and sexuality reflect cultural messages that merge to produce what may be termed "gendered sexuality". For example, the traditional, normative performance of gender places women in the submissive position relative to men (in certain cultures). This submissiveness has implications for decision making in heterosexual relationships, as women (in these cultures) are often unable to express their concerns and desires fully. Moreover, the traditional performance of gender exercises considerable social power outside of these relationships, for example, the emphasis placed on male sexual conquest may encourage men to make unhealthy decisions by encouraging separation/divorce or abandonment when a woman is a victim of fistula. This gendered perspective may be instrumental in discovering why women risk getting fistula, fail to get appropriate health seeking, including care and may help explain the consistent problem of how policy may not adequately address female related health issues in most developing countries including Uganda**.**

CHAPTER THREE

RESEARCH METHODOLOGY

3.1.0. Study Design

This was a descriptive, cross-sectional study that employed qualitative and quantitative techniques of data collection and analysis. The qualitative research techniques used in-depth interviews (IDI) with women affected with fistula (those who have been repaired or not), Focus Group Discussions (FGDs) with carers or their significant others. The key informant interviews with health providers were conducted in addition to review of secondary data about the phenomenon being studied. Qualitative method provided deep explanations and insights about the experiences of study subjects and this formed the main intent of the study.

The second approach used was the quantitative approach which used the questionnaire and this formed a major method that provided statistical data on key variables for the study. The questionnaire was used to interview women and girls affected with fistula. The Table 1.2 below summarizes the objectives, study participants and methods.

Table 1.2: Summary of study objectives, Respondents and Data Collection Methods

Study objectives	Variables	Methods
Establish experiences faced by women and girls during the pregnancy, delivery and post delivery for the pregnancy that caused fistula.	Characteristics of subject predisposing factors. Age, sex, education, decision making, quality of health services traditional practices, social support, health system issues, cultural issues. etc.	In-depth interviews, FGDs, Key informants, questionnaire
To identify psycho-social challenges experienced by women affected by fistula	Social problems e.g. separation, divorce, rejection, stigma, stress, loss of income, trauma, other biological problems, e.g. urine and faecal incontinence infertility, odour, amenorrhea, vaginal stenosis	
To establish coping ways used by women with obstetric fistula	Grief, income, literacy, age, sex, assets (land etc), interaction with neighbour hood, community appeal and accessibility to health services, communication/ support and health costs, coping strategies for caring of victim	KIIs, questionnaire survey, FGDs, secondary sources In-depth interview
To identify factors that enhance reintegration of women affected by obstetric fistula into the communities	Characteristics of service (health service, system factors, enabling factors e.g. accessibility, appeal) Service factors e.g. rehabilitation, counselling cognitive skills development e.g. literacy, numeracy, problem solving skills, carers support groups, victim participation in planning, economic skills development, community/ family education and sensitization	FGDs, survey, KIIs, Secondary sources

3.2.0. Area of Study

The study covered central and western parts of Uganda from which women could easily access health services in the hospitals selected. It covered three hospitals, that is, Mulago National Referral hospital located in central Uganda. The hospital was purposely chosen because it's the national referral hospital that receives most fistula cases in the country, it has specialised care services and personnel to manage fistula cases in Uganda. Kitovu and Kagando hospitals were selected because they are the most active hospitals that provide health services for patients with fistula in the periphery areas of Uganda. These facilities are located in central Uganda (for Mulago and Kitovu hospital whereas Kagando lies in the extreme western part of Uganda in the current Kasese district bordering with the Democratic Republic of Congo in the west.

3.3.0. Study Population

The target primary population was women with fistula. Their attendants and health service providers were also considered because of the health care and support they give the women with fistula. These were secondary samples to give complementary information because of the closeness they had with the primary respondents. The attendants were interviewed in five Focus Group Discussions (FGDs) with eight members in each group. Two male FGDs (with 16 males) and 3 female FGDs (24 women) were interviewed. Two medical doctors, 5 nurses and 2 officials of an NGO providing support services were also interviewed.

3.4.0. Sampling Procedure.

3.4.1 Determining the Samples.

(A) Quantitative component of the study

The sample size for this part of the study was 196 respondents determined using the formula of Kish and Lesley (1965).

$$n = \frac{Z^2 (P(1 - P)}{d^2}$$

Whereby Z = Is the Standard deviation at 95% which is 1.96 .

P = Probability of outcome of interest= expected prevalence of the problem.

There are many outcomes of interest in the data, such as, psychosocial challenges, such as, stigma, shame, feelings of worthlessness among others. This is taken to be at 0.5 when data are not available

d = acceptable error – which in case of this study was put at 0.09.

By substitution $n = \frac{1.96 \times 1.96 \times 0.5 (1-0.5)}{0.09 \times 0.09} = 196.$

The required minimum sample size became 196 respondents. However, the researcher managed to interview 204 respondents which is slightly above the sample size this enhances the quality of findings since the bigger the sample size the better of data in terms of quality. The respondents in this main part of the study were women with fistula. They were samples using simple random sampling from Fistula wards in the three selected hospitals.

Inclusion Criteria

- Thirteen years and above and suffering from fistula.
- Have Consented or assented to participate in the study.

(B) ***Qualitative Sampling.***

The samples for the qualitative part of the study were selected using purposive sampling. The participants in this part of study were key informants and focus group participants. The Key informants included, doctors, nurses and midwives providing services to women with fistula. In the category of key informants the researcher interviewed 2 doctors and 5 nurses. In addition two members of a civil society organisation supporting women with fistula were also interviewed.

Five FGDs with caretakers and spouses of fistula patients were also interviewed and each FGD had a minimum of eight participants and a maximum of ten participants. The researcher conducted two FGDs with males who were either husbands/partners or father to the women with fistula. The male FGDs were done at Mulago and Kagando hospitals. The three FGDs with women attendants were conducted at Kagando and Kitovu hospitals.

3.4.1 Data collection Methods

3.4.2 Quantitative data Collection

A survey was conducted among women with fistula using face to face interviews by use of a questionnaire. Interviews were conducted with Women with fistula found seeking health services at the three selected hospitals during the time of data collection. Sampling was by simple random sampling and the selected respondents

first consented or assented in writing before participating in the interviews. This population was difficult to get because it's not possible to find them in hospitals since most of the fistula repairs are done in the arrangement of surgical camps, the researcher therefore used the surgical camps conducted in the selected hospitals-this prolonged the data collection process for the researcher to get the minimum sample size. The sample size was 196 but the researcher interviewed 204 respondents in total.

A structured questionnaire with closed ended and a few open ended questions was used to collect quantitative data. The questions were developed using variables in the critically reviewed literature guided by the key objectives of the study. Furthermore the theoretical framework and enaecdotal data was also key in refining the questionnaire. Consideration of issues reviewed and gaps identified in the literature on fistula, reproductive health care services and health policy was taken into account.

3.4.3 Qualitative Data collection Methods

The methods used here included Focus Group Discussions (FGDs), Key informant interviews and in depth Interviews. The FGDs were conducted using focus group guide. The purposive method of sampling was used to select FGDs participants. Criteria was being a caretaker or significant other of the patient with fistula admitted in the participating hospitals at the time of the study. The key informants were also selected using purposive sampling and these were the health workers who have been in contact or caring for patients with fistula in the hospitals participating in the study. The researcher used a key informant guide using face to face personal interviews to collect the data.

Some women with fistula and also some care takers who were interviewed in the quantitative part of the study and had experienced long term and multiple challenges with fistula, were identified during quantitative approach and followed up for in depth interviews to get deeper insights women with fistula experience. Some of the results of this method are presented as case studies in a narrative form (5 cases) while some the data is presented in the qualitative presentation of the findings.

3.5.0. Data Collection Procedures

3.5.1 Quantitative data and Qualitative data

After sampling, the eligible individuals who consented and assented to participate in the study were requested to sign/thumb print a consent form. These patients or caretakers were interviewed using a semi structured questionnaire at study sites. The principal researcher carried out the interviews himself with the assistance of three female research assistants who were recruited and trained by the principal researcher.

Criteria for hiring a research assistant included fluency in English and local languages used by the majority of the respondents. Other criteria of recruiting research assistants included; being female because of the gender sensitivity of the study, prior experience in conducting both qualitative and quantitative research on sensitive issues including reproductive health was considered. The research assistants were all university graduates with a bachelor’s degree.

3.5.2 Translation and Pre-testing of Study Tools

Translation and back translation of study tools was conducted with the research assistants during the training. A pilot survey was carried out to pre-test the tools and ensure that they captured the relevant information. The pilot survey was also intended to check the suitability of all survey procedures and also determine the non-response rate, which could affect the sample size.

3.6.0. Data Analysis Methods

3.6.1 Qualitative data

Qualitative data from the Focus Group discussions (FGDs) and Key informants and indepth interviews were audio-taped, transcribed verbatim and typed in word ready for analysis. The initial step was to read through the transcripts several times while making notes and jots in the transcripts. Thematic content analysis method was used. This technique refers to what the text talks about with relationship aspects and involves in-depth interpretation of the underlying meanings of the text. Data was therefore condensed thematically without losing quality and meaning. All responses were logged into a matrix which tracked thematic areas and responses by the various sources of data. Content analysis was used to further analyse and interpret qualitative data.

3.6.2 Quantitative data

The researcher with the research assistants checked for completeness, consistency and validity of every completed questionnaire before entry. Daily debrief meetings were held every evening to discuss field progress and to make adjustments in the research

process where necessary. Extensive validity, consistency and range checks were embedded in the data entry software.

The completed questionnaires were coded and entered into the computer and exported to Statistical Package for Social Scientists (SPSS) for data analysis. Frequency distribution of all variables was run to check for any unfamiliar pattern in the process of data entry. Frequencies, graphs and tables were generated, meanings and interpretation of data deduced therein

3.7.0. Ethical Considerations

Ethical approval was sought from the National Council for Science and Technology in Uganda. In addition, Institutional Review Committees of Mengo and Mulago hospitals was sought and permission granted from those institutions. Written and or Verbal informed consent from the study participants/respondents was first obtained from all individuals who participated in the study. Participation was on voluntary basis. Confidentiality of the participants/ respondents' views was strictly adhered to.

3.8.0. Study Limitations

There are some limitations to this study; first, the study considered girls and women with Obstetric fistula seeking health care from the health facilities. So the data gives the views of one group, the views of the other group not seeking health care was not captured by the study. This was because of the difficulty in identifying women and girls with obstetric fistula from the community.

In addition the study considered the caretakers of girls and women already attending/seeking treatment in the biomedical health care system and those not in this system were not taken care of and it must be acknowledged that they could have divergent views about the phenomena under study. To minimise on this weakness in data the researcher tried to capture community feelings especially from the FGDs.

CHAPTER FOUR

STUDY FINDINGS

4.1.0 Introduction

The results presented in this chapter were collected from 204 women all of them suffering from obstetric fistula. Other data were obtained from care takers and key informants who were health providers and some officer serving with a non-governmental organization providing care and support services to women with fistula. However, it should be noted that, the main study subjects were women with fistula. The discussion section follows presentation of the results and relates data generated from interviews with secondary data showing similarities, differences and new aspects explored and gaps there in.

In all 204 women and girls with fistula were interviewed, 89 (43.6%) at Mulago hospital, 38 (18.6%) Kitovu hospital and 77 (37.7%) at Kagando hospital. Among those 161 (78.9 %) had VVF, 36 (17.6%) had RVF and 7(3.4%) had both VVF.

4.1.1 The Socio-Demographic Characteristics of Respondents

Introduction.

The Social demographic characteristics of respondents were established and are presented in table 1.3.

Table 1.3: Distribution of women with fistula by age

Age in years	Freq.	%
16-20	58	28.4
21-25	31	16
26-30	42	21
31-35	23	11
36-40	25	12
41-45	7	3
46-50	5	2
51 and above	13	6.3
Total	204	**99.7**

Source: *Primary Data of Women Respondents in Quantitative Field Research- September 2012- Feb 2013.*

The modal age group was 16-20 years comprising 27.9% of the sample. The mean age was 30.2, and median age was 28 years. The age range of the respondents was 16 years to 80 years. Accordingly, the majority of the respondents were below the mean age, meaning they were still young. The main reason why fistula is high in the women of young age was not physically being mature to bear the pregnancy since the integrity of the pelvis is not mature enough.

On the other hand, however, there were women who had fistula but were above 51 years (6.3%). This is the time of menopause where we do not expect women to produce children and therefore would not experience obstetric fistula. The reasons why this group in menopause was suffering from fistula were mentioned and these included the following; lack of knowledge where fistula repair services are provided, and very few hospitals in the country providing the services. Inability to access appropriate health services could also be a contributing factor to fistula since majority of these were peasants (66%) and from households with very low incomes below

100,000= Ug.shs. per month (80%) This is equivalent to 39 US $ at exchange rate of one US Dollar to 550 Uganda shillings. Evidence of this is reflected in table 1.8 and figure 1.5 respectively.

Table 1.4: Age Range in Relation To How Women had lived with Fistula-(Range In Years)

		For how long have you lived with Fistula-Range in years				
		1-12months	1-5yrs	6-10yrs	>10yrs	Total
Age range	16-21 years	33	17	3	1	54
	22-28 years	20	10	8	3	41
	29-35 years	10	11	2	14	37
	36 and above	7	6	8	25	46
Total		70	44	21	43	178

Statistical information in table 1.4 revealed that 25/46 (54%)women with fistula aged 36 years and above had lived with fistula over 10 years. Furthermore women with fistula aged 29-35 years 14/37 (38 %) had lived with fistula for over 10 years. On the other hand women in the age range of 16-21 years 17/54 (31 %) had lived with fistula for a period of 1-5 years. This information shows that most women aged 29 years and above had lived with fistula for 10 years and above. 39/83 (47 %) a number of interpretation can be made from this information. First of all they may be unable to access services because for unaffordability or services not available, they may also be lacking knowledge on where the fistula repair services are provided.

Furthermore the researcher can conclude that those women have suffered for lon the psycho social and psychological challenges mentioned later in this study-see section on psychological and psychosocial challenges experienced by women with fistula.

4.1.1 Education status of the Respondents

Introduction.

Education levels attained by respondents (women with fistula) were also established by the study and the results are presented in figure 1.1.

