"I feel myself incomplete, and I am inferior to people"

Experiences of Sudanese Women Living with Obstetric Fistula: A qualitative study in Khartoum, Sudan

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Abstract

Background and relevance: OF is among the most devastating maternal morbidities which happens as a result of obstructed labor. Usually the child dies leaving the women suffering from the implication of both OF and child loss. It is estimated that there are 50,000 – 100,000 girls and women who develop OF each year and approximately two million are currently suffering with it. This condition is often associated with low status of women, illiteracy, early marriage, lack of access to emergency obstetric care and low rate of skilled birth attendance. Women living with fistula are suffering from physical, psychosocial and economic challenges due to incontinence. It is estimated that about 5000 new cases of OF occur in Sudan each year. Few studies were published about OF in general and the experiences of Sudanese women living with OF are left unnoticed and undocumented.

Aim: The aim of this study was to explore childbirth experiences and how OF has impacted the life of Sudanese women living with it. To have better understanding of how their lives were affected physically, psychosocially, and economically by OF and how these women cope with these challenges.

Methods: Using a qualitative study design,19 women living with OF were interviews and 14 women participated in two focus group discussion sessions. The study took place in the fistula ward located in Khartoum hospital and fistula re-integration center in Khartoum - Sudan. The three-delays model, stigma and coping theories guided the data collection, analysis and discussion of these findings.

Findings: The 1st delay was the most frequent barrier identified during women's delivery experiences. OF caused disruptions with their identity, psychological wellbeing, their relationships with others at all levels and worsened financial status. Women used both emotion-focused and problem-focused coping techniques to mitigate the consequences.

Conclusion: The study findings suggest the importance of implementation of OF prevention programs and the urgency of repair surgeries to alleviate the women's suffering. Community sensitization and re-integration of women back to their communities are another important strategies to consider.

This Thesis Is Dedicated To All Women In Sudan

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Table of Contents

List of Figures

List of Tables

List of Abbreviations

AMDD	Averting Maternal Deaths and Disability
AFC	Dr. Abbu Fistula Centre
C/S	Cesarean Section
EmOC	Emergency Obstetric Care
FIGO	the International Federation of Gynecology and Obstetrics
FGD	Focus Group Discussion
FGM/C	Female Genital Mutilation and cutting
FMoH	Federal Ministry of Health
GDI	Gender Development Index
GDP	Gross Domestic Product
MDGs	Millennium development goals
MoH	Ministry of Health
OF	Obstetric fistula
PHC	Primary Health Care
SDGs	Sustainable Development Goals
SHHS	Sudan Household Health Survey
TBA	Traditional Birth Attendant
UN	United Nations
UNFPA	United Nations Fund for Population Activities
WDP	Women's Dignity Project
WHO	World Health Organization

Glossary

Child marriage

Marriage of the child before the age of 18 years old, it is also known as early marriage or child brides (1).

Enacted stigma

The experience of discrimination because of the stigmatizing condition (2).

Felt stigma

Perception of potential negative attitudes from society and fear of discrimination because of a stigmatizing condition (3).

Fistula

An abnormal opening between birth canal and bladder and/or rectum lead to involuntary leakage of urine and/or feces (4).

Maternal morbidity

A direct obstetric morbidity as resulting from obstetric complications of the pregnancy states (pregnancy, labor and puerperium) from interventions, omissions, incorrect treatment, or from a chain of events resulting from any of the above(5).

Self-stigma

Acceptance and internalization of the devaluation and shame conveyed by society (2).

Skilled Birth Attendant (SBA)

someone trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate postnatal period, and in the identification, management and referral of complications in women and newborns (6).

Stigma

An attribute that is deeply discrediting (2, 7)

Stigmatization

The process of devaluation within a particular culture or setting (7).

Traditional Birth Attendant (TBA)

A person (usually a woman) who assists the women in delivery and who initially acquired her skills by herself or by working with other TBAs (8).

Introduction

Pregnancy and childbirth should be a joyful experience for women and families; however, still women die or suffer lifelong morbidities due to pregnancy related causes in the developing world (9). Improvement of pregnant women's health is one of the priorities of the global community; Millennium Development Goals (MDGs) has focused upon lowering maternal deaths. Although countries has made a remarkable progress in reducing maternal mortality, countries were able to reduce maternal deaths by 45% which fell short of the target stated for MDG4 (10). Furthermore, some regions showed lesser progress in reduction of maternal deaths such as sub-Saharan Africa (11). Sustainable Development Goals (SDGs) proposed a health agenda that was based on the unfinished work during MDGs era and implemented in holistic approach because health is a multi-dimensional issue with many sectors involved (10).

Maternal morbidity in turn, has gained less attention on the global agenda to enhance women health. For each maternal death many other women suffer lifelong morbidities (12). Obstetric Fistula (OF) is among the most devastating maternal morbidities. About 2% of women suffered from an obstructed labor eventually ended up leaking urine as a result of obstetric fistula which changed their lives forever(13). For women who lives with OF, the damage is not only a physical hole that leaks urine and/or feces where it affects every aspect of their lives. OF affects women physically, psychosocially, mentally and financially. Women's experiences must be taken into account while planning for prevention, treatment and integration interventions. The purpose for conducting this study was to explore and describe the delivery experiences of Sudanese women who ended up with OF, the consequences of OF and how they cope with it.

Study Rationale and Objectives

There are few published studies that examined OF in Sudan in general; even fewer describing the experiences of women living with fistula. There are studies from other countries that give some insights about the context and challenges. However, without country-specific evidence, the picture remains ambiguous. Knowledge gained from childbirth experiences of women who ended up having OF are important for program and policy development for prevention of the occurrence of OF. Moreover, documentation of women living with OF experiences is important to enlighten policy making and community interventions to minimize the social consequences of fistula and to help women re-integrate back into their communities. Therefore, this study has examined the childbirth and lived experiences of Sudanese women to provide better understanding about the circumstances surrounding the occurrence of OF and how OF affected their lives. Knowledge gained will inform health programs, community interventions as well as rehabilitation and re-integration programs.

Research Objectives

General Objective

The general objective of the study was to explore childbirth experiences and how OF has impacted the lives of Sudanese women living with it. To have a better understanding of how their lives were affected physically, psychosocially, and economically by OF and how these women cope with these challenges.

Specific Objectives

- Explore the circumstances surrounding the delivery that caused OF in the Sudanese context,

- Illustrate the women's perceptions on how their lives have been affected by OF and identify daily challenges they face
- Identify and understand the coping strategies used to mitigate OF's effects.

Literature Review

A fistula is an abnormal opening between the birth canal and bladder and/or rectum lead to involuntary leakage of urine and/or feces (2, 14-16). About 90% of the cases of fistulas happen to be from an obstetric origin in the developing world (17, 18). If the fistula is caused by childbirth or its management, it is called Obstetric fistula (2). Most of the OFs happen from obstructed labor where prolonged lack of blood supply resulted from fetal head compression of tissues against the pelvic wall (19, 20). The dead tissue resulted from the lack of blood supply falls away leaving pathological holes that connect the birth canal to the rectum and/or the bladder through which urine and/or feces leak uncontrollably (19, 20). Severe birth injuries including OF can be prevented through timely access to quality emergency reproductive health services (11). Other reasons of fistulas include the possible injury from radiotherapy, surgeries, and malignancy (17).

OF is nearly unheard off in the developed world (21). It is estimated that there are 50,000 to 100,000 new cases of obstetric fistula each year whereas 2-3 million are living with OF mainly in developing countries located in Africa and Asia (20-22). Some of those countries are; Sudan, Ethiopia, Ghana, and Nigeria in Sub-Saharan Africa and Bangladesh from Southern Asia (21). Those countries harbor most of the women suffering from OF in the developing world (21). Some argue that those numbers can be misleading because it is based on leaking women who seek health care services while OF coexist with poverty and other reasons that may prevent women from looking for treatment (17). OF is a grave condition that typically affects marginalized and poor women in rural areas (11). This condition causes chronic physical and psychosocial disability if women didn't have a quick access to corrective interventions (11).

Consequences of obstetric fistula

The fetus born dead or die within weeks of delivery in 83% of obstetric fistula cases which leaves the woman suffering from consequences of urine leakage and the grief caused by the loss of her child with or without the ability to conceive again (23, 24). In addition to bearing children, there are other tasks these women must fulfill (12). They range from the satisfaction of her husband/partner's needs including sexual needs, cooking, raising children, working on family farms, and participation in community gatherings (12). Women suffering from fistula often lose their identity as women because they cannot perform what is expected of them by their husbands and society (23).

No matter the reason for incontinence, it is a multi-dimensional problem and it affects women's lives including their physical, psychological, social and economic wellbeing (2, 14, 15). Women living with fistula suffer from involuntary leakage of urine and/or feces which can result in having sores and ulcers from the irritation of the skin by urine or pads to the perineum and thighs (2). They also suffer from recurrent infections. Leakage of urine resulted from obstructed labor can be accompanied with other complications of obstructed labor such as total urethral loss, and drop foot (13, 21). In addition, they may suffer from vaginal narrowing and tears that cause painful intercourse and altered sexual life (16). These challenges may persist even after fistula repair (13, 25).