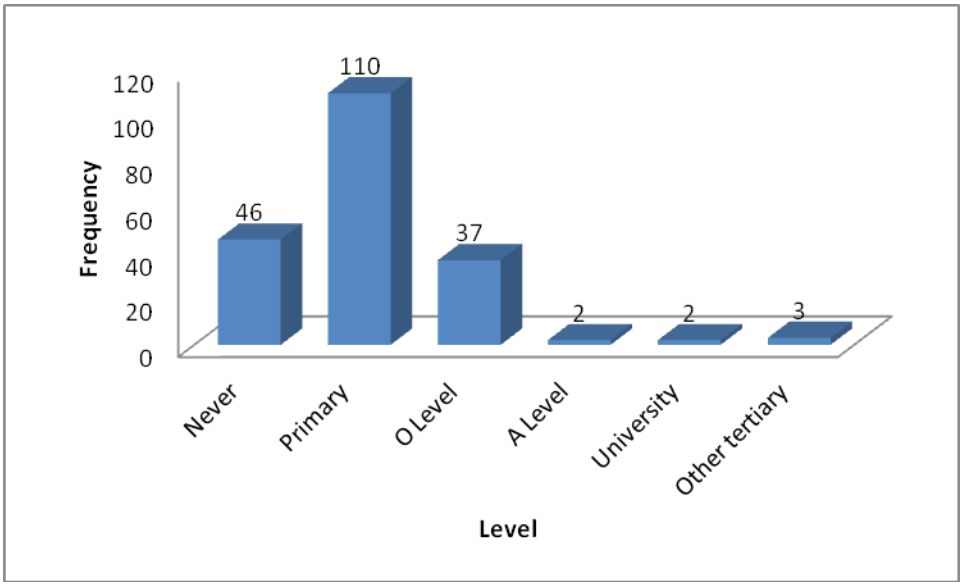

Figure 1.1: Respondents by Level of Education

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013.*

Data shows that education of most women with fistula among the sample was generally low, because about 79% were primary school drop outs or never been to school. Those women with no education or with low levels of education do not get jobs so they have no money to access appropriate antenatal, and delivery services. In

addition their main occupations were in peasantry forming (66%) are peasant farmers refer to table 1.8.

The incomes of these women were also low as in figure 1.5 where majority (80%) were from households earning less than 100,000= (one hundred thousand Uganda shillings) per month. Because of low incomes they may fail to access delivery services from a qualified health worker and as findings are presented in table 1.13 whereby 15% delivered from home and with the assistance of traditional birth attendants.

4.1.2 The Marital Status of the Respondents

The marital status and type of marriage of the women who had obstetric fistula and were interviewed are presented in the table 1.5 and figure 1.4 presented respectively.

Table 1.5: The Marital status of Respondents

Status	Freq.	%
Single	29	14.2
Cohabiting	4	1.96
Married	97	47.5
Separated	61	29.9
Widowed	13	6.3
Total	204	100.0

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013.*

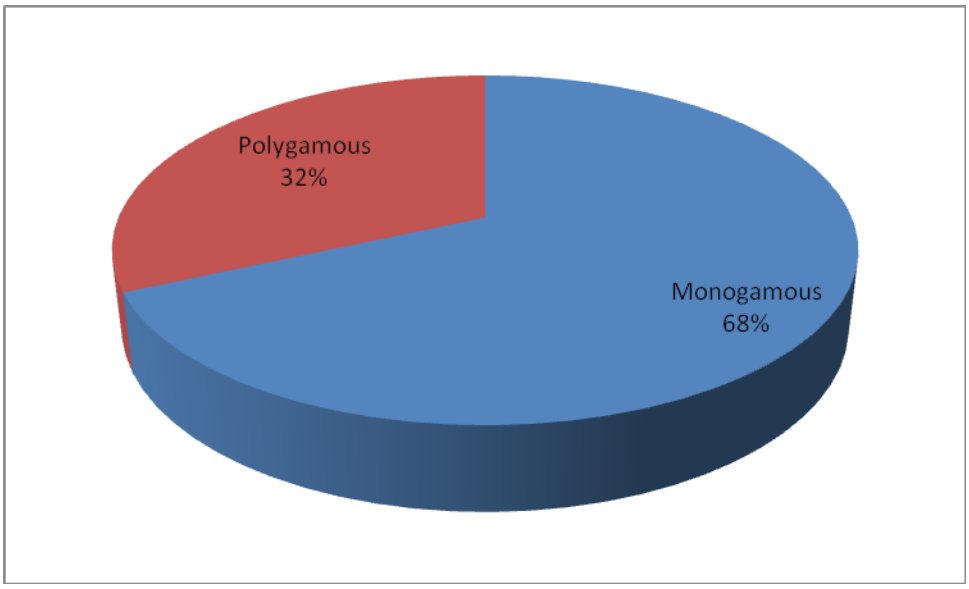

Figure 1.4: Type of Marriage of the Respondents
Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

Most of the women who had fistula 61(30%) were separated and this happened when they got fistula. The partners (male) abandoned them and they went to live on their own or went back to live with their maiden families. Noted however was that even after getting fistula 97(47.5%) of women stayed/kept in their marriage.

Nearly close to a quarter of women 29(14.2%) were single and most likely were living with their biological families or independent and feeding for themselves. Coping with the effects of obstetric fistula, and seeking appropriate health services is more likely to be poor where the fistula victim is separated or single in situations where the respondents were from mostly peasantry households earning less than 100,000= Ug. Shs. As indicated in figure 1.5. Regarding the type of marriage 32% of respondents lived in a polygamous relationship, the reason why this substantial number was not investigated by the researcher. However we need to note that about 89% were Christians who do not subscribe to polygamous. One would probably attribute this to polygamy in this aspect to fistula as most women expressed pessimism to procreation and sexual intercourse in marriage after fistula. This can cause men to look for a second wife.

Table 1.6: Marital Status in relation to years Women Had Lived With Fistula

		For how long have you lived with Fistula-Range in years				
		1-12months	1-5yrs	6-10yrs	>10yrs	Total
Marital status	Single	9	14	1	1	25
	In relation but not married	1	2	0	0	3
	Married	42	13	14	19	88
	Divorced/Separated	18	15	6	15	54
	Widowed	0	2	1	10	13
Total		70	46	22	45	183

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

Statistical information in table 1.6 revealed that nearly half of the women who were married had lived with fistula for a period between 1 month to 12 months, however, 19/88(22%) married women had lived with fistula for over 10 years, and 15/54 (28 %) women with fistula who separated or divorced had lived for 10 years and above. Overall 45/183 (25%) women with fistula for a period of 10 years and above. At the interpretation level on these statistics one can inductively reason that issues of affordability, availability and knowledge about the services may be issues hindering access to fistula services in the few years/ or days of developing the problem/condition. This calls for an intervention in those critical areas by the health service providers.

4.1.3 Religious Affiliation of the Respondents

Introduction

Religious is an important aspect that may influence health seeking, access to health services and information regarding health spiritual development of the people. This study established the religious affiliation of women who had fistula and the results are presented in table 1.7.

Table 1.7: Religious Affiliation of Respondents

Religion	Freq.	Percentage
Catholic	85	42
Protestant	63	31
Muslim	18	9
Pentecostal	31	15
SDA	3	1
No Religious Affiliation	4	2
Total	**204**	**99.73%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

4.1.4 Main occupation of respondents

The main occupations and estimated incomes of the respondents were also an issue inquired on by the study. The findings show that majority of the respondents were earning below thirty thousand Uganda shillings per month. Details are in table 1.8 and figure 1.5.

Table 1.8: Main Occupation of respondents

Occupation	Freq.	Percentage
Farmer	135	66.1
Salaried	3	1.47
Business	14	6.8
Casual worker	3	1.4
Other e.g. Weaving Crafts	49	24
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

Main occupation and sources of incomes positively influence the quality of health seeking of women during pregnancy, delivery and after delivery. The main occupation and sources of incomes of the respondents are presented in table 1.8 and figure 1.5 respectively. Statistics indicated that 135(66.1%) were peasant farmers and 80% of respondents were living in households that earn 100,000= and or less per month.

The responses from the health workers revealed that majority of respondents with obstetric fistula are poor. This they said is even manifested by looking at the property they come with to the hospital for treatment mostly including plastic plates and cups,

one pair of bedsheets with no spare for replacement when they wash and a few dresses. Key informants reported that a small fraction of about 5% of the respondents are rich.

In Uganda provision of health services is free in state owned (government) owned health facilities. However the sector has quality challenges of low staffing levels, chronic stock outs of medicines, lack of appropriate maternal health services at lower health facility levels HCIVs, HCIIIs and HCIIs which are nearer to majority of the people. In this case where the respondents were from peasantry background and have low incomes they may not find it easy to afford transport costs to access timely pregnancy and delivery services more especially on the onset of lobour. This may delay them to reach at health facilities on time or cause them to deliver at home, at place of TBAs and as a result experience obstructed/prolonged labour that exposes them to high risk of getting fistula.

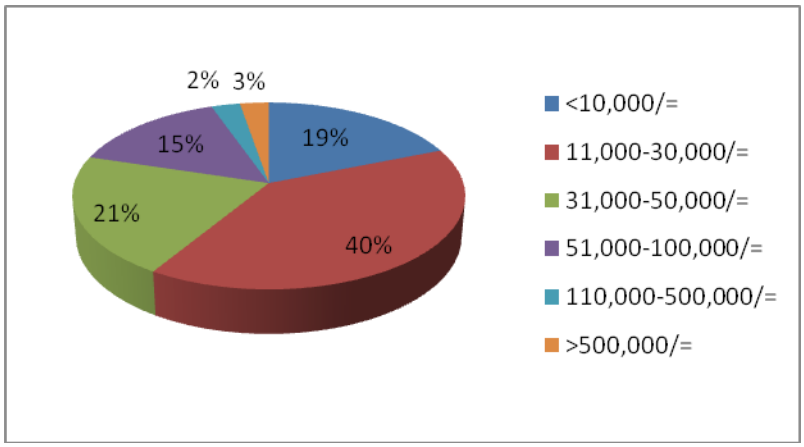

Figure 1.5: Estimated monthly household income of women respondents
Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

4.2.0.Experiences with the Pregnancy, Delivery and Post Delivery When Women Respondents Got Fistula

4.2.1. Introduction

The researcher investigated the experiences of women respondents regarding pregnancy history, experiences with delivery that caused obstetric fistula, the after delivery period when fistula had just happened and the results are presented under this sub section.

4.2.2 Respondents with Fistula by age at first pregnancy

The age presented in years at which women with fistula first became pregnant was of interest to the researcher. The findings are presented in table 1.9.

Table 1.9: Respondents age at the time of first Pregnancy

Age in years	Frequency	Percentage
15-17	85	43.4
18-22	91	46.4
23-27	9	4.5
28-32	1	0.5
33-37	0	0
38-42	0	0
43-47	0	0
58-50	0	0
Total	**204**	**100.%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

According to findings presented in table 1.9, the mode age when women got first pregnancy was 18 years, Mean age was 18 years and medium age of respondents at first pregnancy was also 18 years.

The majority of respondents became pregnant at the mean age. This corresponds with findings in table 1.3 where majority of women interviewed with fistula were at young age of below the mean age of 30.2 years. Low levels of education and income may contribute to early initiation to sexual intercourse early pregnancy and early marriages and cultural beliefs among others causal factors of early pregnancy and motherhood. When women conceive early in years their bodies may not be physically mature to bear a pregnancy up to successful delivery.

4.2.3 Number of pregnancies and deliveries respondents have had in life

The women with fistula who were the quantitative respondents in the study were asked the number of pregnancies they have had in life. The table 1.10 shows the tabulated frequencies of the number of pregnancies the respondents had in life.

Table 1.10: Number of Pregnancies Women Respondents had in Life

Number	Freq.	Percentage
1-3	126	62
4-6	44	21.8
7-9	25	12.4
10+	10	4.9
Total	**202**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

The results show that most of the respondents 126 (62%) only had got one to three pregnancies and deliveries. The fertility rate in Uganda is at an average children of seven children per woman and the fertility rate is higher in women who have not attained secondary education. Bearing in mind this fact it therefore means that these women are likely to continue with child bearing a act that can further risk them to

fistula after successful repair of the current problem. Also hose whose uteruses are still normal they may continue to conceive and bear children even when they are not healed of fistula.

4.2.4. Health seeking behaviour for the pregnancy that caused obstetric fistula

The respondents were asked where they sought antenatal care services (ANC) for the pregnancy that resulted in obstetric fistula. This question got several responses. The majority 176 (86.2%) sought ANC services from government health facilities, 16(7.8%) from Private for Profit Health centres and 12(.8%) Private Not for Profit (PNFP) which include religious and Non-governmental owned health facilities.

The study also investigated the age of pregnancy when the women respondents first sought ANC services.

Table 1.11: Months in pregnancy respondents first received ANC for the pregnancy that caused fistula

Months	Freq.	Percentage
1	3	2
2	21	10
3	36	18
4	71	35
5	40	20
6	22	11
7	7	4
7.5	1	0.5
8	1	0.5
9	2	1.
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013.*

Most of women sought ANC services at least in the 1st trimester 0 – 3 months of pregnancy 60(29%). On the other hand 133 (66%) sought ANC in 2nd trimester where as 11 (5%) sought ANC in 3rd trimester. Going late for ANC predisposes women to fistula as results show that majority went for ANC in the 2nd trimester. Going late for ANC predisposes women to fistula.

4.2.5 The frequency of seeking Antenatal care services by the Respondent

Introduction

The table 1.12 shows the number of times respondents sought ANC services for the pregnancy that resulted into obstetric fistula.

Table 1.12: Number of times Respondents with obstetric fistula Sought antenatal services

Times	Freq.	Valid Percent
1	5	2.4
2	30	14.7
3	51	25
4	75	36.7
5 and above	43	20.9
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

Findings show that the respondents attended antenatal health services (ANC) for a number of times for the pregnancy on which delivery they got obstetric fistula. The majority of respondents 75(36.7%) sought ANC services 4 times, those who went 5 times and more were 43(20.98%), 51(25%) sought ANC three times, 30(14.7%) sought ANC twice and 5(2.4%) went ANC only once.

Some of the services received during ANC visits included; taking body weight, testing HIV, testing urine and measuring blood pressure. Noted however was that majority of women attended ANC services at least 4 times or more (57.6%). This is commendable for its about average recommended by Ministry of Health in Uganda.

4.3.0 Perceived quality of health services at facilities where women with obstetric fistula sought antenatal heath services

Table 1.13: Respondents Perceived Quality of ANC Services Received During the Pregnancy that Caused Fistula

Response	Freq.	Percentage
Very poor	32	15.6
Fair	68	33.3
Satisfactory	101	49.5
Very satisfactory	3	1.4
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

The respondents were also asked whether they were satisfied with the ANC services they received and majority reported that ANC services were satisfactory. This means delivery is the riskiest period where they got problems that resulted in fistula. Also clients may be ignorant about the compliance of health workers with complying to ANC World Health Organisation and ministry of health guidelines. Health workers compliance with compliance with ANC guidelines has been question in addition to health facilities lacking all services for appropriate ANC care.

4.3.1 Birth order at which fistula occurred

The order of giving birth/ delivery that caused fistula was one of the issues investigated by this study. This being the most unfortunate order of delivery that brought about sad reminders in the life of the respondents all of them knew the dates and the years when they sustained fistula. Table 1.14 shows the results of this variable.