Women suffering from OF try their best to conceal their leakage, even from their partners and close family by frequent washing and changing of clothes, padding by pieces of clothes and even by plastic bags which can cause more harm for the women (19, 20, 23). Excessive padding causes irritation of the skin and eventually sores and infections (19, 20).They also try to drink less water to decrease amount of the urine

dribbling (20). Some of the women tried using traditional treatment to heal from OF which deemed unsuccessful and in some cases, moreover, it caused more harm (2, 26).

The smell of urine is unbearable for women and also a cause of embarrassment to women (19, 23). The smell becomes even stronger when they drink less to decrease leakage of urine (20). Living with urine smell is extremely stigmatizing for women (19, 20, 23, 27, 28). The smell of urine and/or feces results in isolation of women living with it either by the community or women choose to isolate themselves because they are afraid of being discriminated against by family and community members (20, 23). Some of them stop going to community gatherings such as weddings, funereal and religious places to avoid people devaluating and ostracizing them (19, 23). Living a challenging sexual life and disrupted marriages are also caused by obstetric fistula (20, 23). OF is also a cause of poverty and worsening of economic status by the loss of ability to work, being unemployable due to smell and costs of treatment and personal hygiene kits (19). Loss of dignity associated with being dependent on others financial support is also a burden women need to live with (23).

Sociocultural and economic factors related to the occurrence of Obstetric Fistula

The vulnerability of women to the occurrence of OF is often context related and multidimensional. Child marriages, early pregnancy, women status, gender roles, and poverty are found to be associated with OF (12, 29, 30). Around 40% of young girls in Africa are married before completing 18 years old (1). Girls are seen as a financial burden when it comes to poor families in Africa, in addition, they are a vulnerability to the families especially in unstable and war context (1). Therefore, marrying off girls at a very young age is seen as protection for the girl and relief for the family (1). Child marriage prevents girls from pursuing an education, getting ties with girls at their age and when the time comes, being able to choose their partners, in addition, it puts young

girls a huge risk for health problems related to pregnancy and childbirth at such young age (1).

In such communities that value women for their ability to produce offspring, young girls and women are expected to conceive and have babies as soon as possible after marriage to prove their ability for reproduction (1, 31). A woman's value is determined by the number of children she has especially male children (12). Girls who are less than 15 years old are at 5-7 times higher risk of dying during childbirth than those at their twenties (1). One of the reasons for such high mortality is obstructed labor which is one of the main reasons for developing OF (1). Globally, 4.6% of pregnancies end up in an obstructed labor (32). The risk for girls who are less than 15 years old to get OF is fairly over 80% because their bodies are not ready yet for delivery due to pelvic bone immaturity (1, 21). The small size of the pelvic cavity and the small diameter of the pelvic opening at that young age predispose to an increased incidence of disproportion between the size of the pelvic and the head of the fetus among adolescents (21). Due to the poor status of women in many of African contexts, they do not have the right to decide on their fertility issues or when to have children (30). Girls who grew up in a poor society tend to be stunted which indicates chronic malnutrition (17). Female children are not prioritized if there is a shortage of food and they are at the bottom of the list when it comes to being fed (17). A study showed that risk of OF increases when the woman's height is less than 150cm (33).

In some settings, cultural factors may intervene with accessibility and acceptability of health services (17). For instance, in some countries, women are not supposed to be seen by a male doctor which will decrease the uptake of reproductive health services (17). In addition, having a male guardian who decides when and where to go for getting an emergency health service (34). There is no doubt that a man would intentionally overlooks a danger sign and keeps his wife at home, however, his lack of knowledge about reproductive issues and well as his lack of involvement in those matters may

affect his judgment (34). Sometimes the delay in taking the decision to go to the hospital during childbirth happens because women wait until their husbands are back from work. Lack of money and the economic status of the household influence the decision to seek health care.

Health seeking behavior during childbirth is affected by the local interpretations of lengthy labor. Since the labor in some contexts perceived to be a natural process, any delays during childbirth are believed to be caused by a supernatural cause (14). TBAs thought that labor is a natural process that should start and end in a natural way without intervention therefore if women did not progress well during childbirth, it is her fault (14). For instance; prolonged labor was attributed to infidelity of the wife who needs to confess in order for the labor to be easy (14). Young girls were perceived by TBAs as exaggerating during delivery so they were ignored and that caused the delay to be transferred to hospital (14).

Women' preferences also affect the uptake of health services during childbirth. Some women in a study considered birth at home as safe because this is what the norm is in their families (35). In addition, women were afraid of bad treatment from nurses and midwives in hospitals during childbirth (35, 36). Lack of privacy during childbirth is also mentioned by women when they discussed their preference for home delivery (36).

Health System Factors related to the Occurrence of Obstetric Fistula

OF happens as a result of obstructed labor that caused by the disproportion between the head of the fetus and the pelvic of women and abnormal presentations during childbirth (21). When an obstructed labor happens, prompt and quality interventions must be availed to save the woman and the baby. OF results from the failure of the health system to provide reproductive health care services during childbirth that is accessible to all women at reproductive age namely skilled birth attendance and emergency obstetric care (EmOC) services such as cesarean section and other necessary

services (37). For instance; according to assessment in 20 countries showed that the C/S was performed in less than 2% of cases in rural areas where the lower limit recommended by WHO is 5% (38). In addition, lack of transportation and referral services is a barrier for women to reach the appropriate delivery care (17). Health system weaknesses such as hindered access to family planning, antenatal care follow up and institutional delivery, low quality of health services and skills of care providers are also highlighted as risk factors for OF (29, 33, 39). In addition, Lack of knowledge about contraception among women especially young girls (39).

Quality of emergency reproductive health care is an important measure that affects the well-being of women. An assessment conducted by WHO to assess the knowledge and the skills of skilled birth attendants in four countries showed that their skills were less than optimum which meant that if women delivered at these health facilities in question they would not necessarily receive the skilled care they needed during that critical phase (6). In addition, supplies and equipment play a major role in the availability and quality of services provided (40). Quality of care provided affects the decision to seek health care. A study conducted in Tanzania showed that perception of women about the quality of health services affected their decision to seek health care where they chose to go to a private clinic instead of a government facility because of the good reputation about services there (36). Another dimension that affects the accessibility of reproductive health service is geographical accessibility and equitable distribution of services between rural and urban areas (35). In addition, scarcity of human resources for health in rural areas negatively affecting the availability of health services in the rural areas (35).

International Response to Obstetric fistula

Despite the huge impact of leaking on women living with OF, the treatment of OF is not prioritized in some of the countries where OF is most prevalent (39). Even if the

treatment is available for OF, a lot of women had lived for years with OF before knowing that there was an existent treatment for their condition (21). Therefore, women continue to suffer from the social effects and the complications of leakage (39). That might be because OF affects the poorest and most marginalized women (39). In addition, women who are prone to have obstructed labor and OF tend to be young in age and illiterate which lessen their chances to seek treatment even more (39). Husbands' blessings and support are crucial for women to seek treatment in such kinds of communities due to the cultural reasons and also because they cannot afford the treatment expenses.

In 2003, United Nation Population Fund (UNFPA) and partners such as the Women's Dignity Project (WDP), the International Federation of Gynecology and Obstetrics (FIGO), Averting Maternal Deaths and Disability (AMDD), and WHO launched the global campaign to end fistula (38, 39). The campaign aimed to make OF as rare as in developed world (38). To accomplish that, the campaign worked for bringing more attention to OF, prevention, treatment, and re-integration of women affected by OF and advocacy for allocation of resources to rollback fistula (38). The campaign included 40 countries (Sudan included) across Africa, Asia, Middle East (38). Each campaign country was encouraged and supported to conduct a need-assessment and according to this assessment a national strategy is designed and implemented in accordance with the country strategic plan for safe motherhood (38). Experts at the campaign highlighted the importance of having correct figures for the incidence of OF especially if the available data was extracted from facilities records (38). UNFPA has supported around 70,000 repair surgeries from the start of the campaign to 2015 (41). The campaign played a role in advocacy, mobilization, and reinforcement of the commitment of the national governments and sensitization of the communities affected by OF (41). The International Day to End Obstetric Fistula is celebrated yearly in countries affected by OF since 2013 to advocate and raise awareness about the OF (41).

Management of Obstetric fistula' Cases

Repair of OF is not merely the closure of the hole alone, in addition, the woman must be able to control urination (39). Not only that, it also includes that women resume an active life and to be integrated back into their communities i.e. rehabilitation and reintegration services (39). Clinical classification of OF into simple and complex is important because it determines the level of expertise and the place of operation according to the complexity of the case since the first attempt carries more chances of success (39). Unfortunately women who have OF in the developing world rarely have a small injury, most likely they have a complicated OF (42). A complicated OF means that the lesion is more than six cm, multiple lesions, near to the neck of the bladder which affects continence and the degree of scarring (42). It can occur with different combinations of the aforementioned criteria. A simple OF can turn into complicated one as a result of a failed repair operation (42). Complicated OF needs an expert surgeon for thorough assessment and for the operation. Management of complicated OFs is generally difficult and it needs a specialist surgeon who is rarely available in low-income countries.