Table 1.14: Birth order at which fistula occurred to respondents

Order	Freq.	Percentage
1 – 3	153	75
4 – 6	32	16

7 – 9	13	6
10 and above	6	3
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013.*

The mean birth order at which respondents got obstetric fistula was one, Whereas mode order of birth order of birth was also one The mean birth order was at 3 (2.6). This indicated that the majority of respondents got fistula at the first order of birth up to the 3rd order of birth. The majority of women getting fistula on the 1st order of birth up to the 3rd order of birth shows a positive relationship with the young age at which most respondents first got pregnant as indicated in table 1.7 where majority first became pregnant between age of 16 – 19 years 166(81%). This may, also show that child birth between this age may highly expose the women to getting fistula. The culture and value to have many children poses obvious risks to getting fistula in the category of older women whose strength to bear a pregnancy successfully may be weakened.

4.3.2 Place of delivery where obstetric fistula occurred to respondents

Introduction:

The respondents mentioned several places where they delivered the pregnancy that cause obstetric fistula. Table 1.15 shows the findings on this aspect.

Table 1.15: Places of delivery where respondents got fistula

Place of delivery	Freq.	Percentage
My home	15	7.3
TBAs home	15	7.3
Govt Hospital	140	69.6
Govt Health centre	15	7.3
Private Hospital	11	5.3
Private clinic	8	3.9

Place of delivery	Freq.	Percentage
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

The findings revealed that majority of respondents delivered in a government hospital 140(70%). Most women reached the government hospital after delays elsewhere either at home, or on the road to the hospital and most would reach when they already have the fistula. The health facility would do the removal of either dead child in most cases or alive child in few cases. Poverty typified in low levels of income and main occupations of respondents indicated in table 1.8 and figure 1.5 may also complicate access to delivery services in terms of affordability. In addition, about 30(15%) of women delivered at home or with the assistance of TBAs. This also contributes to high risk of getting fistula were majority young and prime gravidas 116(57%) got fistula on 1st delivery. We need to note that because of delay to reach the health facility, obstructed labour and few health facilities in rural areas with specialised services that deal with complications of prime gravidas, made most women reach at hospitals with a damage on bladder and or rectum and had to be put under caesarean section to remove the baby in most cases dead to save the mother. See table 1.15.

4.3.3 Perceived quality of service at place of delivery where respondents got fistula

The quality of health services at the places where respondents gave birth when they got obstetric fistula and the level of satisfaction as perceived by the respondents was one of the several concerns and experiences investigated by the researcher. The results on the perceptions of respondents on quality of health service obtained at places where they delivered when they got fistula are presented in table 1.16.

Table 1.16: Perceived Quality of Delivery Services received when the Respondents got Obstetric Fistula

Variable	Freq.	Percentage
Very poor	14	6.86
Poor	51	25
Fair	54	26.4
Satisfactory	85	41.6
Total	204	100%

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

The majority of respondents 85 (41.6 %) were satisfied with the services at the place of delivery, whereas 54(26.4%) mentioned that quality at place of delivery was fair. On the other hand 51 (25%) reported that the place where they delivered pregnancy that caused fistula was poor. Noted was that 14 (6.86%) women respondents mentioned that services at place of delivery were very poor. Overall 65 (31.86%) respondents delivered in a place perceived to be poor or worse in quality.

4.3.4 Type of Delivery Respondents had when they got Obstetric Fistula

The types of delivery which respondents got for the delivery that caused them obstetric fistula are presented in table 1.17.

Table 1.17: Type of Delivery experienced when women respondents sustained Obstetric Fistula

Type of Delivery	Freq.	Percentage
Normal	56	27.4
Assisted	37	18.1
Caesarean	111	54.4
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

The majority of women delivered by caesarean section 111(54%), and also 18% delivered by assisted delivery. The majority of these were referral cases, or those with prolonged labour that failed to do deliver normally. The majority of women respondents interviewed 111(54.4%) delivered by caesarean section, 56(27.4%) had a normal delivery and 37(18.1%) had assisted delivery. Need to know that majority would reach hospital after delay and when they already have fistula.

4.3.5 Women's Knowledge on Family Planning Methods and Utilisation

The knowledge women had on family planning and utilisation of family planning methods are presented in table 1.18 and 1.19 respectively.

Table.1.18: Respondents Knowledge on Family Planning Methods

Response	Freq.	Percentage
Yes	180	88.2
No	24	11.7
Total	**204**	**100%**

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

Table 1.19: Respondents who were using modern family planning methods

Response	Freq.	Percentage
Yes	49	24
No	155	75.9
Total	**204**	**100%**

Source*: Primary Data collected from Respondents, Sept 2012- Feb 2013*

The researcher inquired on whether the respondents were aware of Family Planning Methods and findings to this show that 180(88.2%) were aware of Family Planning methods while 24(11.7%) were not aware of any Family Planning Methods. In as far as the current use of any of the methods of family planning methods was being used by any of the respondents, findings showed that 155(75.9%) were using a method of family planning to space child births whereas 49(24%) were not using any method at all. Most women were interviewed before successful fistula repair and the 24% who were not using any family planning method risked getting pregnant and in case where most lived in rural areas with limited access to skilled health workers to help them during ANC and delivery their condition could be worsened making it very complex and difficult to repair successfully.

4.4.0 Psycho Social Challenges Experienced By Women Living With Obstetric Fistula

A number of issues were investigated under psycho social challenges, these include; secrecy on condition of fistula, psychological and social problems respondents have faced ever since they got fistula. The results are presented in the sub sections below. A number of diseases and health conditions cause stigma and discrimination to people among the community members where the sufferers live and may render the patient

discriminated upon or marginalised in one way or another as it has been the case with fistula patients according to results of this study. In addition health conditions are treated with utmost confidentiality between the person with the disease/health condition, the caretakers and health workers managing the condition or disease with this kind of background, the study first sought to explore whether the women with obstetric fistula would have wanted it to remain a secret (between themselves and health workers and husband (partner) and to this question responses shows that 119(58%) wanted fistula condition to remain a secret, whereas 85(41.6%) did not want it remain a secret.

The reasons why they did not want it as a secret was that when revealed to members of community they would be turned into laughing stocks in the community. Those who did not want it remain a secret wanted the people to know so that they get advice and information on how to better treat the disease/condition and get better.

Noted also was that 195(95.5%) had disclosed the disease to other members of the community, whereas 9(4.5%) had not disclosed to any member of community including their kith and kin.

The table 1.20 shows the categories of people respondents disclosed to.

Table 1.20: Categories of people respondents disclosed information on the fistula sickness to

Response	**Yes**	**No**	**Not applicable**
	f %	**f %**	**f %**
Partner	186 (91.1)	9 (4.5)	9 (4.5)
Parents	185 (90.6)	10 (4.9)	9 (4.5)

Response	Yes	No	Not applicable
	f %	f %	f %
Sibling	187 (91.6)	8 (3.9)	9 (4.5)
Other relatives	160 (78)	17 (8.3)	27(13)
Friends	167 (81.8)	28 (13.7)	9 (4.5)
Religious leaders	128 (62.7)	67 (32.8)	9 (4.5)

***Source**: Primary Data collected from Respondents, Sept 2012- Feb 2013*

4.4.1 Familial and Social Challenges Faced by Women with Obstetric Fistula

Introduction

There were several challenges faced by women with fistula at family level and community level that affected the social life of these women. These are presented in table 1.21. and the explanation follows after the table.

Table 1.21: Social challenges reported by respondents due to Fistula.

	Yes	No	Not applicable
Challenge	**f %**	**f %**	**f %**
Marriage breakup	61(29.9)	114(55.8)	29(14.2)
Physical abuse by partner	21(10.2)	174(85.2)	9(4.4)
Neglected by maiden family	25(12.2)	178(87.2)	1(0.49)
Disowned by marital family	42(20.5)	129(63.2)	33(16.1)
Discrimination by health workers	4(1.96)	196(96)	4(1.96)
Discrimination by employers	5 (4.9)	45(43.7)	53(51.5)
Discrimination by peers	29(14.2)	171(83.8)	4(1.96)

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

The study findings show several Social Challenges suffered by women because of suffering from obstetric fistula. The key Socio-Economic challenge faced because of suffering from obstetric fistula (for those who were once married) was separation from the husband/partners. It was reported by 61(29.9%) of the respondents that their

marriage broke up because of fistula. This is quite a substantial percentage. In addition 21(10.2%) reported physical abuse from partners/husband when they got fistula. On the positive side though, 114 (55.8%) did not experience marriage breakdown, and 174(85.2%) did not experience physical violence from husband or partners. On the other hand some who stayed in marital relationships reported that their husbands/partners had opted to quietly neglect them by marrying the 2nd wife, husband/partner starting womanising or some coercing them into sexual intercourse which had become distasteful and painful to fistula victims. Noted also was that 25(12.2%) of the respondents mentioned that they were neglected by their maiden families, whereas 42(20.5%) were neglected or disowned by the marital families.

On the positive note, however, 178(87.2%) reported that they were supported by their maiden families and 129(63.2%) never experienced neglect by the marital families. The researcher did cross tabulation to find out the relationship of length of stay with fistula and break up of marriage/ relationship with partner. The results are indicated in table 1.22 and discussed thereafter.

Table 1.22: Women's Marriage breakup in relation to length of living with Fistula

		For how long have you lived with Fistula-Range in years				
		1-12months	1-5yrs	6-10yrs	>10yrs	Total
Has any of the following happened to you as a res ult of disclosure of your fistula status?-Marriage breakup	Yes	20	16	8	16	60
	No	39	19	13	23	94
	NA	4	4	0	0	8
Total		63	39	21	39	162

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

Information in table 1.22 showed that 60/162 (37%) women who got fistula had their marriage break up. On the other hand 94/162 (58 %) women with fistula did not suffer break up of marriage when they got fistula. The number of women who had lived with fistula for 10 years and above 16/60 (27 %) suffered marriage break up when they got fistula, also 20/60 (33%) of women who had lived with fistula for a period between 1 month-12 months suffered marriage break up. This percentage is higher than their counterparts who lived with fistular for over 10 years. This means that people who are newly married have a high degree of marriage break up when they get fistula.

4.4.2 The economic challenges of living with Fistula

Most women who had obstetric fistula isolated themselves from the public and communal activities. Most reported not going for church/mosque prayers, attending markets, only going by public transport when they must not avoid it like when going for health services, not attending funeral services and marriage ceremonies.

The study found out that fistula victims suffered from poverty because they had to spend a lot of money seeking health services, maintaining proper personal and body hygiene, buying pampers to control the flow of urine or faeces and withdrawing from public economic activities because of urine or faecal incontinence. These included the following, Fistula caused other diseases/conditions like skin excoriation caused by wetness of continually flowing urine, offensive odour, paralysed legs, uterus making noise, gassing out air throughout the anus in most cases for those who suffered Recto-vaginal fistula, a combination of all these did not allow women to have full concentration of Economic activities to earn a living. In addition these conditions

reduced their energy to work, failing to go to dig or do garden work for the majority who earned through peasantry. Those who could have opted for public jobs like trading reported that they could not try those opportunities because of the stinking they experienced.

Furthermore all reported the cost of maintaining appropriate hygiene when living with fistula as one of the critical challenges-buying soap to keep cleaning oneself, washing clothes that need to be changed after few hours and buying pampers to hold faeces or urine. The cost of this was unaffordable for majority rendering them into isolation, shame, and desperation. The quotes below clearly confirms the findings above.

"*I got this problem when I was married, and when I was delivering. I got vesico-vaginal fistula (VVF) because of this problem, my husband abandoned me since 1991. He left our marital home and went to rent somewhere in another place where he also married another wife. For me ever since I have lived with my four children alone".*

(Woman living with VVF from Luwero District who had lived with condition for 21 years and had come to Mulago National Referral Hospital for first repair).

When she was asked why she delayed to seek health services; she had this to say:

I did not have the money for an operation, by the time I came to know that there were free operations-the planned seasonal surgical VVF repair camps would have ended-but this time I got the information from the radio early enough to come in time.

"I cannot go to dig or look for food and yet this is the only way I can survive-my right leg pains me a lot. I do not know the cause, maybe an artery was damaged and my thighs are all sores because of the constant flow of urine".

(VVF case aged 36 years from Mubende who had come to Mulago hospital for repair).

For us you cannot go to the mosque for prayers when you are leaking urine. You should go to pray at the mosque when you are physically clean, but when you are in my current condition of continuous leakage of urine you are regarded unclean. I feel bad because I cannot go to the mosque for prayers. Though I pray from home on a mat of Muslims-I do not feel I have prayed well for Allah to sole my problem".

(VVF case aged 26 years-Mulago hospital).

"No money to buy pampers (pampers are expensive) they cost between Ug. Shillings 4,000-5,000= for adults. I put on pampers meant for babies which I buy at 800-Ug.shs .but they are filled with urine in a few minutes. So now I first put on a knicker, polythene paper, and then cotton pieces f cloths. When it's wet I replace it with another cotton piece of cloths. Pampers are expensive and I use polythene paper, cotton pieces of cloths and go with about three knickers and several dresses. (Today I came with 3 skirts and one dress) and bought the black big polythene paper which can be wiped of urine when wet."

(Woman aged 20 years from Wakiso district who has lived with VVF since October 2012).

“People would not allow me to vend cooked food and they refused to buy it because of the foul smell of urine and poverty became a chronic problem on one”.

(VVF aged about 65 years who had lived with the condition for 50 years-from Nakasongola district).

4.5.0 Psychosocial challenges experienced by respondents because of suffering from Fistula

Introduction

There were several psychosocial challenges faced which were mentioned by women living with fistula. Nearly all women 202 (99%) reported that they had endured shame because of suffering from fistula. Similarly 202 (99%) were saddened while 186 (91.1%) felt that they were worthless in the family and the community. The condition of sleep loss because of suffering from fistula was reported experienced by 173 (84.8%) whereas a smaller proportion of 31(15.1%) did not experience sleep loss because of the condition of fistula.

Reduced self esteem and pessimism were also experienced by 197 (96.5 %), and 192 (94.1%) respectively by the respondents. However, noted was that 12(5.8%) had never been pessimistic in life as a result of fistula. Table 1.219(a) shows some of the psychological challenges faced by women because of suffering from fistula.

Table 1.23 (a): Psychosocial challenges experienced by respondents due to Fistula

Challenges	Yes		No		Totals
	f	%	f	%	
Worthless	186	(91.1)	18	(8.8)	204
Sadness	202	(99.0)	2	(0.98)	204
Guilt feelings	184	(90.0)	20	(9.8)	204
Self dislike	186	(91.1)	18	(8.8)	204
Shame	202	(99.0)	2	(0.98)	204
Sleep loss	173	(84.8)	31	(15.1)	204
Pessimism	192	(94.1)	12	(5.8)	204
Low self esteem	197	(96.5)	7	(3.4)	204

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013.*

In addition to the above, the respondents revealed that they found themselves crying most of the time because of suffering from fistula, this was experienced by 178 (87.2%) whereas 26 (12.7%) did not cry most of the time as a result of the condition. Another undesirable challenge faced was concentration difficulties experienced by 190 (93.1%), isolation was faced by 196 (96%) and a small number of 8(3.9%) who were not isolating themselves from the community. Loss of interest in sexual intercourse was experienced by 198 (97%) and only 6(2.9 %) reported that they did not lose interest in sexual intercourse. Some women on the other hand had ever had suicidal thoughts or wishes whereas 148 (72.5%) never had suicidal thoughts because of fistula. Also to note is that 147 (72%) felt that their social position was negatively affected by fistula though 57(27.9%) ware not affected at all. Furthermore 123 (60%) felt that they experienced increased sympathy from the neighbours whereas 81 (39.7%) did not get increased sympathy from the neighbours. The quotes below

verbertim presented from the interviews demonstrates the magnitude of the challenges faced:

" It's bad, peace less throughout life, worried, crying becomes part of you, you feel you cannot fit in the community, you have a brain torture throughout life-if this condition gets you when you are not a Christian and not a person of prayer you can commit suicide". (Woman with RVF since 2004 who had come for repair first time at Mulago hosp.)

"Whenever I have sexual intercourse with my husband I get a burning pain in the Vagina passage and he does not make reasonable penetration-but I courageously keep on though the whole exercise is painful. I usually boil water and use warm water and mix it with some herbs to soothe the vagina pain I get." (Woman with VVF Mulago hospital)

"I live like a baby, I'm no longer happy where I sleep at night all will be wet, my thighs get sores because of all time leaking urine.....I potentially stay at home I stopped going to social gatherings, stopped having sexual intercourse with my husband and sleep alone-my husband also sleeps alone for he cannot tolerate constant urine wetness and the stinking smell". (VVF Patient from Mityana district aged 30 and got fistula on the 8th birth order and only had 2 children alive).

Table 1.23(b) provides an illustration and frequencies of these challenges presented under this subsection.

Table 1.23(b): The psychological challenges faced respondents due to fistula

Challenge	Yes f %	No f %	Total
Crying frequently	178 (87.2)	26(12.7)	204
Concentration difficulties	190 (93.1)	14(6.8)	204
Punishment feelings	178 (87.2)	26(12.7)	204
Isolation	196 (96.0)	8 (3.9)	204
Disinterested in sex	198 (97.0)	6(2.9)	204
Suicidal thoughts	56 (27.4)	148(72.5)	204
Increased neighbours sympathy	123 (60.0)	81(39.7)	204
No moral support from neighbours	82(40.9)	122(59.8)	204
Low social position in community	147(72.0)	57(27.9)	204

Source: *Primary Data collected from Respondents, Sept 2012- Feb 2013*

Narrative cases of women with Obstetric Fistula

Case I: Woman Repaired Several Times Of Fistula Since 2005. (Eby'omukazi Owabaire Agwaire Endwara Y'akahago Okwiha 2005 – *kandi ashemezibwe emirundi mingi*.)

Interviewer: I would like you to tell me your experience with obstetric fistula?

Response:

Janet (not real name) aged 45 years got fistula in 2005 went through a repair period of up to 2009 got healed she shared with this researcher who found her at Kagando hospital where she had come for periodic health reviews.

"The labour pains began when I was at home in Kamwengye, blood oozed out of my vagina, my husband was a polygamous man so he was not at home on that day for he was at the home of the second wife which was over four kilometres from where I lived.

He was called to come and take me to the hospital for delivery, he refused to come and said that I will deliver at home as usual since I had had 6 deliveries before all at home.

When he refused to come I sent for my cousins to come and take me to the hospital but before they could come the arm of the child came out (at this time I was alone with my mother-in-law. My cousin (male) came, immediately and went to look for a car to hire and take me to hospital. We had no money in the house but I had a harvest of maize in my house. When the car came its owner after negotiation accepted to take me and on return we would crush the maize and pay for his service of car hire. He drove us heading now to Ibanda hospital. We left my home at 9:00pm and it was raining. We delayed to depart from my home because we had to negotiate with the car owner since we did not have money to pay, also my cousin had to look for men to carry me in (Engozi) to take me to the road where the car was packed a distance of about one kilometre. The cost of the car was eighty thousand Uganda Shillings (80,000=) we drove but along the way we got stuck the road was being worked on by a grader and we reached the hospital at 5:00am. By the time I reached the hospital the lower parts of my body were already swollen including my abdomen. At the hospital the nurses were hostile to us, that why did I keep at home for long without rushing to the hospital. I was operated at midday the same day and I had a still birth. I stayed in hospital for two months, the parts of my abdomen were damaged and were rotting. I would wet the bed all the time and I had a catheter to pass out urine I was told my bladder was perforated and was told after healing the scar of the caesarean I would be referred to Kagando hospital for VVF repair.

The dead child I gave birth to was taken home for burial and my husband was forced to come to see me in the hospital this was after his brothers summoned him to police for arrest. He came saw me and left and later he migrated with his wife to an unknown place, my children were left with their grandmother. When I was discharged I went to my maiden home and was cared for by my mother and my children joined me there. Later I went to Kagando hospital for VVF repair I was examined by a doctor after a weeks' stay at that hospital and was told I had such a terrible injury and that he had never seen a person with a terrible damage like mine. I was prepared for an operation which took place in the 2nd week of my stay at hospital the doctor put 3 tubes(Bupira) inserted into my stomach (to pass out urine) because the bladder was pronounced too damaged. The 2 tubes were removed after 3 weeks and stayed on with one which stayed on for a year and it would be replaced after every 3 months, the vessel was painful and at one time because of pain I invaded the doctor in theatre requesting him to remove it and he counselled me and later told me he is going to repair my VVF. He repaired the bladder which had 3 holes, repaired two holes and the third hole was not covered. Other doctors came and operated me later covering the third hole and this made me start urinating normally. After sometime when I was moving on the motorcycle I got an accident and damaged the bladder and started leaking urine again and was operated again-though I say I'm okay some urine can leak I have been operated (VVF repair) 6 times. When I get cough and start coughing the bladder enlarges-so when I cough urine can leak uncontrolled. My uterus was removed while I was at Ibanda hospital but they did not tell me about it, I later asked the doctor why I was not getting menstruation periods and he told me that the uterus was removed. I however recalled when I was to be taken to theatre the doctors asked me whether I wanted to conceive again and I said no-but they did not

tell me why they asked me that. They also did not tell me that they were going to give me a permanent method family planning by removing the uterus.

Interviewer; Would you please tell me your satisfaction with the health services at Kagando hospital during the times she underwent through the various operations?

Response: "They helped me, I was stigmatized, could not be in public. We paid a lot of money for the health services until when we became poor. My mother and sisters used to foot the bills by selling local alcohol (Waragi). I sold all my domestic animals, and at Ibanda hospital I failed to pay 330,000= Ug.Shs. Which was paid by my brother in-law (brother of my husband). We had stayed at the hospital (in detention) for not paying the hospital bills. My in-law was sympathetic to me and paid because I had taken care of his children when his wife separated from him. We, however, refunded him in instalments. During my sickness church people prayed for my recovery and would contribute some money and send to me when I was at the hospital. This disease requires a lot of money because you have to keep clean, soap, pads, my mother would buy soap for me and at hospital I would stay alone because Kagando gives VVF/RVF patients free food and health services.

At church whenever I could go I would put on polythene paper on top of pieces of cloths and go to church. One time while in church the polythene paper got too filled with urine and as a result it burst and urine leaked/splashed all over with much pressure and people in church got scattered in a stampede-not knowing what had happened but I stayed seated on one position until all people went out. The few who stayed behind and got to know sympathized with me. I cried a lot and from that day I

avoided going to church. Sometimes when going to hospital for treatment I would be taken by my brother and would wet the seat of the vehicles we travelled in-at one time my brother took me to hospital and reached when wet because of my urine and in public vehicles other passengers would cry out wondering where the offensive smell was coming from and the vehicle owners would sympathise and bear with me.

Interviewer; How have coped with VVF?

I have ensured that I urinate whenever I Response.

Interviewer ; Other experience with VVF?

Response;

I feel like going. I use a basin at night because I cannot keep going outside so frequently. I also stopped going to church I would only go for healing sessions. One woman who got to know of my problem once commented that I need prayers to die well-because she told me that I will never heal. With this comment and remark I felt so low spirited because this was an unfortunate comment from the person I knew-later she met me and I told her that I got better and she replied that I should thank God who healed me.

I have been offered political leadership positions but I can't take them up, I cannot walk long distance and cannot be on a boda boda. What I know VVF patients need counselling services from the health workers because I would keep crying all the time, whenever I could see my skin on thighs excoriated, sored buttocks caused by wetness of continually flowing urine. Why we need counselling is that I have a colleague, we went together to Kagando hospital for VVF repair. She dreamt dying while in theatre while undergoing a VVF repair operation. The following day she escaped from the

hospital and up to now she has never been cured of the problem.

Omukyondoza abuza: Nshobororera nyabo oku oburwaire obu bwakukwasire N'Okwotwirenabwo?

Omurwaire Okugarukamu*: Nyowe nkaza aha bisha ndi omuka kamwengye, eshagama yatandika okuturungiza eraraba "omubukazi".*
ekiro ekyo ibanyi akaba araire ow'omukazi we owakabiri – ahabwokuba aine abakazi babiri. eka y'omukazi we ondijo okuruga ahayangye nihingana mailo ina.

Abantu ababaire bari nanye bakaza kweta ibanyi ngu ayije antware omwirwariro mbe niyo naza kuzarira. kubamwesire yayanga; yabagambira ngu ndaza kuzarira omuka nkaburijo ahabwokuba nkaba nzaire emirundi mukaga abaana ndabazarira omuka.

Ibanyi ku yayangire kwija kuntwara omwirwariro, natumaho bazaara bangye bakaba batwire haihi naitwe ngu baije banyambe bantware omwirwariro. konka bazaara bangye batakaizire omukono gw'omwaana gwarugayo haza obwire obu bwoona nkaba ndi na maazara wenka.

Muzaara wangye omushaija yaija, nikwo akanguha okuza kuronda motoka y'okupangisa kuntwara omwirwariro. muzaara wangye akaija na motoka, konka mukama wa motoka akabanza yayanga kututwara ahabwokuka nkaba ntaine sente omunju z'okumushashura. Tukabanza twateisa nawe twikirizana ngu antware omwirwariro, reero nagaruka mpure ebicoori ebinabaire nyine omuka, mbiguze

nyihemu esente z'okumushashura. ahanyima yekyo owamotoka akaikiriza kurungi kuntwara omwirwariro erya ibanda.

tukakyererwa okuruga omuka ahabwokuba muzaara wangye akaza kuronda abashaija bokumpeka omungozi okumpisa ahu motoka yabaire eri - orugyendo rureingwa nka mailo emwe ahabwokuba enkuto ekaba etarahika ahaaka ahunabaire ndi. mukama wa motoka akaikiriza kuntwarira ahabwa shiringi emitwaro munana. orugyendo rw'okuza omwirwariro tukarutankdika shaaha ishatu zekiro twagyenda kwonka kutwahikire omumuhanda turagyenda emokoka yakwama – hakaba hariho ekicweka ky'enkuto eki karakita yabaire nekora kandi ebiro ebyo bikaba biri ebyenjura nyingi kwonka tukahika omwirwariro shaaha ikumi n'emwe z'akasheshe. obwire obutwagire okuhikira ahairwariro enda ekaba yanzimbire munongo, n'ebicweka byangye ebyamanyanya nokushumira kimwe ahamaguru bikaba byahagire (byazimbire). omwirwariro abanasi abatwakirire bakatugambira kubi munonga batubuuza ahabwenki twacererereirwe okwiija ahairwariro. abashaho bakanshemeza shaaha mukaga z'eihangwe banyihamu omwana afiire.

Omwirwariro nkamaramu emwezi ebiri haza obwo ebicweeka byangye ebyenda bikaba byashishikaire kandi bikwaise birajunda. ahanyima y'okushemezibwa abashaho bakantamu akapiira kokushesheramu bangambira ngu oruhago rwangye rukatika rwazamu obwina. Abashaho bakangambira ngu naheza kukira ekisebe kyahubanshemeize ngu nibaza kunyohereza kagando hospital banshemeze bazibye obwina bw'aharuhago rwangye orwayatikire.

Omwaana owu banyihiremu afiire bakamutwara omuka owaitu bamuziika. ibanyi akaba atakaizire omwirwariro okundeeba – akaba ayangire. Akaija ahanyima ya

baramu bangye/baine nyina bamara okumutabariza aha polisi okumuta omukihome. ibanyi akaija yandeebaho kakye kwonka yaagyenda we n'omukazi ondijo bafurukira ahu twabiire tutaramanya, abaana bangye bakasigara bararebererwa mazaara.

obwire bukahika bansibuura kuruga omwirwariro nagaruka omuka owaitu ahunazarirwe. maama yatandika okundeberera, n'abaana bangye baija okutuura naitwe.

ahanyima yaaho nkaza omwirwariro erya kagando kushemezibwa oruhago. nkamara esabiiti emwe ahakitanda omwirwariro, ahanyima nabona kukyeberwa omushaho owangambire ngu nkahutaara munonga munong okuyabire atakareebagaho. abashaho bakantebekanisa nashemezibwa omusabiiti yakabiri yokubera omwirwariro.

kubanshemeize bantamu obupiira bushatu bwokushohoza enkari ahabwokuba oruhago gwangye bakashanga rwasisikaire ekirengaine. obupiira/enshekye ibiri abashaho bakazihaho ahanyima y'okumara nazo esabiiti ibiri, reero akapiira kamwe nkamara nako omwaka ariko ndashesheramu kwonka nkaba nasibirwe ndy'omuka ndaguma ndagaruka omwirwariro ahanyima y'emwezi eshatu barantamu akapiira akasya. obupiira/orushekye oru abashaho babaire bantiremu rukaba nirushasha ekirengaine.

rimwe ndi omwirwariro obuhuruzi burikuretwa akapiira bukarengana narumba omushaho ori omu theatre ndamushaba nti anyihemu akapiira akabaire karengaine

okumpururа. kwonka tiyakaihamu, omushaho akampumuriza yandaganisa ku araza okugarukamu okunshemeza. hanyima yekyo akanshemeza oruhago orwabaire rwineho obwina bushatu, yabaziraho obwina bubiri, ekina ekyakashatu kyasigara kitasibirwe.

abashaho abandi bakaija banshemeza omurundi ogundi basiba ekiina ekyakashatu ekyaharuhago rwangye ahanyima yeki nagaruka okushesha nkaburijo.

nkamara obwire ndigye, kwonka nashuba natandika okutonyatonya enkari buri shaaha ahanyima y'okwetera ahansi ndi aha pikipiki. eki kukyabireho nagaruka kagando ahairwariro bagaruka banshemeza hati ndabasa kugira nti ndimu habasa/ndimu nkagye kwonka nakorora enkari nefwa kwereta bwereta – eki ndagira ngu kiraruga omukwehaga nkahaga n'oruhago nakorora. bahisya emirundi mukaga baranshemeza ahaburwaire bw'oruhago.