According to studies, operation by a skilled surgeon and careful post-operative care determines the success of the repair surgery with a success rate of 85-90% (23, 43). However, some of the women will still suffer from some leakage according to the degree of damage and scarring that happen after repair operation (23). Physiotherapy after the operation is important to restore continence such as pelvic floor training. Women must receive counseling for their future reproductive and sexual lives (43). Thus, they must be informed about contraception and ensure its accessibility, the importance of antenatal care and planned C/S delivery at the hospital if they got pregnant (43). A study conducted in Ethiopia showed that women status improved by treatment of OF (44). Furthermore, integration of women after the operation to ensure that they restore their social role and decrease the stigma that those women encounter.

That can be achieved by proper counseling, enrollment in literacy classes and vocational training. And for the last pillar, different health actors such as government, voluntary organizations, and UN agencies must work together to facilitate that. Special attention must be paid for integration interventions since some studies showed that suffering of women and lack of integration continued even after repair surgeries (2, 44-47).

Prevention of Obstetric Fistula

Women empowerment plays a major role in the prevention of OF as well as better access to family planning methods for pregnancy spacing or delaying first pregnancy (32). Promoting women's rights to decide on her own body and gender equality are key long-term interventions (48). Studies showed that birth outcomes are better in an educated and empowered woman both for her and the baby, therefore, investing in female education is one of the interventions to prevent maternal mortality and morbidity (48). Education increases the uptake of health services by women such as contraception, antenatal care and institutional delivery (48). Women' personal empowerment is higher when they are educated. Therefore, higher Gender Development Index (GDI) and female literacy rate are predictive of lower maternal morbidity and mortality in countries (48).

The community that women live in is also important when it comes to prevention of OF because it plays a major role in decision making in health seeking behavior and the uptake of maternal health services (34). The decision to go to the hospital is delayed if the community perception about the quality of services is bad even if they recognized the possibility of danger (34). In addition, health education and engagement of local communities and their leaders are important in the improvement of women health via mass campaigns, radio announcement, and health education sessions (34). Health education about the importance of family planning, antenatal care and skilled birth attendance for the community is needed to improve childbirth outcomes (34).

Engagement of communities is not only important for prevention of maternal death and morbidity, in addition, it decreases the stigma and the social effects for the existing OF cases (34, 49). Not only that, community leaders can help inform women about the availability of treatment and where to find it when they develop OF (34).

The tragedy of OF can be prevented through access to quality obstetric care especially emergency care and skilled birth attendance (32). Training of midwives especially on the management of labor and how to monitor its progress is beneficial since skilled birth attendance lower the probability of complications (50). Better maternal health and pregnancy outcomes are achieved when there are referral services and adequate access to good quality health services (51). For instance, obstructed labor cannot be identified without proper monitoring of the labor progress (48). In addition, acute management of cases of obstructed labor is crucial such as the importance of emptying full bladder via catheterization before any intervention to avoid injury to the bladder (48). There are risks when a Caesarean section is performed in complicated cases of obstructed labor such as peritoneal infection resulted from opening the uterus that contains infectious matter (48). Therefore, most practitioners choose to manage delivery vaginally by forceps or vacuum especially if the fetus is already dead (48). Availability of EMoC services that is accessible and affordable to women along with skilled health personnel and available commodities are needed to improve birth outcomes (51).

Sudan Profile

Birth registration is unacceptably low where only 59% of children are registered at birth (52). According to the latest Sudan Household Health Survey (SHHS) in 2010, only 46% of the Sudanese children go to primary schools, moreover, almost 30% drop out of school before finishing the primary school (52). Poverty appears to affects schooling of children especially girls in Sudan where the attendance of primary school is dropped to half when we consider the children of poorest families in comparison to the wealthiest

ones (52). The figures are even worse for the literacy rates of girls and women especially in the rural areas (52). Sudan has one of the least female literacy rates in the world (53). One third of women in Sudan never been to school and another third only completed primary school (52). In addition, there is a significant difference between urban and rural areas regarding this indicator (52). Women constitute 51% of Sudan's population and 66% of them live in rural areas (52). The tradition of female circumcision is quite common in Sudan where 88% of females in the northern part are circumcised (27). However, infibulation rate for the younger generations is declining due to the efforts of the Sudanese government and UN agencies to eradicate Female Genital Mutilation and Cutting (FGM/C) (54).

There is no minimum age for marriage of girls specified in the Sudanese Personal law for Muslims (16, 53). Girls can be married off by their families by the age of 10 years old as long as her guardian allows that (16, 53). According to SHHS in 2010, nearly 10% of girls got married before they reached 15 years old and 40% before they reach the consenting age i.e. 18 years old (52). The majority of child marriages happen in the rural areas in Sudan and it is associated with the educational level of the household they came from and the husband to be (53). Furthermore, child marriage is associated with the size of the family and their financial status. For instance; if the family has many children and with the poor financial status, they tend to marry their daughters early to lower their expenses (53). They marry an older man because men in Sudan need to work and gather money to be able to pay wedding expenses (53). Most of them rarely meet the man they are supposed to marry before marriage (53). Soon after, those young girls are responsible for a household and supposed to get pregnant as soon as possible (53). According to SHHS, early childbearing i.e. having a live birth before 18 years old is about 14% (52). Girls being illiterate and without the knowledge and access to contraception are vulnerable to pregnancies at such young age before their bodies are ready for childbearing (53).

There is an extremely low usage of contraceptives in Sudan, according to SHHS in 2010, only 9% of women in childbearing age are using contraceptives (52). A study conducted in Sudan has shown that refusal of the husband that his wife use contraception and religious reasons are the major reasons hindering contraceptives uptake and use by Sudanese women (55). Therefore, the study suggested involving religious leaders in advocating and educating women and their husbands for the importance of family planning (56). Despite the noticed decline in maternal deaths, the maternal mortality ratio is still high in Sudan (311 per 100,000 live births in 2015) (16). There is relatively high percentage of women who have been seen at least once during their pregnancy (52). A study has shown that maternal deaths happen due to hemorrhage, difficult labor and septicemia (57). Around 60% of women died at home although the family has recognized the problem but yet, they didn't seek health care (57). According to SHHS, 72% of women had skilled birth attendant with them during childbirth (52). However, this figure might be deceiving because the majority of those considered as skilled birth attendant are village midwives (57). Those village midwives don't have a fixed-term job and they are dependent on incentives given after birth completion (57).

Health System in Sudan

The Sudanese government allocates only 1.8% of the Gross Domestic Product (GDP) for health (16). The small local component allocated for health is clearly reflected in the poor health outcomes in Sudan. The health system in Sudan follows a decentralized management modality (58). Decentralization was part of the health sector reform where management and planning of health services was the responsibility of states and localities (58). To implement the concept of the Health for All, health sector was based on primary health care concept (58). The local state government is responsible for financing and planning of health services provided at all levels; primary, secondary and tertiary health care levels at the state (58). The federal level role is to set the overall polices, strategic planning and it also takes part in the monitoring of states teams (58).

Sudanese public health services witnessed a huge liberalization and privatization changes which burdened the Sudanese people with high cost of health care and drugs (59). Low coverage of health insurance and low quality of public health services led to more burden on people (60). More than 60% of public health expenditures come from "out of pocket" source (60).

Obstetric fistula in Sudan

The prevalence of OF in Sudan is yet unknown since there is no nationwide study till now to measure its prevalence. However, OF is estimated to be high in Sudan where there are 5000 new cases of OF occurs yearly (30, 61). A study conducted in Sudan showed that poverty, illiteracy of women in Sudan and early marriage are risk factors to have OF where approximately 60% of the study sample were married before the age of 18 and 75% of women were illiterate (30). Illiteracy makes women more vulnerable. The same study shows that nearly half of the women with OF who participated in the study did not go to the antenatal care and 42% delivered at home (30). About 60% of women delivered at a hospital by forceps delivery or by emergency C/S, women came late due to retention by the midwife or difficult transportation to the hospital or other reasons (30).

Sudan's Response to Obstetric fistula

Recognition of OF as a problem in Sudan started the early 1980s where a small ward to treat cases with OF was established in Khartoum Hospital (62). Then a fistula treatment center was built and officially started to work as a referral center in Khartoum the capital of Sudan to treat women with OF from all over the country and abroad (62). The center was the only center treating complicated OF cases (62). The center was named after its founder, an obstetrician Dr. Abbu Hussein Abbu to be Dr. Abbu Fistula Center (AFC) (59). AFC acted as a training center for junior doctors and professionals (59). This center was internationally recognized and it used to be the second biggest fistula center

in Africa after the one in Addis Ababa (59, 62). A number of women treated annually in AFC ranged from 400 to 600 (62). Though AFC was relatively independent, it was an extension of Khartoum Hospital which is located in a central area in Khartoum city. Later on, four fistula centers were established in the states, Kassala, Alfasher, Nyala and Zalengi centers (59, 62). Those centers operate seasonally when there are treatment campaigns organized by the MoH or UNFPA (62). Complicated cases were referred to AFC. Surgeries were offered free of charge in AFC, yet the patients needed to pay for medicines (62).

MoH and UNFPA in collaboration with AFC established a re-integration center for women with fistula. This center is used by women awaiting the repair surgeries as well as in post-operative periods. Vocational training and other integration services were offered in the re-integration center (62).

In 2015 the government decided suddenly to dismantle Khartoum Hospital and dislocated services to peripheral hospitals in Khartoum (59). The dismantling process included AFC premises, however, unlike the other departments, fistula treatment services were relocated to a smaller old ward within the un-dismantled part of the hospital (59). This process affected the capacity of the center and the quality of services (59). The unprofitability of fistula surgeries and that OF affects one of the most marginalized and poor society members are reasons that the treatment services are not prioritized nationally (59).

The national progress on the indictors for the national capacity to prevent, treat and re-integrate women with OF reported by UNFPA in 2015 suggests that there is lack of national political commitment towards OF (41). For instance; The report showed that there is no costed strategy for ending OF was incorporated in the national health strategy and there is no national taskforce for OF in place (41). Not only that, there was no national register for cases affected by OF(41).

Conceptual Frameworks

OF is one of the maternal morbidities that affects women in all aspects of life. To understand the circumstances that surround the delivery that caused the OF, we used the three-delays model. We also used stigma and coping theories to comprehend the lived experiences of women living with OF.

Three-delays model

This model was developed by Thaddeus and Maine when they noticed that complications and adverse outcomes of childbirth can be averted if detected and managed in a timely manner (51, 63). The model highlights that the time is a crucial factor after the arising of complications to receiving an adequate treatment for it. Thaddeus and Maine used the term "delay" to describe what happened to women who end up dead or with severe morbidity due to childbirth. Three delays were identified (51, 63, 64).

- Delay in taking the decision to seek health care. Health seeking behavior is influenced by sociocultural factors, educational level of mothers and household, gender roles and women autonomy, perceptions about the quality of health care services provided and geographical and financial accessibility of healthcare facilities (51, 63, 64).
- Delay in reaching a quality obstetric health facility. This is dependent on the geographical accessibility of health facilities. For instance; how far is the nearest health facility that provides emergency maternal care services and how much does it costs to go there (51, 63, 64).
- When women reach the health facility, the delay in receiving a prompt and adequate emergency maternal care services. This is influenced by the presence of skilled staff and availability of commodities and services needed to rescue women at such a critical time and condition (51, 63, 64).

Three-delays model was initially developed to study the conditions related to maternal death, however, after some time many studies used the same model to understand maternal morbidity and maternal near-miss as well since they share the same risk factors and discourse (63). As OF is one of the most devastating maternal morbidities, the three-delays model was used to connect the dots regarding the circumstances surrounding childbirth for women who ended up having OF in this study.

Social stigma theory:

The word stigma is originated from Greek culture that appearance of body signs which signifies odd or awful about the moral status of the person. It can be a cut or a physical sign that identify or show other community members that this individual as a slave or immoral i.e. blemished person to be avoided by the others. Goffman describes stigma as "an attribute that is deeply discrediting" (2). Each society defines what is normal and gives social identity for each member. Failure to adhere to the normative criteria of this social identity makes the person different from the 'others' which make him/her devaluated in their eyes especially when the discrediting attribute is massive. Negative labeling leads to the development of so-called 'spoiled identity'. Certain conditions are considered stigmatizing due to presence of the physical features or deviated behavior according to the standards of the specific community. (20, 65, 66) The process of devaluation i.e. stigmatization is dynamic and it can continuously change and be reshaped by coping strategies adopted by the labelled person. Social integrity can be restored, i.e. the process can reverse itself if the person does not have the discrediting condition. Conversely, stigmatization can become worse if symptoms persist or worsen (66, 67).

Leakage of urine and/or feces is stigmatizing or discrediting because the act of not controlling one's bodily functions is considered deviant (20). Persons with negative attributes, such as the women participating in the current study, rapidly know how

they are seen and labeled as the 'others' which make them develop strategies to mitigate the effects of devalued status and negative attitudes from the community, and even family members and friends (65, 66). Women living with fistula often suffer from the psychosocial effects of negative labeling or stigmatization more than the physical implication of the condition (20). Stigma can be either self, felt or enacted. Self-stigma is the internalized feelings of shame of the labelled woman, felt stigma is the fear of discrimination due to a stigmatizing condition where enacted stigma is explicit maltreatment or negative reactions towards the women, in this case, due to merely having the stigmatizing condition of OF (20, 66).

Transactional model of stress and coping:

Coping is the cognitive or behavioral tactics used by the person to tolerate or mitigate the effects of a stressor. The transactional model of stress and coping was developed by Lazarus and Folkman. The model conceptualizes how individuals cope with stressful situations. When a person faces a stressful situation, he/she measures the magnitude of the stressor if it is manageable, endurable, or irrelevant. People also evaluate their abilities to stand against a particular stressful condition. This model conceptualizes two types of coping approaches; problem-focused and emotions-focused coping strategies. According to the intensity of stressor and the perceived self-abilities to handle the situation; people can use methods to alter the source of stress, i.e. problem-focused coping, if the stressor is controllable or they can regulate the emotion elicited by stressor if it is relatively unchangeable or intolerable. The majority of stressors elicit two types of coping responses problem and emotion-focused coping strategies, However, one of them can predominate according to the intensity of stressor along with losses or harms that can be caused by it. (68, 69).

The results of this study were analyzed and discussed in light of the previously mentioned frameworks. Three-delays model was used to describe and discuss the birth

experiences of women and how the delays affected the birth outcome. Stigma and coping strategies can interlock in a paired manner to help us understand lived experiences of women living with obstetric fistula. A phenomenological approach was used to describe how women are experiencing life with leakage of urine and/or feces, i.e. describe their lived experiences with OF. Their experiences were juxtaposed with stigma theory to see if those women are labeled or devalued because of the smell of urine and/or feces they have. What women encountered were categorized according to the operational definitions extracted from the stigma theory. Coping strategies that are used by women to handle consequences of obstetric fistula were also explored in this study and categorized according to the two main modalities suggested by the coping theory i.e. emotion and problem-focused strategies.

Methodology

Study Design

Due to the nature of the objectives of the study, an exploratory qualitative study was used to look at participants' narrated experiences. Qualitative study design is optimum to try to understand how specific population relate to and interpret reality in their lives. It seeks better understanding of phenomena that are linked to their experiences (70). Research about the incidence and prevalence of obstetric fistula are not enough to describe the magnitude of the problem, thus we needed to understand the context in which those women live and act, as well as, the influence of this context upon their lives.

Study Site

Sudan is located in northern-east of Africa; Sudan used to be the largest country in Africa until 2011 when the southern states of Sudan are separated to be another country 'South Sudan'. Sudan has suffered decades of civil war and security instability

especially in the southern and western states which affected its resources. Sudan is divided into eighteen states (Figure 1). The total number of population 40,235 million and the main language in the country is Arabic. The dominant religion is Islam.
The study was based in the Dr. Abbo Fistula Centre (Figure 3) (AFC). It was established in early 1970s and was the biggest Centre for treating fistula in Sudan and second biggest center in Africa (figure 2) (59). It received cases from all around Sudan and the neighboring countries (59). AFC used to act as a training center for junior doctors it played a major role in the national campaign to prevent and treat fistula (59). AFC was included in the dismantling process therefore the building which was built by donors and Dr. Abbo was demolished (59). Instead of relocating the whole center to another building with the same quality in a peripheral hospital, it was substituted by a ward that is located in the same hospital i.e. Khartoum Hospital. The new ward is still called Dr. Abbo fistula center although it doesn't refer to the AFC specialized center that used to exist. Our study took place in the new fistula ward that substituted AFC and the fistula re-integration center (the fistula home). The study site was selected because it receive fistula cases from all states in Sudan (Figure 1). The fistula ward relies on two doctors and a retired surgeon, twelve nurses and one social worker. When the study took place, the ward constituted of two floors, upper floor where women were awaiting their operations. First floor contained two post-operative wards, operating theatre with a small room attached where examination of case take place. Four to six women are operated upon weekly in the fistula ward. The fistula re-integration center was established in 2009. The reintegration center is locally called 'Fistula home'. This center offers pre and post repair, physical and reintegration programs with vocational training and literacy classes. (See Figures 2-6.)

Figure 1 : Map of Sudan obtained from http://www.emapsworld.com/images/sudan-political-map.gif

Figure 2 : AFC before destruction in 2015 – Khartoum, Sudan - Picture obtained from https://waha-international.org/sudan-waha-to-partner-with-khartoum-teaching-hospital-to-increase-fistula-treatment/

Figure 3 The new location for the fistula ward *(The sign of AFC (written in Arabic) is fixed outside the new ward) - Picture taken by the researcher in October 2016*

Figure 4: Pictures from the ward in the upper floor where the women waited for operations (please note the small charcoal stove women used for cooking food)

Figure 5: Post-operative ward

Figure 6: Women with fistula waiting outside the examination room at the first floor

Study Participants and Sample Size:

The women who lived with OF were central to describe their experiences, therefore, a purposive sampling was used. Purposive sampling means that researcher selected specific groups from a population to join the study according to given criteria to ensure that participants will give insights which are related the most to the phenomenon being studied (71). Women who matched the inclusion criteria were sought.