nyinenda yangye abashaho aba eirwariro erya ibanda bakagihamu kwonka tibangambira yaaba bagihiremu. kusha ndijuka obu babaire baraza okunshemeza bakambuza yaba nkyayenda kugumizamu n'okuzaara, nabagarukamu nti ingaha kwonka tibarangambire enshonga eyibamburize ekibuuzo ekyo. kandi kwo bo tibarangambire ngu baaza kunsibira kimwe oruzaaro n'okunyihamu nyinenda.

omucoondozi wa research akabuuza ati:

obujanjabi obuwatungire omwirwariro erya kagando emirundi n'obwire obuwamazireyo omutindo gwabwe okabishanga ota?

okugarukamu kw'owabaire nabuzibwa/omurwaire:

“nyabura bakanyamba munonga ahabwokuba nkaba narekire kandi ndikuturira kimwe omukushwarira nokuza ahabantu abandi bateranire – oburweire obu okubujanjabisa kukatumaraho esente nyingi munonga kwatukyenesa. maama na bene maawe bakaba baraguza waragi okutunga sente z’okundwaza. nanye nkaguza amatungo agunabaire nyine kushashura esente eziringa n’emitwaro ashatu neshatu ezabaire zirabanjibwa eirwariro erya ibanda – esente ezi nkaba ntazineho batusibira ahairwariro ibanda okuhisya obu esente ezo zashashwirwe muramu wangye babona kutwikiriza kuruga omwirwariro. esente ezo nkazimugarurira ahanyima nahika omuka. muramu wangye ogwo akaba nankunda ahabwokuba nkamureberera abaana be obu omukazi we yabaire ayangaine.

omu kurwara oku abashomi aha keleziya yaitu bakaba baranshabira kandi banshororeza na sente bazinyoherereza omu eirwariro. oburwaire obu nibutwara sente nyingi ahabwokuba omurwaire nayetagisa okuba nanaba/nayeyonja nayozya, nayesibisa n’emyenda oba pads nahabwekyo nayetenga okuba na sabuuni obwire bwoona. maama akaba nangurira sabuuni kandi omwirwariro kagando nkaba ningumayo nyenka ahabwokuba kagando eirwariro tiririkushaba sente z’okujanjaba abarwaire akahago, eirwariro nirihereza n’ebyokurya bya abarwaire batarikubishashurira.

omucoondoza okubuza:
ngambira ahabindi bintu ebyorabiremu/ebyobugaine n’oburwaire obu ebi otangambiraho kubirabe biriho?

omurwaire okugarukamu:

kunabaire nza aha keleziya okushaba nyesiba ebitambara omu mayasha reero njwariraho n'ekipapura kyakavera akokutanga enkari eyabire neyereeta erikuguma netonya.

orunaku rumwe kunabire ngiire aha kaleziya kushaba njwire nk'okunakugambira enkari yaguma netonyokyera omubitambara nakavera ebinabire nyesibisize. ku akavera kayijwire enkari kashandara (katurika). kukashandire kabaruka enkari yaturungiza yayeshesha reero abashomi bo tibamanya ekyabaireho bairuka nibaruga omu keleziya! nyowe enshoni, n'enaku bikankwata naguma hamwe nshutami ahantebe omu keleziya. abashomi abamwe abagumire omu kaleziya bashasha nanye. nkarira munonga, okwiha obwo nkareka kugaruka aha keleziya okushaba.

omurundi ogundi nkaba ningaruka omwirwariro kagando ndi omu motoka (taxi) munyanyazi niwe yabaire nantwara omu eirwariro, emotoka ekaba erimu abantu abandi. Okuza kuhika nkaba najubize entebe y'amotoka eyinabire nshutamiho, na munyanyazi owabaire ankwatirire akaba yajegyire ahabwenkari yangye, kandi n'abantu abandi ababire bari omu motoka barikwebuza ekinuuko ky'enkari ahukyabire kiruga. Kwonka bakama ba motoka bo kubabire bareeba enaku yangye bangumisiriza.

Omukyondoza okubuza:

ogumisirize mu miringo eha noburwaire obu bwa ruhago okushishikara?

Omurwaire okugarukamu:

Ningyezaho okureeba ngu ninguma ninshesha nahurira nayenda nk'okushesha.

naba mbyami omukiro ninguma ninshesha aha basin eyindikuraza aharubaju

rwekitanda ekindabyamamu – eki ndakikora ahabwokuba tindikubasa okuguma ninza okushesha aheru yenju emirundi mingi obwire bwekiro.

ekindi nkareka nokuza okushaba aha keleziya ndazayo rimwe na rimwe haba hariyo okushaba kwokutambira abarwaire. Omukazi omwe owabaire arashabira aha keleziya eyi nabaire nanye ndashabiraho kuyamanyire endwara yangye akangambira ngu ninyetenga eshara nfe kurungi ngu ahabwokuba tindyakira. Ebigambo ebi bikamaramu amaani nayehurira byambuza obusingye haza owa bingambire ogu nomukazi owabaire namanya – ahanyima yobwire namazire okushemezibwa nabaire gye akambona yambuza ahandwara yangye egi namugarukamu ngu nkakira – nawe yangira ngu nsiime ruhanga owankirize.

Abantu ahakyaro bampire n'obwebembezi omubuhereza bwa gavumenti lcs nabwanga ahabwokuba tindabasa okutambura nebigyere orugyendo ruraingwa, kandi tindabasa n'okugyendera aha boda boda.

Eki ndamanya ahaburwaire bworuhago, abarwaire babwo nibetenga okuhumurizibwa okuruga ahabashaho ahabwokuba nkanye naturaga ndarira nemiziga obwire bwingi – ahabwokuba enkari erikuguma neyereta eratonyatonya buri shaaha ekaba yanyokize ebibero, hamwe nekibunu kikaba kyahire kiri ekisebe.

Ekindi ekirikutwetagisa okuhumurizibwa/nokugarurwamu amatsiko neki – nyineho mugyenzi wangye owabaire aine oburwaire nkobu, tukaza kagando hamwe okushemezibwa – kuyahikireyo ekiro kimwe yaroota nafiira omu theatre barikumushemeza. Eki kukyabaireho nyensakare yaaho yatoroka omwirwariro nahati

takakiraga oburwaire obu.

Case II: A Woman who had lived with VVF over two years

Interviewer: Please tell me your experience with obstetric fistula?

Response:

Case of VVF aged 36, with 3 deliveries (only 2 children alive and has has VVF since August 2010. I was in labour for 3 days while at Kawolo hospital on the time for delivery, the child looked for a way to go out-the head was out first but the shoulders could not go out through the reproductive canal-so it died and this was at 9:00am in the morning. I was taken to the theatre for caesarean at 3:00am while the head of the child was out for all that time. The head of the child was cut off-and later alone stitched on the main body later (my stomach had swollen and bulged to maximum-I was badly off nearing death) God saved me. What happened next after operation I don't know because I was unconscious. After the operation I stayed for 2 weeks in the hospital and was inserted in a catheter to drain out urine. From Kawolo hospital I was referred to Mulago hospital where a catheter was removed and was told that I have VVF.

Interviewer: What was your experience about the quality of Health Services at place of delivery?

Response.

"*It was poor, everything we had to pay for it, in 2 weeks we paid 280,000 Ug.Shs.*

Interviewer: Would you have preffered your VVF condition to remain a secret or not told to other people?

Response:

"I didn't want people to know, but whoever could come to see me, I would tell them. I

felt so bad and ashamed. But when I came to Mulago hospital for treatment I stopped hiding people. I also stopped being anxious because I saw many women patients with this condition. I have been operated 4 times for VVF repair but it has not taken, I was last operated on December 15th 2012, the health workers told me to wait for 3 months and today I have come for review.

On my third operation I felt so weak-I was to die no person caring for me except my husband others-my in-laws rejected us.

Interviewer .After getting fistula have you visited other people or go to the mosque for Juma prayers?

Response.

I keep at home and only leave my home when coming here to this hospital. I feel ashamed to go to the public.

Luganda Translation (Omukazi Amaze Emyaka Ebiri N'okusoba Ng'alina Endwadde Y'akawago)

Okubuuza:

Nyabo, nkusaba onyinyonyole ko engeri gye wafunamu bunno obulwadde, n'engeri gye bukuyisizaamu.

Omulwadde adamu:

Nafuna ebisa by'okuzaala nembeera nabyo okumala ennaku ssatu nga ndi kawolo hospital. naye ssebo, esaawa y'okuzala bweyatuuka omutwe gw'omwaana gwe

gwasoka okufuluma era ebibegaabega by'omwaana nebigaana okuyitawo. Abasawo abakyaala abaali banyambako okuzaala bagezaako nebaremererwa – zino zaali saawa nga ssatu ez'okumakya. Nabeera mumbera eno paka sawa mwenda ezekiro bwe natwalibwa mu dongoosezo okunongoosa.
abasawo abanongoosa basooka kutemako mutwe gw'omwaana kubanga yali yaffude dda nebagugattako oluvanyuma kubitundu ebilala nga bamaze okunongoosa.

Mukuntwala okulongosebwa olubuto lwange lwali luzimbye nyo era nga ndibubi enyo nga ndi kumpi kufa. abasaawo bwebamala okunnongoosa nazirika okumala ekiseera, nga sitegeera kili munsi. Nabeera mudwaliro wiki bbiri ng'abasawo bantaddemu akapira akafulumya omusulo.Oluvanyuma lwa wiki biri nebansindika ku dwaliro e mulago, abasawo abe mulago nebankebera nebangamba nti nayononeka akawago. banzijanjaba okumala ekiseera nebansibula nebampa ennaku z'okuddayo okulongosebwa ku kawago akakoseddwa. akapiira akafulumya omusulo bakanzijamu nenzirayo awaka.

Nadayo ewange ng'omusulo guja buzi, ekintu kino kyamalako emirembe, nembeera nga nekyaaye, ate nga mbeera ne nsonyi eri abantu abaali bajja ewange okundaba. okusoka natyanga okubabulira olumbe lwange naye nali sirina kyakukola nga nina okubabulila ekyantukako. Nali ssagalira ddala bantu kumanya nnaku gyenaliko munange, kubanga endwadde eno emalako emirembe. naye munange nga bw'omanyi abantu bo tosobola kubakweeka ndwadde gy'olina era wesaanga obabuulidde nga tokakiddwa.

Ennaku zokuddayo e mulago ng'abasawo bw'ebaali bagambye zaatuka nenzirayo nebanongoosa naye sawona. baakanongoosa emirundi essatu naye akawago kaganye okuwona, omusulo gukyaja buzzi. Banongoosa mweezi gwa kumi n'ebiri (2012) n'ebangamba okubeera awaka amyeezi esattu era kati gyaweddeko nkomyeewo okunkebera naye omusulo gukyajja.

Okusokera ddala nga nakafuna obulwadde bunno nali mwerarikirivu nnyo, naye bwenagenda e mulago n'ensangayo abakyala bangi abalina endwadde enno ate nga bamazze nayo ebbanga eriwerako ku lyange nenfua essuubi n'okweralikirila nekukendeera. Ekintu kinno kyanyamba era kati sikyekweeka nga abantu abalala.

Abuuza:

Nyabo nkusaba ombulire engeri z'ogezaako okumalawo byonna byosanga/byosanze ng'olina endwadde eno?

Omukyala omulwadde okuddamu:

Mbonyeebonye nendwadde eno, bwebanongoosa omulundi ogw'okusatu nagwamu amaanyi, nembeera muyi nnyo nga ndi kumpi nakufa. Sirina muntu mulala anyamba ko okugyako bba wange, balamu bange batukyaawa, ntera kubeera wakka ebiseera ebisinga, sigenda bantu webakunganidde nga bangi okwewala okuswaala olw'omusulo oguwunya gwantekako. Awakka nvaawo nga nzijja wanno mu dwaliro.

Case III: Woman with VVF separated with husband

Interviewer. ***Please tell me your experience with obstetric fistula?***

I got VVF On 18th September 2012, and I have been with it for 4 months now, I think my uterus is weak and that is why I got problems. But when I got labour, I stayed at

home for 2 days, then I was taken to Mubende hospital, the hospital did not have electricity that day, when the time for delivery approached the health workers told me that the theatre machines are not functional, so we were referred to Mulago hospital- I gave fifty thousand shillings for an ambulance to transport me to Mulago hospital, I came with 3 other expectant mothers and each paid 50,000/= as ambulance charges to Mulago hospital. When I reached at Mulago I was operated free of charge but had a still birth.

Interviewer: ***Whats your current relationship with husband after getting VVF?***

Response:

"My husband complains that I have been sick for long without getting healed. He was a divorcee, now when I got sick he married another woman who was a widow. It's my parents who are supporting me, my husband refused to care of me I have even sued him to police. He only wants to live with a wife who does not get sick. He abused me that he is going to neglect me and I will lot at my maiden home. The police sent him a summons last Friday to appear at police on Monday (today), but I went to police to inform them that I'm going to the hospital-they advised me to go for health care and I will sort his issues at the police later when I return home.

This woman was at the hospital waiting for 1st operation, she is aged 24 years and had her first pregnancy at 22 years.

Abuza:

Nyabo nkusaba onyinyonyoleko engeri gye wafuna obulwadde bwa kawago ate ombulireko n'ebyoyiseemu okuva bwe wafuna obulwadde bunno?

Omulwadde addamu:

Nafuna obulwadde bunno obw'okwonooneka akawago nga enaku zomweezi kumi na munana omwezi ogwe kumi nebiri omwaka gwa 2012. Kati maze emyeezi ena n'obulwadde buno. Ndowooza nabaana wange munafu kye kyavirako obulwadde buno.

Bwenakwatibwa ebisa by'okuzaala namala nabyo ennaku bbiri nga ndi wakka. bwe nalemerelwa okuzaala bantwala mudwaliro e mubende. bwetwatuuka mudwaliro olunaku olwo tewali masanyalaze. Esaawa y'okuzaala bwe yatuuka abasawo nebangamba nti ebyuuma by'omudongoosezo ebimu bifu, n'olwensonga eyo nina okugenda e mulago gyemba nzalira. Bwenatuuka e mulago nalongosebwa naye omwaana bamujamu nga affudde. Okulongosebwa e mulago kwali kwabwelele.

Bwenafuna endwadde eno, eyali omwaami wange yandekawo era kati yawasa omukyala omulala eyali namwandu. nze yangamba nti ankooye tageenda kubeera namukazi alwadde okumala ekiseera ekiwaanvu nga tawona. Omusajja ono nali namufumbirwa nga mukazi we eyasooka anobye.