The inclusion criteria were:

- Being clinically diagnosed with OF.
- Living with it for more than six months.
- Attending AFC but still not operated upon 'during preoperative phase' i.e. still leaking.
- Willing voluntarily to participate in this study with informed consent.

Those who weren't willing to participate in our study or was not capable to provide consent to join the study e.g. mental incapability etc. were excluded.
Nineteen women were interviewed by the researcher, and six of them consented to participate in an FGD session (two FGD sessions; four of them joined the first session and two participants joined the second one). Two FGD sessions were conducted. The first session included six women, four of them were interviewed women and two of them were new comers. The second FGD included eight women of which two of them were interviewed previously and six of them were new comers. Initial screening for new comers was done to insure that they match our selection criteria and the homogeneity of the group. In order to explore the different experiences of women, maximum variation sampling in study participants was ensured. Women with different age, literacy level, ethnic backgrounds, marital status and severity and duration of OF were selected. Data collection continued until saturation level was reached i.e. there were no new concepts coming out from data. Reaching the level of data saturation is important to enhance the trustworthiness of research and it is concerned with the depth of data obtained rather than the number of participants (72).

Sample Recruitment

With the authorization letter, the researcher approached the fistula ward and fistula home. The director of the center agreed to the facility participating in the study, and he assigned the social worker to introduce the researcher to eligible participants. With the help of the social worker, women who were identified as having OF were invited to participate in our study. The researcher spent some time in the fistula ward to familiarize herself with the setting and to gain the trust of the women.
Those who identified as eligible for the study were approached first by the social worker to seek their initial acceptance and then by the researcher who informed them individually about the objectives of the study and sought their informed consent. The researcher described in brief the objective, benefits and possible risks, respondents'

rights and confidentiality measures. After approaching individual eligible participants, the researcher read the oral script and asked for their consent to participate voluntarily in the study.

Two of the women interviewed were recruited from the fistula home while the rest were recruited from the fistula ward at the hospital. It was initially planned that all the interviewed women would be invited to FGDs, however, it was difficult to gather them at one time and place because the interviews took place during different times according to the availability of new admissions and discharges from the fistula ward. It was initially planned to use the snowballing technique to recruit women from the community in addition to those recruited from the fistula ward and the fistula home, however, it wasn't possible to use it because almost all study participants were not residents of Khartoum state and they didn't have networks in Khartoum.

Data Collection

This study was looking at how actions and meanings were shaped by the unique circumstances women face. Therefore, semi-structured interviews and FGDs were used because realities, to some extent, are best communicated in narratives and probing with open-ended questions. Giving the participants the opportunity to discuss their experiences in their own words was paramount to give more comprehensive accounts of their narratives, therefore, a flexible data collection tool was needed; therefore, semi-structured interviews and FGDs were used to collect data from the participants. Women were consulted on where they preferred to have their interviews. All of them preferred to have their interviews in situ so the researcher used the office of the social worker. The time of interviews was delayed until the social worker left her office, after 1 pm to have the office empty to ensure privacy. The researcher used semi-structured interviews because this style gives the respondent the chance to talk and explain their views and experiences related to fistula in their own words rather than merely answering with yes or no. The interview guide (Appendix C) contained areas to be

covered central to the research objectives which was meant to guide the discussion rather than limiting it. The areas discussed during interviews included: childbirth experiences, consequences of OF, and coping mechanisms. The interviewer used open-ended questions. Probing questions were used to encourage respondents to talk more about the topic or to gain clearer responses. The researcher made notes about the non-verbal signs made by the interviewee. The interviews were recorded if the woman agreed to and also some written notes were taken to remind researcher about thoughts encountered or to highlight some information during the interviews. If the woman did not consent to the audio recording thorough notes were written instead.

Interviews took place first; then women who agreed participated in an FGD of six to eight women to discuss their experiences of living with incontinence (Figure 7). The researcher utilized group interaction and exchange of ideas to generate richer information about the topic discussed. The discussion was controlled by the group participants and the researcher acted as a moderator and note taker. An FGD guide (Appendix D) was used to moderate the discussion. Consent for audio recording was sought and obtained.

The researcher ensured that the atmosphere/place of the interviews and FGD was comfortable for participants as well as the researcher. Privacy of the place was also ensured. Interviews and FGDs were conducted in Arabic since it is the mother tongue for the vast majority of the Sudanese people and the official language of the country as well as the researcher.

Figure 7:One of the FGD sessions

Data Management and Analysis

Audio recordings were transcribed in Arabic along with notes taken by the researcher. The researcher then translated transcripts into English. The analysis process started during the data collection phase while the researcher was still in the field. Through an iterative process of reading and re-reading transcripts, recurring, emergent themes were identified. For example, the transcripts were read carefully to form a general impression of what participants said about their experiences with childbirth and living with obstetric fistula. The transcripts were then re-read to understand the context in which participants lived and coped with obstetric fistula and derived codes. The aim was to identify frequent themes in the accounts given. These emergent themes were compared across transcripts and categorized. Some categories were drawn directly from transcript

text while others were based on topics asked in the interview that were related to childbirth experiences, consequences of OF, the dimensions of stigmatization, coping and topics extracted from the existing maternal health literature. In addition, theoretical frameworks which included the 3-delays model, stigma theory and coping mechanisms helped inform the analysis. All helped in determining the initial coding scheme and relationships between the codes. For each category, the data was re-examined to determine whether subcategories were needed. The themes were interpreted further and compared to the objectives of the study to generate the final conclusion.

Ethical Considerations

The research obtained ethical approval (Appendix E) from the Regional Ethical Committee system in Norway (Reference Number: 2016/952/REK sør-øst A) and Sudanese MoH Research Ethics Committee (Appendix G) before starting data collection. An authorization letter (Appendix F) was issued from the Reproductive health department at the FMoH. The study was carried out in compliance with the Helsinki Declaration. The researcher discussed with the potential participants in Arabic (Appendix B) the objectives, benefits and possible risks of the study; respondents' rights, confidentiality measures and how the results would be used and reported. Since some of the study participants were illiterate or had a fair amount of education, more time was used to communicate the aforementioned information in a very simple language and the researcher made sure that they understood what they were told. The researcher also stressed that the participation in the study was strictly voluntary. Each participant was encouraged to ask questions so that they understood the nature of the study. All of these steps took place before obtaining their informed consent. The participant was instructed to explicitly state her acceptance to participate in the study then the participant signed or fingerprinted the consent in case she could not write. Our study included two participants who were under 18 years old at the time of data collection. Since OF is linked to early marriage and early childbirth, the participation of

these participants deemed acceptable, culturally appropriate and ethical for our study. Special ethical consideration was ensured to those two young ladies where the researcher communicated everything related to study to both the potential participant and the guardian or elder person present with them. One of them was accompanied by her grandmother and the other one was accompanied by her mother. After initial explicit consent from the potential participants, the grandmother present with her fingerprinted the consent. The same process was followed in the other case where the mother signed the consent form.

The interviews and the FGDs took place in an empty place where no one unrelated to the process was present to safeguard the privacy of the participants. The researcher did not include personal identifiers in the draft or final report of the study to ensure confidentiality. The researcher made sure that respondents' rights were not affected. To comply with research ethics the researcher ensured confidentiality of information gathered from interviews and FGD. Pseudonyms were used in to protect privacy through anonymity. Only the researcher had access to the list linking pseudonyms to real participants names and data and all data were stored in a password-guarded portable computer with a secure back-up online on a Dropbox drive. The researcher didn't link responses/quotes to any identifying characteristics such as individual names. After submitting the final draft of thesis, all audiotapes will be destroyed. Written data will be deleted after a year.

Reflexivity

Growing up in the same country and speaking the same language, I am somehow familiar with the setting from where women came. That made me an insider to some extent. Women may have found it easier and more comfortable to share their deepest thoughts with an insider. But that at the same time, being an insider might have influenced the way I perceived information that women shared, in a way, to take some issues as normal or for granted.

I used to work in the field of public health as a project officer in Sudan for five years which made me familiar with disparities between rural and urban areas in terms of accessibility to health care services. In addition, I have the experience of working in reproductive health issues as an NGO staff in collaboration with MoH programs. Spending nearly my whole life in Sudan made me familiar with women status in Sudan. I grew up in a relatively conservative household in a semi-urban society but at the same time an educated one. Since I was young, I have had an independent and strong personality questioning everything around me including politics, religion and gender roles. Growing up as such is difficult in a country like Sudan. My personality might have also influenced how I perceived things. At the same time, it made me understand how women in some parts of Sudan suffer because they cannot communicate and express themselves.

Sudan is a country with a huge diversity of tribes, cultures and tribal languages. In addition, there are disparities between urban and rural areas. Growing up in a Semi-urban society, being highly educated and traveling abroad to study might make women think about me as an outsider. That is sometimes true when it involves inside tribal customs and cultures because I wasn't aware of it. I was aware of such possibility during my contact with women and I tried to mitigate it by spending quality time before I started to conduct my interviews with women in order for them to become familiar with me and my presence there. We (women and I) spent time just sitting and chatting about topics that are not related to OF and doing regular activities, for instance; I accompanied some of them to laboratory and blood bank during their pre-operation preparation. That might be a simple thing to do but it helped me a lot to make bonds with them and to gain their trust. the effect of that was clear when I compared my first approach to women and the quality of my first interview to what I had after that. My first participant didn't consent to using the audio recording and after 15 minutes she

said that she is sleepy. After spending time with them, I had a full and a very informative interview with the same participant and she agreed to use audio recording. I also didn't mention to them that am a doctor when I have introduced myself because the relationship between doctor and patient is authoritative and it potentially would have affected the quality of the data collected. However, the social worker used to call me doctor Salma and sometimes that happens in front of women. That might have influenced their willingness to share and the type of information they shared. I encouraged women to call me by first name same like what I did with them. I was also cautious about my dress code to be very simple, wearing a scarf and not wearing trousers when I went to the hospital. That was because I didn't want women to feel that am different than them in any way and not be seen as "the other".

Findings

The findings are categorized into three main areas: 1) Demographic characteristics of the women 2) Circumstances surrounding and contributing to the development of the OF, including two cases 3) The consequences of OF in the form of disruptions to women's everyday lives; and 4) Coping mechanisms used by these women to mitigate the aforementioned disruptions.

Section One: Demographic characteristics of the women

Interviews

Nineteen women were interviewed in this study. Their ages ranged from 16 years old to 58 years old with an average age of 30.9 years old. Ten of the participants came from villages located in the western region of Sudan, where four participants came from the middle region, one participant came from northern region of Sudan, two participants from the southern region of Sudan and none from the eastern region. One participant is south Sudanese. All of them were Muslims. Their current marital status were; eight were either separated, abandoned or divorced where nine were currently married and two were widowed. Eleven of them were illiterate (they cannot read or write), four had a primary education where other four had secondary education and above. Twelve of the participants were housewives, two were teachers, one was a midwife, one had a small home-based income generating activity, three were former seasonal farmers and one is a former cook. Three of the participant have had OF for less than a year where the rest have had it for a duration ranged from two to 18 years. This information is summarized in Table 1. All of the participants except one are leaking urine only. This single participant used to leak both urine and loose feces at the beginning but she had a surgery that stopped urine leakage and at the time of data collection she could not control loose feces and gas.

FGDs

Two FGDs were conducted where part of women interviewed also joined the FGDs and the rest were first comers. Six women composed the first FGD session. The average age was and ranged from 18 years old to 33 years old. Two were illiterate and one left school very early, one didn't complete primary school and two had secondary school and above. Four of them were housewives, one former farmer and one midwife. three of them were married at the time of data collection and the other three were divorced. They had OF for a duration ranging from one year and a half (1.5) to seven years. Eight women composed the second FGD session. The average age was and their ages ranged from 19 years to 50 years old. All of them were illiterate. Seven were housewives and one owned a small home-based business. Four of them were married at the time of data collection where three were divorced or abandoned by their husbands and one was widowed. They have had OF for a duration ranging from one year to 17 years.

Table 1: Demographic characteristics of study participants

Pseudonym	Age (yrs)	Residence[1]	Education	Occupation	Age she got married (yrs)	Current Marital status	Age she developed OF (yrs)	Have had OF for..	OF during her .. Childbirth	Living child	Have had operation before
Sakeena	24	village near Nyala, West Sudan	illiterate	Former Seasonal farmer	19	separated - divorced but no papers	20	4 years	first	None	twice
Aisha	16	Abujbaiha (four hours from Kadugly) West Sudan	left school at 5th grade	HW	14	married	15	5 months	first	None	none
Haleema	32	village near Kosti, South Sudan	illiterate	HW	24	divorced	28	4 years	first	None	none
Fatima	30	Alkamelin, Middle region Sudan	illiterate	HW	18	abandoned	23	7 years	second	one son	none

[1] refer to the Sudan' map in methodology section

Marwa	20	Abu Osher, near Alhasaheesa Middle region Sudan	illiterate	HW	18	divorced	19	10 months	first	none	none
Altaya	17	Almanagel, Middle region Sudan	9th grade	HW	15	married	16	8 months	first	none	none
Sara	20	AbuZabad, (two hours from Elobaid) West Sudan	illiterate	Former seasonal farmer	17	separated	19	1 year	first	none	None
Mona	18	Sudery, (three hours from Elobaid) West Sudan	illiterate	HW	15	married	17	1 year	first	None	once
Samia	58	Kaddam (two hours from Alfula) West Sudan	educated	teacher	20	widower	30	18 years	sixth labor	3 and adopted daughter	once

Sit Albanat	45	Eldoweim, South Sudan	illiterate	HW	15	married	30	15 years	first	none	twice
Maha	18	Alginaina, west Sudan	illiterate	Former seasonal farmer	15	Abandoned	16	1.5 years	first	none	twice
Zeinat	27	Ed Alfirsan, near Nyala West Sudan	university - first year	HW	16 – (first time divorced her due to OF)	Married	21	6 years	fourth	one girl - 6years	six times
Asma	47	originally from Alobaid, west Sudan. Living in Omdurman	primary school	used to work at food place, she stopped after OF	12 - first time (died) married another man 14 years ago	Married	40	7 years	11th - gave birth to a living boy	11 boys and girls (7 with the first husband and 4 with the second husband)	twice
Sitana	50	Originally from Zalengi, west Sudan. Living in Omdurman	illiterate	She makes yogurt at home and sell it.	15	widower-he died 8 years ago	35	15 years	5th	2 sons	once

Amira	27	Alabasia (three hours from Om Rawaba) South Kordofan West Sudan	illiterate	HW	13	divorced	15	12 years	second	none - first boy died when he is 2 years old	three
Khadeeja	33	Sora' Aljamal, (3 hrs from Alnohood) West Sudan	she went to midwifery school 1 year after her first husband died	midwife	15 years old (died) remarried 3 years after he died	married	28	5 years	fourth (first delivery with the current husband)	three: two daughters (16 and 14 years) and one son (12 years)	Once
Maysa	23	Originally from South Sudan, currently lives in Omdurman	7th grade	HW	14 years, she got divorce because of the OF - remarried	divorced	16	7 years	first	three: two sons and a daughter	Once

Ensaf	33	Aldindir (three hours from Sinnar) Southern region Sudan	illiterate	HW	15	abandoned for 4 years and got divorced 8 years after OF	16	17 years	first	none	11 times
Tahani	30	Atbara, North Sudan	university graduate	teacher	22	married	28	2 years	third	Has one living boy and two deceased babies during childbirth – living boy is the second.	once

Section Two: Circumstances Surrounding the Occurrence of Obstetric Fistula

This section is about the delivery experiences of women living with OF. It is divided into two parts. First, all of the study participants went through difficult childbirths. Two cases with the most extreme childbirth experience are described below. They have been selected as illustrations to give an impression of the varying conditions and circumstances women face while going through labor and deliver The second part provides a summary of all of the women's labor and delivery experiences, highlighting the factors that might have contributed to the onset of obstetric fistula based on the three-delays model.

Part 1: Selected Cases

Case one

Sara [pseudonym] is a 20 year old young lady originally from a small village near AbuZabad, West Kordufan state, West Sudan. At the time of interview, Sara was staying at the fistula rehabilitation center or what is called locally the "fistula home". Sara and I [the interviewer] sat together for about an hour where Sara left a wet spot on the mattress wrapped with black plastic-like material. She was wearing a black *toub* with small printed flowers on it [Sudanese traditional cloth that is wrapped around the body]. At first, Sara didn't want to talk with me because she was sad. However, after a while, she willingly decided to talk to me. I learnt after the interview that she just came back from a doctor's appointment where she was informed that her injury was very complicated and her operation was likely to fail.

Sara has never been to school neither did her husband. She got married at the age of 17 to a man that she didn't choose nor knew his age. She is still married, however, her husband has never contacted her since she came to Khartoum for treatment nine months ago. She used to work in farming with her husband before getting obstetric fistula. Sara became incontinent and lost her baby as a result of difficult labor that

happened in January 2016. It took her eight days from when she felt labor pain until she finally delivered her deceased baby at the hospital. These eight days were excruciating for her.