Kati okuva bwenalwala teri buyambi bwonna bwampa abazadde bange be bandabilira. yanvuma nangamba nti ngende nvundire ewaffe gy'ebanzaala.
Olwokuba nti omwami ono tyampa buyambi mubulwadde bunno ensonga nazitwaala ku polisi nemuwabila. era leero lwe babadde bagenda okutuula munsonga zaffe naye bwe nawulidde nti wano e mulago waliyo okulongosebwa kwabalwadde bakawago nengenda okutegeza polisi. Ku polisi bangambye nsooke nfune obujanjabi ensonga zange bajja kuzikolako oluvanyuma nga nvudde mu dwaliro.

Case IV: Woman aged 28 who has lived with fistula for 3 months

Interviewer: I would like you to explain to your experience of living with obstetric fistula?

Response:

First of all, if you have like diarrhoea, it just comes you have to go to the bathroom and clean. When you are with other people they will say you are unclean. You like become a baby and you are peeing in your pants. If you are not clean you smell-flies will be on you. The rectum has the fluids which keep coming out-you always "stamp" your clothes/dresses like as if you are in menstruation period. You have to pad yourself and cotton has burnt my thighs. When you go out of home you have to be with spare cotton-you have to keep cleaning and while cleaning it's terrible! It smells bad, you start isolating yourself even if you try to be in others you are smelling.

Interviewer: Do you think RVF can be cured/ repaired successfully?

Response:

"In my opinion I think yes, they told me they can work on it, it can end. I don't know whether it can end. I don't know whether it heals, I only have faith in them. Even in community if you got this problem you would live with it forever.

Interviewer: Have you ever heard about this problem before it happened to you?

***Response*:** *I have never heard about it, I only got to know it when I got it.*

Interviewer : For now have read literature on it?

Response: *I have not read about it, I only depend on the stories of health workers, and those who have heard about it, or stories from people who have seen some women suffering from it. But when I got it they said it's not a new thing, that even it's not an emergency. I do not know whether doctors were trying to console me-they said*

that even an operation they will just do anaesthesia on lower part.

Interviewer Mod: How has obstetric fistula affected your has relationship with your partner?

***Response*:** *He fears it may not cure or no more sexual intercourse because he fears can push faeces inside in process of intercourse and what can happen if you push faeces inside there you can never know the adverse impact! He is very worried.*

Interviewer: Whether she has received counselling on how to cope with the problem.

Response: *No, no one has counselled me. Emotionally my husband has supported me-whenever I come he comes with me, he waits to find out where I'm going and how I'm doing. Emotionally my maiden family and where I'm married they want to know when I'm going for treatment and the results. Economically they support me-when we do not have the money they give us the money. I now fear leaving the house because if you go for long call you have to wash -I would find it very inconveniencing to be in public. I'm anxious, I don't know how it's going to end, I think it may not stop. Probably there are people outside there with it and they say it may not end.*

Case V: Man who has cared for wife with fistula.

Interviewer:How did your wife got fistula and what experience have you and her passed through since she got fistula?

Response:

My wife is aged 46 years and she got fistula when a hailstorm hit our house and the

wall of house collapsed on her causing VVF.

The health status of my wife has deteriorated, for instance her legs are swollen and she is very weak-with her problem of VVF now even our marriage is no more because you give up with "matrimonial obligations". She no longer goes out to be with other people in public because she is ever leaking urine. Now it's 3:27pm, we left our home coming to this hospital at 5:30 am. We reached here (at Mulago hospital at 7:15 am), so far she has changed clothings three times and all these have to be washed when we reach home. I do the washing myself, I do not give them to our children. I go out to work and when I come back I do the washing myself. This has made me reduce on my hours of work I go home early to do household chores. All our children are in school, so those in day schools come back home late-so I now do all household work myself.

Interviewer: How have VVF of his wife and mother has impacted on household welfare?

Response:

"The household work have stalled, if I had something to do from home (working at home) I would opt for that so that I care for her well. Unfortunately currently I'm a trader dealing in fresh agricultural produce vending it in the markets. Also if I had money I would consider giving her an improved diet-like more to drink which she prefers.

Interviewer Do you think that VVF can get healed/ be successfully repaired?

Response:

It's possible she can get cured, I have heard about many people who have healed from this condition.

Omusajja Eyali Ku Dwaliro N'omukyala We Alina Vesico-Vaginal Fistula ("Obulwadde Bw'akawago")

Abuza:

Ssebo, nkusaba ombulire ku ndwadde y'omukyala wo jalina ey'okwononeka akawago. nkusaba ombulire yabufuna atya? ate ogisanze otya nebilala byoyiseemu ssebo ngolabilira mukyalo wo mubulwadde.

Omusajja addamu:

Mukyala wange ono alina emyaka ana mumukaaga era yafuna endwadde eno ng'ali wakka. enkuba y'ekibuyaga yatonya nnyo ekisenge ky'efumbiro mweyali nekigwa nekimukuba era nekimukosa ebitundu bye eby'ekyama nafuna okwononeka akawago. era okuva kwolwo atonya omusulo buli kiseera kyonna. Obulwadde buno bunafuyiza obulamu bw'omukyala nnyo. ekyokulabilako amagulu ge gazimba ate n'obulamu bwe tebweyagaza era n'amaka gaffe gali nga agafudde.

Omukyala ono takyabeera wali bantu balala kubanga atonya omusulo buli kiseera tegwesiba. nga leero kati ziri saawa mwenda nedakiika abiri mumusanvu ez'olwegulo. Twavudde awaka e mpigi saawa kumi neemu kitundu ez'okumakya netutuuka wano kudwaliro e mulago saawa emu nedakiga kumi nataano ez'okumakya. Naye olwokuba nga omusulo gutonya yakakyusa engoye zayambala emirundi esatu ate engoye zino zetaagisa okwoza bwetutuka awakka. Nze njoza engoye zino, sisobola kuziwa balala kuzooza. Okuva bweyafuna obulwadde bunno nsooka nengenda okukola bwenkomawo n'enjoza engoye z'omukyala weziba zononesse.. Ekintu kinno kindeetedde okukola esaawa entono nsobole okukomawo nkole emirimo gy'awaka gyeyali ng'akola nga tanalwaala. abaana baffe bali musomero era emirimo gyonna gitunuulira nze.

Abuza:

Endwadde y'omukyala elina egeri gyekosezaamu embera y'amaka go?

Omusajja addamu:

Emirimo gy'awaka giyimiridde/gigootanye era singa mbadde n'omulimo ogw' okukolera awaka nandisazeewo nenkolera awaka. Kino kyandinyambye okulabilira mukazi wange obulungi. naye kyanaku, ndi musubuuzi webilime ebibisi mbitwala mu butale, n'olwekyo sisobola kukolera wakka.

Ekilara omulwadde ono tafuna mmere nungi kubanga silina sente zisobola kugimuwa. Naye nsuubira nti agenda kuwonna obulwadde bunno. batugambye nti abakazi abawelako ababba n'obulwadde buno bawonna.

4.5.1 Discussion and Interpretation of Case Studies

The cases presented above, case one and two shows the incidences of prolonged and obstructed labour and neglect by husbands/partners. They also show poverty and a tradition or practice of delivering at home-case one reveals that all the past 6 children were delivered at home.

This case also shows poor road network, long distances to the hospital that offer caesarean services and also lack of a delivery plan by the women and their husbands/partners. Furthermore fistula repair services are not easy to get for they are offered in very few hospitals in the country and indeed have very few specialised doctors to handle the operations. Case one shows the woman who passed through a

painful (both physically and psychosocially) and agonising life. She is, however supported by her maiden family-her mother in particular, sisters, and brothers-her family painfully sought health services and supported her materially until when they became so poor. The story also shows how fistula repair can be complicated and expensive-for she had to undergo surgical repair for six times at different intervals of time from 2005-2009.

The story shows a suffering woman and two families (her maiden and marital family for she had to leave her children under the care of other people).Her maiden family is however determined to ensure that their daughter gets better. This implies that fistula is not only an individual issue but also a family problem. The fistula victim loses her marriage and her children (6 children) are cared for by her extended family. The husband and father of her children disappears and was never interested to know what was going on at all until when forced by other family and community members. Several other cases of this nature are presented where men simply abandon their wives/ partners when they get fistula (quantitative results show 29% of women separated because they got fistula). The families affected seem not to have a mechanism to manage the situation and keep cohesion and order when faced with this circumstances.

In case III, We see a similar situation of prolonged and obstructed labour, delay to reach hospital and spousal neglect and eventual separation. However we see an Institutional problem where a Regional referral hospital (Mubende Hospital) did not have a functional theatre and refers three women including the case that eventually

got fistula to a national referral hospital which is over 160 Kilometres away and the result is this case that got VVF and a stillbirth.

These two particular cases and the other two cited in the report above shows powerlessness of women in decision making and access to economic power at family level-perhaps this can be explained by a culture of male dominance at family and community level. This may leave women with less power in decision making, limited incomes that hinder access to appropriate health services and social justice.

In addition these cases show how not well prepared are the health facilities to handle adequately maternal related conditions both delivery and post delivery conditions and services. At the centre of it all, it becomes obvious that families also do not draw up delivery plans for their expectant mothers and every moment of child delivery waits for chance and this may not be so for every mother for some end in death, stillbirth or getting fistula and the terrible experiences that follow as portrayed in the four cases presented in this report. Important to note, however, is a man who among some few was found taking care of his wife who had VVF through an accident when a house fell on her during a hailstorm. He is seen struggling to seek health services, nursing and support for his wife, but is overwhelmed by the situation-for he finds it difficult to mantain his work in the public domain where he can earn money for upkeep of the family and at the same time perform the domestic chores that can keep the family going on in addition care for his wife. Amidst all he goes through, he shows of a husband and father with a spirit of determination, love and hope to see his wife get better and his family move on. He shows a rare kind of person the researcher found with some other few men /partners in the hospital wards where interviews with 204 women with fistula took place.

4.6.0 Coping strategies used by women suffering from obstetric fistula

A number of coping strategies were being used by fistula victims and their families. The copying ways varied from individual depending on the effects/impacts of fistula on the victim. However, some commonalities existed as revealed by findings from respondents, key informants and the focus group discussions. The most common coping ways reported were the following:-

Coping with urine and faecal incontinence-All women would impose ways of keeping the urine absorbed, by some barriers-the rich or those who could afford pampers would buy them and use them some regularly others when going out to the public. The poor would use pieces of cloths, polythene papers as pampers.

Isolation as much as they can was also used in several ways as a way of living with the disease or avoiding embarrassment in the public. Most informants mentioned that they isolated themselves by sleeping in separate beds other than those they shared with their partners before (those who were still in marriages), some used slept on sisal bags and polythene papers for the case of poor respondents. Whenever going out to the public most respondents would go with 2 or more dresses/skirts, underwear or knickers to change in case of eminent wetness. Another strategy used was ensuring that they go to urinate or defecate whenever they felt like going before embarrassment by the uncontrolled urine or faecal incontinence. Some would use a basin at night kept next to where they sleep because they could not afford to keep going out to

urinate many times in a night a case with the majority who did not have toilets in house.

Some women abstained for practicing sexual intercourse.Accordingly some women when they got fistula stopped having sexual intercourse for fear to worsen the condition, even when successfully repaired some feared that the practicing sexual intercourse would make fistula re-occur. Most had stopped also from going to the publicplaces and gatherings such as, markets places, churches, public meetings and funeral ceremonies.

The women who had separated from their husbands were cared for by their maiden families or parents. Nearly all women interviewed had also coped by seeking health services at several hospitals for the fistula repairs or associated ailments- there were some who sought health services from the traditional healers or elders and were treated with some herbal concoctions.

There were fistula victims who had experienced problems of constipation and they would normally eat yellow/ripe bananas or change diet by eating green vegetables. Some who had experienced a problem of dry faeces in the stomach had their caretakers (mostly mothers) remove the hard faeces by inserting the hand into the anal canal (hand folded in polythene paper) and remove the hard balls of faeces or would apply herbs to induce diarrhoea and solve the problem of constipation.

There were some women who experienced palsies of legs and could not walk properly these would use motorcycles for transport, go through exercises (physiotherapy) to correct the condition. The following quotations show the coping strategies used by fistula victims.

"Socially, because I could not hold gas, I would fear to go to the public-sometimes when in public gas could escape and make noise and the people would laugh, even at home when in front of my children I would feel shy and ashamed because they would hear me gassing most of the time. My children would ask why I'm passing out the gas through the anus most of the time. I would not tell them the truth and would jokingly confuse them that they are the ones who had done it. At school where I teach I resorted to teaching in the lower classes and gas has never come out when I'm in front to school children I try to hold faeces and gas as much as I can and where I fail I rush outside quickly and do it and come back and sometimes I would fear to go to teach the upper classes whenever I go I stay with them for a few hours. Ever in staffroom I would not stay in staffroom I would sit outside even for lunch I take it under a tree outside alone (women with recto vaginal fistula Kagando Hospital).

"If you keep holding (gas) it escapes through the other opening and when you are about to stand up some noise would be made and my colleagues would think it's the uterus which has made noise because everyone at work knows that you are a new mother (Nakawele). (Woman with recto-vaginal fistula Kagando hospital).

"I have to bathe all the time, so when I go to the toilet and defeacate, I have to use toilet paper and clean with water the vagina and anus 3 times because when I'm walking the feaces come out some of it goes into the vagina. If I delay to go for a long call the feaces comes by force, it's uncontrolled, so I postpone eating because I wasn't to avoid going to toilet so frequently or accumulate feaces. This affects my life because if I take a day without eating food it affects my health and nutritional status, what I do I just take a drink because this has no problem with me. I do not go out with men because all the time I'm dirty. I also sleep in panties and try to keep clean.

(RVF woman who has lived with fistula since 2007-found at Mulago hospital where she had come for repair).

Nearly all women with fistula coped with the condition through prayers, some getting saved, this was because of the belief that this problem was so bad that they sought its God who will heal and cure it. The following quote from the respondent shows this clearly.

"I accepted Jesus and got saved I put all my hope in Jesus who can solve all problems". (RVF aged 31 years lived with fistula for 12 years had come to Mulago hospital for repair).

4.7.0 Integration of women living with fistula in the community

Reintegration of fistula victims according to the responses from women who were living with fistula Focus Group Discussion participants' responses and Key Informants included repair and ensure full recovery from this painful and dehumanising life long health conditions rehabilitative, community awareness about causes, prevention of fistula, care and support for women with the condition and economic empowerment. These are detailed below.

The Key Informant majority of whom were health workers and few non-governmental organisation (NGO's) workers mentioned that the hospitals in partnership with donor (engender health) and Terrowodde (NGO) were doing community mobilisation, through teaching the people about fistula, prevention and the repair services available in the country. They were mostly passing on information to

the communities encouraging women from delivering at home delivering at the places of traditional birth attendants and seeking antenatal care services and deliver services at health facilities with qualified health workers. Most respondents (women with fistula) mentioned that one major way how we can help women was through sensitization, sensitizing them that they can access the services and have life again the way they were. Most fistula victims interviewed especially those who had lived with the fistula condition for several years, remorsefully mentioned that if they had known the services early enough they wouldn't have suffered for long unrepaired.