She narrated, "***The pain came in the evening, it wasn't so strong pain so I walked to my mother house on foot. My mother house is far, I walked on foot all the way to it, I walked a bit and I took a small rest. I started my journey in the morning and I reached there about 8 pm. I was alone, I left my bag so my husband would bring it with him in the evening when he come by the motorcycle***". When she arrived there her mother offered to make food for her since she was walking the whole day. Sara was so tired that she laid on the sandy floor and slept while waiting for her mother to cook the food. Her mother woke her up to eat. Sara barely ate and she told her mother that her tummy was hurting. Sara continued" ***My mother asked me if it is a labor pain, I told her I don't even know how labor pain is. She went to the village midwife, when they came back they found me on the same spot lying on the ground. "this girl is still [early labor], she is only one finger wide [meaning her birth canal]" said the midwife". She [the midwife] came again and she said every time not yet, not yet!***

Interviewer: Is she a registered midwife?

Sara: She claims that, he attended the midwifery course in Kadugli and she had a bag, she delivers [assist deliveries of] women.

Sara continued her story ***"She [the midwife] told me to hold the branch on the tree so the baby would come down, I did that but still the baby didn't come down. I spent two days like that. I didn't even know if the baby is alive or not, she told me nothing.***

My father is living in the same village with his youngest wife so people said to my mother "let us send her to her father" so they brought the donkey wagon and brought me to my father. "that might be because her grandmother was not happy with this marriage because she didn't want this man for her, maybe that is why the delivery is not going well " said my father -our Nubian people say that- so we went to my grandmother house. I spent three more days and the baby didn't come out." On the sixth

day, Sara's father called a doctor to be present with the midwife who was there the whole time. The doctor examined Sara and told the family that the labor was not there yet and he brought her with him to his house. Sara narrated, ***"again they brought donkey carriage and they sent me to the doctor's house, we spent the night there. I couldn't sleep, the pain was so bad so I was crying and they [her legs] became swollen. I couldn't feel the pain in my tummy anymore but the legs pain to the extent that I forgot about the labor pain, I was just crying. My legs became cold so that the wife of the doctor brought a fire near my feet. At that time the baby was already dead and poisoned my whole body, my body become black just like this toub [pointing at her black dress]".*** Finally on the eighth day, the doctor decided to send her to the hospital when he saw how bad her condition has become. Sara mentioned ***"The doctor called my mother and told her "she looks worn-out, you should come and send her any place" when he saw me vomiting blood. So they [her family] came and brought me to Abu Zabad hospital by car which is about two hours' ride. The midwife brought me up the table [delivery table], I don't even recall if she gave me anesthesia or not but I felt everything, I felt how was she cutting my body down there. When she cut me, the urine came out and the blood came out then the baby. Four days and I didn't pee or feel the urge to pee. I stayed four days at the hospital, they fixed a catheter since that time. They didn't tell me what is happening, they just wrote me a referral note and they told us to go to Khartoum"***

Soon after that, Sara was transferred by her family to a hospital in Khartoum where she stayed for two months. She was discharged with a paralyzed foot and leaking urine. She went to the fistula ward where she was examined by the doctor there and they told her that she has OF but she has to finish physiotherapy for her foot first before the operation.

Case two

Maysa [pseudonym] is a 23 year old young woman originally from Malakal, South Sudan. Maysa went to primary school until her 7th class and she stopped her schooling

because of marriage. Maysa got married when she was 14 years old and got pregnant the same year. She delivered when she was 15 years old back in 2009. She developed OF during her first labor but the baby survived the difficult labor she had, he is a boy. The injury which she endured during her childbirth made her both, urine and fecal incontinent. She had an operation there which helped her re-gain control over urination but not with defecation. She had a turbulent relationship with her husband after she got OF where she spent most of the time at her family's house. However, she went back to her husband place when her son was ten months old and she got pregnant right away. Maysa had another baby (a boy) soon after that with her first husband and got divorced few months after the delivery of her second son. Soon after her divorce, she came to Khartoum seeking treatment and settled there. In 2014, she remarried to a university student and had a daughter and she got divorced eight months after the delivery of her daughter. She currently lives in Omdurman sometimes with her family and sometimes alone.

Maysa narrated "***I didn't have labor pain but there was water, many things had happened and it [labor] was very difficult***.

Interviewer: please tell me what happened in detail.

Maysa: When I woke up in the morning I found out that my water broke, the water stopped when it was 12 pm after that I had labor pain on and off till 8 pm. I was ready for labor, they [her family] brought me to Malakal hospital when the labor pain started. I was in the labor room since 6 pm but I couldn't deliver the baby because they said that he was too big. There were two midwives on watch that day, they called the doctors who said that they won't intervene unless the consultant came. The consultant came to see me and said that I need an operation, he told them to prepare me for surgery. But he went out of the hospital because he had an operation outside at a private hospital and he didn't come back. I was so exhausted at that time because the baby' size was big so I couldn't even push. They [the midwives] started putting pressure on my abdomen so the baby would come out, they [the midwives] cut me three cuttings

down there two at the sides and one in the middle and maybe that what caused me the problem. The baby was exhausted when he was delivered and out of breath, we thought that he is dead but he woke up half an hour later. The midwife used suction for the baby and he was alive.

The consultant arrived two hours after I delivered about 10 pm. They discharged me after 24 hours.

The midwife who delivered me was intentionally bad with me, when I was there she asked me if am Maysa and I said yes. She said "you didn't recognize me? I took the boat with you and you refused to give me water?" I said I don't know. She responded, "now you will know! If I want, I won't even deliver you!" I told her that this is her job and she should do it anyway. Turned out that when I was small nine or ten years old I was travelling with my mother and she [the midwife] met us. And she intentionally didn't call the consultant when things went bad during the delivery. My family and the general manager of the hospital knew about what happened. He [hospital manager] told the midwife "if you have a personal problem with the patient do not bring it here". He [hospital manager] said that she needs to take responsibility of what has happened to me and that she should stay in jail until I am treated and that her salary should go to the treatment. My mother refused that and she said that nobody should be in jail but that they just need to pay for the treatment.

Part 2 Circumstances Related to the Three-Delays Model

Women suffered long and obstructed delivery. Number of days women spent in labor ranging from one to eight days. As noted in the table below (Table 2), most of them had a first-delay i.e. delay in taking the decision to seek health care. Women were kept at home by midwives or family for days until the baby was dead or women showed severe signs of complications. Almost half of the women had more than one delay, either two or the three delays combined. The least prevalent delay was the delay to reach health care services where the second common delay was receiving a quality emergency reproductive health care services. Almost all deliveries eventually happened at the hospital either vaginally (assisted or not) or by a cesarean section (C/S). Vast majority of babies were born dead (except in two case where the lady went to hospital fairly early).

Table 2: Childbirth circumstances related to the three-delays model

Pseudonym	Age (yrs)	Residence	No. days in labor?	Where did the delivery take place and the mode of delivery	Baby outcome	1st delay	2nd delay	3rd delay	Notes
Sakeena	24	village near Nyala, West Sudan	4 days	at the hospital – forceps delivery	born dead	X	X		kept at home by a TBA for four days because family think that primi should be patient and wait, hospital at town "Nyala" three hours away unpaved road during rainy season where only big cars can go. Family rent a car

Aisha	16	Abujbaiha, West Sudan	3 days	at home – Vaginal delivery	born dead	X			stayed home because her grandmother is a TBA
Haleema	32	village near Kosti, Southern region Sudan	5 days	at the hospital – forceps delivery	born dead	X			kept at home for three days then transferred to the house of the doctor where she spent two more days.
Fatima	30	Alkamelin, Middle region Sudan	3 days	at the hospital - C/S	born dead	X	X	X	stayed home one day before she went to the nearest hospital where she stayed for another 24 hours, they tried to pull the baby by a forceps but they couldn't, they referred her to another hospital because they cannot perform C/S there. The hospital is three hours away. She was blood-transfused and was unconscious for two days.
Marwa	20	Abu Osher, Middle region Sudan	3 days	at the hospital - C/S	twins born dead	X	X	X	twin delivery and a primi-gravida - the midwife kept her at home for two days without saying that she need to go to the hospital - when she finally did, the hospital nearby does not have C/S where she was referred to Madani hospital. Hypertension was discovered after delivery.