They however reasoned that sensitization should be made to women who have the problem and also all women out there in the country who whether still in reproductive age or not. In addition they reported that its very important to sensitize and educate the men (husbands/partners) men should be told that if you marry /or is in a relationship with a wife/woman who has been normal and she gets an abnormality of fistula while giving birth they should be patient and then seek health services and help the woman get out of the problem. Men should need to be told where to access services and give encouragement and all forms of support the woman needs when faced with the condition of obstetric fistula.

The respondents were sudden and more traumatized when the men abandon them and get more tortured. Yet they did not leave their homes when they were like this. The following verbatim quotation was from one of the female respondents.

"Yes men should be educated to support their wives and partners, they should be supportive, they should really care, not just abandoning. They need to be told that if a wife gets such a problem they can be successfully repaired and get cured. This needs to such that the men also have hope because they sometimes take off thinking

that you can be like that for the rest of your life, so they can't bear, they look for those ones who are normal maybe they should be educated that your women can become normal so you don't take off. And also they should know that not only wives could get such a problem maybe such problems are with other people also and that there are those ones who have helped their wives out of it and they have managed it.

(Fistula victim who had lived with the problem since 2004*).*

The respondents further mentioned that as part of reintegration the health workers who handle fistula patients should be educated on how to handle patients well and in a good way. This is because the fistula victim will have gone under a lot of torture-tortured so much so when they come seeking health services the health workers should be really very cooperative.

The government need also to take the problem of obstetric fistula seriously, through training health workers so that all major hospitals in the country have specialists to handle the problems and give appropriate nursing care. This can be done by providing scholarships to the relevant health workers. The health facilities should also be equipped with equipment and other necessities that facilitate appropriate provision of antenatal, delivery and post natal health services.

It was also noted that families and communities there where women with fistula live need to be sensitized and educated and get to understand the problem and trauma these women face. Therefore the families need to give moral encouragement, material support, the husbands/parents should be told and know that they need to work with the patient to secure better life and health for her. This can be done by taking her to hospital the community can contribute some financial support so that the affected woman can access health services. The communities need to understand and

give respect to the victim and not scorn her or discriminate her for this leads to isolation more psychological torture and how low self esteem. The women who have the problem need to have access to information most information on fistula prevention, repair is aired on radios and newspapers which most women do not access most do not even know how to read and write, live in rural areas and are poor-all being barriers to access the information.

The respondents and key informants mentioned that because of the unfortunate condition of fistula which makes most women victims leave service in the public sector, they find themselves poor-so it was mentioned that for women to regain their dignity whether successfully repaired or not they must have an income and be able to live on their own sustainable income and source (job) that can make them survive and live.

Some health hospitals like Kitovu hospital had tried to link women who seek services at the hospital to a non governmental organisation (NGO) called SEND A COW which sensitises people on farming methods.Officials from this NGO came to the hospital and educated women on how to do organic farming-unfortunately these women most do not own land for farming. Some women have been training on jobs that can be done at their own homes-like knitting and weaving. These can be done at home and earn reasonable incomes for them. Some respondents suggested that there should be a government fund to help the women get access to financial services that can help them start up small scale income generating activities or businesses to enable them live a life of their own not as dependents and be able to meet their daily needs-like seeking health services, payments for materials required for padding, keeping proper hygiene, appropriate nutrition and shelter.

The key informants observed that most women with fistula were illiterate or had not completed primary level of education –to correct this and make them economically active and know their human rights-they reported that these women need to have adult education services to help them know how to read, write, have knowledge on elementary mathematics which can help them do business. This intervention can help stop them from having inferiority complex and enable them live normal lives like other women.

Responses also indicated that civil society organisations would provide material support to poor women with fistula such support can be inform of monthly pay, some money to help start business. The children of women with fistula can also be supported by NGOs by providing school fees for and scholastic materials. The counselling services should be given by the health workers. Women with fistula keep it as a secret fearing shame, abuses, being scorned by people in the communities where they live. Counselling would help build the self esteem of the victims and even empower them with knowledge to seek appropriate support and health services.

Furthermore it was noted that for integration to be realised for women with fistula- the fistula victims or survivors need to form an association that can bring together women with VVF/RVF, their spouses and families. The association can help them share experiences, challenges, and how to deal with the problem. The following quotation from the respondent who got better provides an interpretation for need of the association

“I would keep crying all the time, whenever I could see the sowed thighs, abdominal skin burnt by urine soared buttocks because of the urine-so we need an NGO/association to help us deal with these challenges.

(Woman who successfully got fistula repair after operations Kyenjojo district.)

The health workers wee of the view that some women who has separated from their partners or husbands would need to be re-united with their husbands after all parties got counselling services. This would improve on the support and care for these women. Outreach services were also recommended as one of the ways to continue rehabilitation and give health care services for fistula victims and survivors. Follow up and research on these women is very important for it provides continuous care and counselling, including provision of family planning services, advising on when it's not appropriate to have keep producing children or even counsel couples not to have violent sexual intercourse that can make fistula re occur.

CHAPTER FIVE

DISCUSSION, SUMMARY, CONCLUSION AND RECOMMENDATIONS

5.1.0 Introduction

This section provides the discussion of findings, Summary, Conclusion and Recommendations.

5.2.0 Discussion of Results

The results show that the majority of fistula victims in the targeted population got fistula aged between 13-20 years 57(27.9). In addition to this166 (81.3%) first become pregnant between the age of 13-19 years. This finding is in agreement with findings by (Donny *et al* 2006) and Women Dignity Project Report 2006), who found out that in Uganda 25% adolescents have began child bearing and that adolescent pregnancy was highly associated with higher morbidity and mortality including fistula. Results further show that 116 (56.8%) of fistula victims interviewed got fistula on their first order of delivery.

Furthermore 135 (66.1%) women and girls with fistula were farmers which also means that majority were based in rural areas, had less economic power refer to figure III) on the levels of income for households of fistula victims 40% had an income of less than 30,000= Ug.shs per month. This is equivalent to about US$12 per month. His is far below the poverty line. This could be one of the reasons why they delay to reach health facilities in time and later alone face economic challenges to access appropriate care for fistula and have to wait until when sponsored fistula surgical repairs are scheduled by donors or government.

The study found out that majority of women with fistula 97(47.5%) were married. This concurs with other studies done in Uganda that showed that most women who had fistula stayed with their spouses. However notable was 61(29.9%) who separated/divorced when they got fistula. This is a substantial member which presents a third of the sample size for the study. This affirms the link between gender, power, reproduction and sexuality which put women in the submissive position relative to men and such submissiveness has implications for decision making in hetorosexual relationships that make men decide to divorce/separate from the women when they get fistula. The case studies presented shows this clearly and it's in agreement with the theoretical frame work presentation on which this study is premised; reference to (De Gaston, *et al* 1996). Polygamy on the other hand featured prominent at 32% for the women who suffered fistula. This according to qualitative findings was because men couldn't tolerate the stenching smell, constant wetness or faecal incontinence of their wives. Polygamy in households where majority were not earning above 30,000= per month further incapacitates care, support and appropriate health seeking practices for the women with fistula and risks her to abandonment and a miserable life with poverty.

The psychosocial challenges were over whelming and isolation, crying most of the time, worthless shame etc. Results further show that 27% of respondents had ever had suicidal thoughts. Persons who experience such problems for a long time are more likely to be unproductive, live as social out casts and fail to contribute to the development of themselves as individuals, their families, community and nation at large.

5.3.0 Summary of Findings

This study reveals that obstetric fistula cases are still coming up even when the government of Uganda has made interventions in provision of health services to majority of people accessing services within a distance of five kilometres.

The study reveals several psychosocial challenges among which include isolation, shame, tendencies of suicidal thoughts, breakdown of marital relationships and despair among women with fistula. The study established several coping ways including use of pads, pieces of cloths, keeping proper hygiene, engaging in activities outside the public domain as some of the coping ways used by women with fistula. In addition most women with fistula were peasant farmers whose households were poor.

5.4.0 Conclusion

The majority of women with fistula in the study were aged between 13-20 years, most had never been to school or only attained primary level of education and were from households majority of which earned less than one hundred thousand shillings Ug.Shs. per month. One can therefore conclude that young age in this case adolescent age, and very low levels of education and poverty are highly associated with high risk to suffer from fistula during child birth. This can be so because married or child bearing adolescents are more likely to have limited economic access to reliable and quality health services for this case antenatal, delivery and post delivery health services. They are not skilled (trained) enough to hold high income jobs and therefore while depend on their spouses or parents and guardians for decisions made regarding where, when and how to seek pregnancy and delivery health services. In situations

where you depend on “others” for health seeking it may come late or never and you end up with fistula.

5.5.0 Recommendations

Leaking urine or faeces uncontrollably was one of the most devastating conditions women with fistula lived with. This resulted into several psychological and social challenges, people scorned their presence for some separation resulted sleeping and living a life of wetness-underneath the smelly clothes are women who were determined and capable of living normal lives. Fistula is preventable and can be cured. This study therefore recommends that the health facilities especially the district hospitals and regional referral hospitals be facilitated with appropriate personnel skilled and knowledgeable to provide free preventive and fistula repair services.

There is therefore need to provide training to the doctors and nurses to provide the necessary services. The families and communities where women and girls fistula live need to be sensitized and educated on about obstetric fistula. They need information and knowledge about fistula. This knowledge includes on how to prevent occurrence of fistula because new cases are coming up daily, they also need information of seeking timely and appropriate maternal health services, these include regular antenatal care, seeking delivery services and postnatal services from qualified health personnel and following health advice accordingly. Families/spouses and communities to know that fistula is preventable and curable and also need to be compassionate and understanding and be able to support girls and women with fistula under their care.

There is need for health workers, political leaders, religious leaders to be sensitized and educated about obstetric fistula and pass this information and knowledge to the communities-all communities need this information and knowledge so the ministry of Health should lead the sensitization and education campaign, by providing well packaged accurate data o prevention and care including treatment of women and girls with fistula. The print and electronic media can be utilized, also health education programmes at maternal and child health departments of Ministry of Health and health facilities need to always give this information schools and churches and other public areas can also be used to give out this information and knowledge to the public. A reasonable number of women had lived with fistula for years-the reasons for this were several including poverty, shame, ignorance on where to get the fistula reconstructive services, and few health facilities available to provide specialised health services for obstetric fistula.

For this problem above mentioned the researcher recommends political leaders and health workers, schools and religious institutions be given information or where fistula care and surgical services are provided. In addition people in community can be mobilised to fund raise money for the patients and enable them economically access health services wherever they are offered-we saw a few cases in this study where friends, families and some churches contributed funds to enable fistula victims to seek health services.

Obstetric fistula according to findings was most common in girls and women of young age between 13-20 years and mostly primigravidas. This group is a young age group and a number of issues arise-this group is not fully skilled to be in gainful

employment (most were not educated or only completed primary level of education), their capacity to make decisions on when, where and how to seek appropriate health care services has limitations and may be dictated by their male partners/husband, guardians of male care takers.

This study recommends for delay on age when these girls/women should start having children they need to be of mature age when the intergrity of pelvic bones is strong enough to allow the baby delivered well.This can be realised through the following interventions; keeping in school and continue to secondary school level, families not marrying of girls when still young. All these require a concerted effort of health workers, educationists, political and religious leaders to work with communities and families in supporting girl education, and discouraging early pregnancies and marriages. Community dialogue meetings need to be encouraged to deal with the cause of fistula among young women and girls.

Findings show that majority of women/girls with fistula had sought antenatal care for more than four times, and delivered at health facilities-though most reached after prolonged labour. This means that there is a lost opportunity to prevent fistula-at antenatal care level. There is therefore strong need for health facilities to put up mechanisms of follow up on women who seek antenatal care- the follow up can be by health workers physically visiting the homes of these women, or keep reminding them on phone on the need to adhere to advice and delivery plan of these women. A close schedule of follow up, notification and appropriate referral is crucial if we are to reduce or eliminate occurrence of new fistula cases country wide.

For the fistula victims, they need hope, need care and support so it's important that counselling services need to be provided at health facility level for a start. In addition, civil society organisation dealing with child and maternal health should target fistula victims by providing counselling, education on home based economic skills and also forming and supporting community, country or district association of women and girls with fistula. This can help promote the emancipation of this group and reduce isolation, shame and several psycho-social challenges faced.

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APPENDICES

Appendix 1:. (Questionnaire to be answered by Fistula patients)

Experiences, psychosocial challenges and social reintegration of women with obstetric fistula in Uganda.

Mr/Mrs ……

I am called Aryeija Warren, a student at Moi University pursuing a Master of Philosophy in Sociology degree. I am collecting information on experiences, psychosocial challenges and reintegration of Women with Obstetric Fistula. I very much appreciate your participation in this research study. This information will help us to understand the experiences of women with fistula better. The interview will take around 60 minutes. Your participation is purely voluntary and the information you provide will be kept strictly confidential and will not be shown to any other person.

May I begin the interview now?

1. Respondent agrees to be interviewed……..
2. Respondent does not agree to be interviewed …….

Interview started at …….. AM/PM.

Interview ended at ……AM/PM

District :

…….

County/Division …….…….

Parish/LCII Zone…….…….

Name of Health Facility ……..

Ownership of the health facility

1. Government ……..
2. Mission/NGO …..……..
3. Private …….

SECTION A GENERAL CHARACTERISTICS OF RESPONDENT

District :

…….

Sub-county/Division…….……

Parish/LCII Zone…….…….

Name of Health Facility ……..

Ownership of the health facility where interview/ patient is found/ interviewed from

1. Government ……..
2. Mission/NGO …..……..
3. Private c …….

Introduction:

Mr/Mrs ……

I am called Aryeija Warren, a student at Moi University pursuing a Master of Philosophy in Sociology degree. I am collecting information on experiences, psychosocial challenges and reintegration of Women with Obstetric Fistula. I very much appreciate your participation in this research study. This information will help us to understand the experiences of women with fistula better. The interview will take around 60 minutes. Your participation is purely voluntary and the information you provide will be kept strictly confidential and will not be shown to any other person.

May I begin the interview now?

1. Respondent agrees to be interviewed (TICK ACCORDINGLY)…….
2. Respondent does not agree to be interviewed …….

Interview started at …….. AM/PM

Interview ended at ……AM/PM

Section A: General characteristics of the respondent

1- Serial number of the respondent……

2- District of where she resides…….

3- Sub-county……..

4- Parish……..

5- Village……

6- Telephone…….

7- Date of interview……...

8- Hospital where interview was done……..

9- In what month and year were you born?

Month ……..

Don't know month …….. 98

Year …….

Don't know year …….98

10- How old were you at your last birth day?

Write age in complete years ……..

11- Have you ever attended school?

Yes…… 1

No …… 2

12- What is the highest level of school you attended?

Primary …… 1

O'Level …… 2

A'Level …… 3

University …… 4

Other tertiary …… 5

13- Marital status of respondent

Single …… 1

Cohabiting ……..... 2

Married …… 3

Divorced/Separated……4

Widowed …… 5

14- If married what type of relationship are you in?

Monogamous…… 1

Polygamous …… 2

15- How old is your partner/ husband ?

…… Years

Don't know…… 98

16- What is your religion?

Catholic…… 1

Protestant…… 2

Moslem …… 3

Pentecostal…… 4

Seventh Day Adventist…… 5

Others (specify)…… 6

17- Main occupation of respondent

Peasant Farmer …… 1

Salaried …… 2

Business/Commercial..…… 3

Casual worker …… 4

Other (Specify) …… 5

18- What is your income per month?

Less than 10,000/= …… 1

11,000/= - 30,000/= …… 2

31,000/= - 50,000/= …… 3

51,000/= - 100,000/= …… 4

110,000/= - 500,000/= …… 5

>500,000/= …….. 6

19- What is the distance from your home/ permanent residence to this hospital in Kilometres (Kms)? …….

20- If married or living with partner what is the highest level of education attained by your partner/ husband?

None …….. 1

Primary …… 2

O'Level …… 3

A'Level …… 4

University …… 5

Tertiary (specify) …… 6

SECTION B- Pregnancy and Delivery Related Health seeking Behaviour

21- How old were you when you first became pregnant? …….. years

22- How many pregnancies have you had in your life?……

23- What number of deliveries that resulted into live babies ……

24- Number of children do you have who are alive? ……

25- What was/is order of delivery that caused fistula ……

26- How many pregnancies have you had since you got fistula? ……

27- Number of unsuccessful deliveries (still births, miscarriages) after you got fistula……..

28- When did you get fistula (date/months)? ……

29- For how long have you lived with Fistula (years/months)? ……

30- What type of fistula are you currently suffering from.....

31- Did you see anyone for antenatal care for the pregnancy that caused fistula? If yes, whom did you see? (***The pregnancy referred to in this question is that one you had that caused fistula***)

Table 1. Type of Health workers consulted during pregnancy that caused fistula.

Categories of health staffs	**Yes**	**No**	**Don't know**
Doctor ……			
Nurse/Midwife ……			
Medical Assistant/Clinical Officer …			
Nursing Aide……			
Traditional birth attendant ……			
Other (specify) ……			

32- Where did you receive antenatal care during the pregnancy that caused fistula?

Did not go for ANC ……..…… 1

TBAs home …… 2

Gov't hospital …… 3

Private hospital/clinic …… 4

Mission/NGO facility …… 5

33- How old was the pregnancy when you first went for antenatal care for the pregnancy that caused fistula?

Months ……

Don't know ……..

34- How many times did you receive antenatal care during the pregnancy that caused fistula?

Number of times she went for ANC ……

Don’t know ……..

35- As part of your antenatal care during the pregnancy that caused fistula, were any of the following done at least once?

Table II. Conditions examined during ANC for pregnancy that caused Fistula.

Variables	**Yes=1**	**No=2**
Were you weighed? ……	1	2
Was your blood pressure measured? ……	1	2
Was your urine checked? ……...……	1	2
Was your blood tested for HIV? ……	1	2
Your HIV status	HIV Negative	HIV positive

36- Overall what would you say about the quality of ANC services that you received?

Very poor ……

Fair ……

Satisfactory ……

Very satisfactory …….

37- Where did you deliver the child that caused fistula?

Table III. Facilities/Areas delivered for pregnancy that caused Fistula.

	Yes=1	**No=2**
My home ……		
TBAs home ……		
Neighbours/Relatives		
Government hospital/health centre		
Private hospital/mission/NGO		
Private clinic		
Others specify…….		

38- Who assisted with the delivery that caused fistula?

Table IV. Category of personnel that assisted on delivery that caused Fistula.

Category of Health/workers	**Yes=1**	**No=2**
Doctor ……		
Nurse/Midwife ……		
Medical Assistant/Clinical Officer …		
Nursing Aide……		
Traditional Birth attendant ……		

39- Overall what would you say about the quality of delivery services that you received?

Very poor …… 1

Poor …… 2

Fair …… 3

Satisfactory …… 4

Very satisfactory ……. 5

40- What type of delivery did you have?

Normal …… 1

Assisted delivery …… 2

Caesarean …… 3

41- Are you currently pregnant ? Yes 1 No 2 Don't know 3

42- At the time you become pregnant did you want to become pregnant? (For those who are currently pregnant)

Yes, …… 1

No …… 2

Not sure …… 3

Don't know……. 4

43- Did you and your partner/ husband discuss when to get pregnant or when not to get pregnant?

Yes …… 1

No ….…… 2

Not sure……. 3

44- In general, who do you think is the main decision maker in your relationship/life?

Partner …… 1
Both equally …… 2
Self …… 3
Parent/guardian …… 4
Other (specify) …… 5

45- Have you ever heard of ways or methods that women or men can use to avoid pregnancy?

Yes …… 1

No ….…… 2

46- Are you currently using any method of family planning?

Yes …… 1

No ….…… 2

Section C: Health seeking and satisfaction with the services received for fistula healthcare.

47- What Health services have you received at this health facility for the fistula problem? ……..

48- How would you rate the quality of service you have received today (***during your stay for in-patients and or for OPD cases***) at this health facility?

Very poor …… 1
Poor …… 2
Fair …… 3
Satisfactory …… 4
Very satisfactory ……. 5

49- Did you get the kind of service you wanted?

No, definitely not …… 1
Can't say Yes or No …… 2
Yes, generally …… 3

50- If a friend was in the same need as you were would you recommend the same service and place for her?

No, definitely not …… 1

Somehow, can't say Yes or No …….. 2

Yes, generally …… 3

Yes, definitely ……. 4

51- How satisfied are you with the help you received?

Very satisfied …… 1

Dissatisfied …… 2

Indifferent/can't say Yes or No …… 3

Satisfied …… 4

52- Has the service you have received helped you to deal more effectively with your fistula health problems?

No, they seem to make things worse …… 1

No, they didn't help …… 2

Somehow, can't say Yes or No …… 3

Yes, they help …… 4

Yes, they helped a great deal ……5

53- In an overall, general sense, how satisfied are you with the service you have received?

Very satisfied …… 1

Dissatisfied …… 2

Indifferent/can't say Yes or No …… 3

Satisfied …… 4

54- If you were to seek help again for fistula, would you come back to this facility?

No, definitely not …… 1

Somehow, can't say Yes or No …….. 2

Yes, generally …… 3

Yes, definitely ……. 4

Section D: Psychosocial Problems you have experienced since you got fistula.

55- Would you want this fistula problem that you have to remain secret ?

Yes …… 1

No …… 2

56- Have you disclosed your fistula status to anybody?

Yes …… 1

No …… 2

57- Please allow me to go back to ask you about disclosure, who are those you have disclosed to your current fistula sickness ?

Table V. Categories of people you have Disclosed to Fistula Condition.

Category of people.	**Yes=1**	**No=2**	**N/A**
Spouse/Partner ……			
Father/Mother ……			
Brother/Sister ……			
Friends ……			
Religious leaders ……..			
Health workers			

58- Has any of the following happened to you as a result of disclosure of your fistula status?

Table V1. Events you have experienced after Disclosure of Fistula Condition.

	Yes=1	**No=2**	**N/A**
Break up of marriage ……			
Physical abuse by partner/ husband ……			
Neglected by maiden family……			
Disowned by marital family……..			
Discrimination by health workers ……			
Discrimination by employers ……..			
Discrimination by peers …….			
Increased emotional support by employers ….			
Increased emotional support from family/relatives			
Increased emotional support by peers ……			

59- Ever since you got fistula, have you experienced the following because of that condition?

Table VII. Some Psychological events/ situations experienced since I got fistula.

	No	**Yes**
(a)Worthless		
(b) Sadness		
(c) Guilty Feelings		
(d) Self Dislike		
(e) Shame		
(f) Sleep loss		
(g) Pessimism with Life		
(h) Reduced Self Esteem		
(i) Improved self esteem		

60- The condition of VVF/ RVF has made you suffer the following challenges.

Table VIII. Conditions experienced due to fistula.

	No	**Yes**
(a) Crying most of the time		
(b) Concentration difficulties		
(c) Punishment feelings		
(d) Isolation		
(e) Loss of interest in sexual intercourse		
(f) Suicidal thoughts or wishes		
(g) Increased sympathy from neighbours		
(h)Negatively affected moral support from neighbours		
(i)Affected negatively my social position in community		

61- In case people in your neighbourhood/community don't know your status, would you be willing to disclose your fistula status to them?

Yes …… 1

No …… 2

a) If No, Why? ……

b) If Yes, Why? …….

62- Now that you have fistula, is your family/partner will to care for you?

Yes …… 1

No …… 2

63- Now that you have fistula, how has it economically impacted on your life?

…….

…….

64- Now that you have fistula, what are the main four physical (medical) impacts has this condition caused you?

1……

2……..

3……

65- Now that you have fistula, what are the main four social impacts it has caused you?

1……

2……..

3……

66- How have you dealt with each of the problems faced in 407 – 409 above?

1……..

2……..

3……..

4…….

67- How accessible are fistula health services (Probe for geographic, social and economic access)

…….

…….

68- In your opinion would you say that fistula is preventable? Explain

…….

…….

69- In your opinion, would say that fistula is curable? Explain

…….

…….

70- How are women who have failed to get healed from fistula assisted to get better and get reintegrated into community?

…….

…….

(a) Are there programs that help women with fistula re-enter society after receiving services?

…….

…….

(b) What are they doing? Probe for information, education about prevention, management, and other activities in the community.

…….

…….

(c) Mention barriers to provision of services at the facility

…….

…….

(d) What do you think could be done to improve the quality of fistula patients?

…….

…….

71- How many times has your fistula been repaired (operated) and what has been the outcome of each operation?

Appendix II: Key Informant Guide *(for Health Workers/Policy makers)*

Experiences, psychosocial challenges and social reintegration of women with obstetric fistula in Uganda.

District :

…….

County ……..……...

Village ……..…….…….

Place of Interview …….

Language used in discussion ……..

Position of respondent ……..

Age …….

Qualifications ……..

Good morning/afternoon/Evening Sir/Madam,

You are welcome to this discussion. My name is Aryeija Warren, a student pursuing a Master of Philosophy in Sociology Degree at Moi University. I am doing a research as part of my academic requirement for the degree.

I would like to discuss with you the issues that concern you and the community. I would like to explore the challenges and needs regarding Women with Obstetric Fistula. The purpose of this study is provide information on the experiences, psychosocial challenges and factors that enhance reintegration provided will be useful in designing relevant interventions of care, control and prevention of obstetric fistula.

Feel free to discuss with me some issues pertaining fistula, and seek clarification where necessary. Your participation in this study is purely voluntary and there are no economic benefits that you will get as a result of being interviewed. All the information is strictly confidential and nothing you will say will make me unhappy and you don't have to reveal any personal information if you don't want to, but if you are willing to share your experiences, it is will be very helpful to us in understanding what you go through and the needs of women with fistula/needs of your community.

I request that you be audible so that all your views are understood and written down. I also have a tape recorder that will help me capture the discussion to ensure that I do not miss anything. May I use it? (Interviewer asks for consent)

Thank you very much

1. What are the key characteristics of the girls and women with fistula? (Probe for age, sex, education level, marital status)

2. What causes fistula?

   a) What health services are provided to obstetric fistula patients at community level and facility level?

   b) To what extent do you feel that this facility deals with fistula problems? Probe for capacity gaps, (personnel, drugs, equipment, etc)

3. How accessible are these services? Probe for geographical, social and economic access

4. What are the most common problems faced by obstetric fistula patients in this community? Probe for stigma, discrimination, and issues arising from treatment/non treatment

5. What coping mechanisms do these clients have?

6. What kind of post operative care is offered at
   a) Health units?
   b) Community?

7. How are clients helped to get better and re-integrated into the community?

8. Are there programs that assist women re-enter society after fistula (whether successfully repaired or not – what are they doing? Probe for community interventions in place.

9. How are clients helped to recover and get re-integrated into the community?

10. How many Obstetric Fistulas do you see in a month on average and what types of obstetric fistula do you get at this facility?

11. Describe the barriers you meet in provision of Obstetric Fistula services at this facility.

12. If a new centre for management of fistula was to be established, please describe the rationale, advantages and what it might require running it well.

13. What are the needs in terms of advocacy for policy makers, providers, professional associations and the general public?

14. What are the kinds of community and social needs that are required to help women with fistula live as human beings (enjoying all rights as normal human beings)?

15. What are the current sources of funding specific to Obstetric Fistula to these health facilities? Probe for public sector support such as ministry of health /government, private institutions, external assistance, client costs, etc. where services are paid for. Probe to see if the charges are reasonable for clients.

16. What do you think can be done to improve the quality of life of fistula patients?

Appendix III: Focus Group Discussion Guide *(for attendants of obstetric fistula patients)*.

Experiences, psychosocial challenges and social reintegration of women with obstetric fistula in Uganda.

1. What are the key characteristics of the girls and women with fistula? Probe for age, sex education level, marital status, etc.
2. Is obstetric fistula a problem in your community? What in your view causes fistula? Probe for all factors – socio-cultural, biological etc
3. How has obstetric fistula affected patients' lives, their families and the community at large?
4. What health services are provided to obstetric fistula patients? Probe for community facility level
5. To what extent do you feel that this facility deals with fistula problem?
6. What are the most common problems faced by obstetric fistula patients in your community? Probe for abandonment, divorce/separation, stigma, poverty, etc
7. How do women with fistula deal with these problems?
8. In your community are there programs that help women re-enter society after getting fistula (whether successfully repaired or not)?
9. How are women assisted to recover and get re-integrated into the community?
10. Mention barriers to access fistula services in your community and at this facility
11. What do you think could be done to improve the quality of life of women fistula?
12. What problems have you faced as carer, caring/supporting and living with fistula patients?
13. What can be done to solve the problems you have faced in caring/supporting and living with obstetric fistula clients?
14. Any other comment you would like to make?

Thank you.

Appendix I V: Indepth Interview Guide

1. I would like you to explain to me your experience of living with obstetric fistula (Probe: How obstetric fistula was got, health seeking, and experiences).
2. Do you think obstetric fistula cab be cured/repaired? Explain.
3. Have you ever heard about obstetric fistula before you got it? Explain theknowledge you knew about obstetric fistula before getting the problem.
4. What counselling services haveyou got on fistula (Probe: how to cope with obstetric fistula effects, health seeking advice).
5. Do you have any advice/comment to give on obstetric fistular.

Thank you.

Appendix V: Focus Group Guide to be answered by significant other of fistula patients

Appendix V: Letter of Approval from Uganda National Council for Science and Technology

Appendix VI: Letter of approval from Mulago National referral hospital Institutional Research Review Committee

Appendix VII: Letter of approval from Mengo hospital Institutional Research Review Committee

Appendix VIII: Letter of Research Clearance from Moi University School of Arts and Social Sciences