Altaya	17	Almanagel, Middle region Sudan	1 day	at the hospital - C/S	baby died after few hours	X		X	transferred to hospital after almost a day. The doctors were pulling the baby by a forceps for one hour, then she was operated upon (C/S).
Sara	20	AbuZabad, West Sudan	8 days	at the hospital – Vaginal delivery	born dead	X			kept by a (trained) midwife for three days at her mother's house. She spent the next three days being moved around to the father house and getting the blessing of the grandmother because the family thought that the disapproval of grandmother for the marriage caused the delivery delay. then she spent two days at a doctor house where she suffered severe complications. at that point, the family decided to take her to the hospital according to the "doctor" advice which is two hours away
Mona	18	Sudery, West Sudan	5 days	at the hospital - C/S	born dead	X			the family brought a TBA and she kept her at home for five days
Samia	58	Kaddam, West Sudan	3 days	at the hospital – forceps delivery	born dead	X		X	kept at home for two days, when she reached the hospital, she was told the baby is dead. The hospital had no equipped theatre for performing C/S. the doctor was pulling the baby by a forceps so hard to the point that the baby's head was perforated

Sit Albanat	45	Eldoweim, Southern Region Sudan	3 days	at the hospital – Vaginal delivery	born dead	X			kept at home by a "government" midwife which decided to get her to the hospital after the baby died inside her tummy
Maha	18	Alginaina, west Sudan	4 days	at the hospital - forceps delivery	born dead	X			kept by a TBA that was telling her you will deliver soon, you will deliver soon until she didn't feel the baby's movement anymore. She was transferred to the hospital after that.
Zeinat	27	EdAlfirsan, West Sudan	3 days	at the hospital – forceps delivery	born dead	X		X	the family brought her a TBA at home, she stayed home for two days. The doctor told the husband that she need a C/S because the baby is coming by his feet but the husband refused. At the end they pulled the baby by a forceps. The family brought her home before she was officially discharged because they didn't want to pay for the hospitalization.
Asma	47	originally from Alobaid, west Sudan. Living in Omdurman	2 days	at the hospital - C/S	born alive	X		X	she felt the labor pain but she decided to stay home for a day because she is used to deliver at home. a midwife checked her at home and advised that she must go to hospital because the baby is coming by his jaw. She went to the hospital where she

									was given a period of four hours that might the baby change its position. The doctors tried to pull the baby by a forceps. Then they decided that she must have an operation.
Sitana	50	Originally from Zalengi, west Sudan. Living in Omdurman	3 days	at the hospital – forceps delivery	twins born dead	X		X	she was in labor at home for two days, her mother in-low is a TBA who decided that she must go to hospital because they were twin. The doctor used a forceps which caused the injury.
Amira	27	Alabasia. South Kordofan West Sudan	6 days	at the hospital – forceps delivery	born dead	X	X		she was kept at home by a TBA for four days. Finally the family decided to bring her to the hospital. The family rent a car and they spend a whole day on the way to reach the hospital
Khadeeja	33	Sora' Aljamal, (3 hrs from Alnohood) West Sudan	3 days	at the hospital - C/S	born dead		X	X	a midwife tried to deliver her but she failed because the baby was lying transversely so she advised her to go to the hospital. They went to the hospital nearby where they didn't have the capability to perform an operation for her. then they referred them by an ambulance to Anohood hospital, it was three hours away. Khadeeja was

									hospitalized for 14 days, she was discharged and stayed home for 10 days. the bleeding didn't stop nor the uterus become smaller. She went back to hospital where she had curettage twice. at the end her uterus was removed due to infection.
Maysaa	23	Originally from South Sudan, currently lives in Omdurman	1 day	at the hospital – Vaginal delivery	born alive			X	she went to the hospital right after her water broke. When she went into labor, the midwives found out that the baby is big so they called the consultant. The consultant examined her and told the midwife to prepare her for a C/S then he went to a private clinic to perform an operation there. eventually the baby was pushing and she delivered vaginally before the consultant come back to hospital. he came two hours after the delivery.
Ensaf	33	Aldindir, Southern Region Sudan	4 days	at the hospital – forceps delivery	born dead	X	X		She didn't want a doctor to see her baby because she wanted to have a delivery like the one that her grandmothers had. she was kept at home by a TBA for three days until the baby died, the hospital was six hours away.

Tahani	30	Atbara, North Sudan	1 day	at the hospital – forceps delivery	born dead			X	she had history of babies being pulled by forceps, her two previous deliveries. One of the babies survived. During her third delivery, the doctor was pulling the baby by a forceps for long time to the point that she had a cervical tear. She was transferred to another hospital to suture the tear.

Section Three: Consequences of Obstetric Fistula

This section includes six of the main themes that emerged as consequences that women reported having to endure due to OF. They are: 1) physical disruptions, 2) role and identity disruption 3) mental and emotional disruptions 4) spiritual disruptions 5) women's relationships disruptions (namely their marriages, relationship with family and friends and their social lives) and 6) Lastly, financial disruptions.

3.1. Physical Disruption

Living a Physically Challenging Life

The women had to live with the continuous wetness resulted from urine leakage. Asma 47 years old originally from Alobaid, West Sudan having OF for seven years mentioned "***Having fistula is difficult, urine is there all the time and you are always wet***". In addition, they described how difficult it was to live with the complications of continuous padding and excessive cleaning of their groin area such as bruises, infections and burning sensations. Almost all the participants used old clothes as diapers due to their financial inability or inaccessibility of other options. Using the pieces of old clothes combined by the wetness was harsh and unhygienic for their skin. Some of them decided to stop using diapers because they couldn't stand it. Aisha, 16 years from Abujbaiha, West Sudan living with OF for five months said **"I *put a piece of cloth or gauze then I wash it and let it out to dry. But now I don't use a napkin because it was hurting me a lot. It caused me burning sensation and bruises.".*** Also Zeinat 27 years old from Ed Alfirsan, West Sudan living with OF for six years said ***"I have to sleep with diapers which is very discomforting and I get infection."***

Almost all study participants had a urinary catheter after they started leakage that was installed for a period ranging from few weeks to months. Sara, 20 years old from AbuZabad, West Sudan mentioned, ***"The catheter itself was too tiresome to me, it was***

there for four months. The catheter was irritating me and I was crying the whole time. They [the doctors] were saying that 'we are fixing this because otherwise the urine will go nonstop', I kept saying to them that I don't want this catheter because it doesn't let me sleep comfortably". Ensaf 33 years old lady living with OF for 17 years narrated her suffering with having urine coming from a stoma on the side. She said "***A doctor came to me with others and they started to talk in English, things that I couldn't understand. They agreed that the urine go by the side, I was like that for three years and I was so ill, screaming and crying. Then they did an operation for me, Alhumdulillah [Thank God] I urinated normally but the urine goes uncontrollably***". The previous quote gives an example of how women living with OF were suffering from the treatment options they endured as well as their lack of involvement in the decision made for them.

Most of the women interviewed used to work in agriculture, however, they were no longer able to execute heavy duty tasks like working in farms. Fatima 30 years from Alkamelin is living with OF for seven years, she said "***I used to cultivate but since I had this fistula I couldn't do that anymore because walking a lot cause burning and farming itself make urine flow more***". Some of the participants said that they can do house shores and singular activities such as cleaning the house, washing and ironing clothes. They confined their tasks to be in-door. Khadeeja 33 years old from Sora' Aljamal, West Sudan, living with OF for five years who is a midwife reported that she has limited working ability after OF and she gets tired faster now, she said ***"I do deliveries but if I walked a lot or sat for long time I feel tired. Before I used to work for long time without being tired. I need to work because I need money to raise my kids"***.

Leaking and waiting

Getting to the hospital was not easy for the women especially those who didn't know about the existence of the treatment for OF. Asma 47 years old originally from Alobaid,

West Sudan living in Omdurman and having OF for seven years said ***"I didn't start quickly because we didn't know that there is a treatment for it. We went to hospitals but they just gave me medicines and nobody told me what is this or if there is treatment for it or not".***

Fatima 30 years from Alkamelin, Middle region Sudan living with OF for seven years said ***"I stayed seven years and nobody told me that my condition can be treated. Nobody told me what to do I figured it out myself, I take a bath three times a day and put old clothes for three days and wash it with soap and use it again***".

The women suffered waste of time when they didn't afford to get treated from OF.

Maysa 23 years old originally from South Sudan, currently lives in Omdurman, living with OF for seven years said ***"I was just sitting [staying as she is] because I didn't have hope for treatment because".. "Our financial status was bad, my mother sells tea at an open market and my husband didn't care about my treatment because he didn't want to spend the money that he gained on it".***

During the period of waiting, some of them attempted to look of other options for treatment which wasn't helpful. Haleema 32 years living with OF for four years said ***"I didn't go anywhere [to seek treatment] for a year then I went to Sheikh [religious healer] who told me that he cannot treat this because it is a 'doctors matter'. Then I didn't go to anywhere else***.". They received advices from neighbors and family about activities to do to reduce the leakage. Maha 18 years from Alginaina mentioned ***"I went to hospital, people also told me to sit over a pot of lard. Also the water of garad [herbs]. They also told me to sit over the water of chicken [soup]. Another one told me to put in something to block the place [the leaking place] but I didn't do it, they said put in the small chicken after you clean it. There is a woman who did it but she was not treated until she was brought to Khartoum for treatment"***

Even after reaching the hospital, it took a long time before getting an operation. Haleema said ***"The issue of treatment, we stay here for months for it but it doesn't happen. It is a problem to stay in hospital without getting treatment"***. At the same time getting an operation does not mean that they will be treated right after the first one since some of them had more than once and still leaking. Ensaf 33 years old from Aldindir who is living with OF for 17 years said ***"This issue [incontinence] took so long and I suffered a lot; I had 11 operation and still the urine won't stop"*.** In addition, women were worried about the success of the operations and the long pathway that awaited them to be treated. Khadeeja 33 years old from Sora' Aljamal living with OF for five years said ***".. But it [the operation] doesn't succeed right away"*** Khadeeja continued ***"Also the people there [her husband and family] think that going back and forth is a waste of money, it is supposed to be a one-time operation".*** Being untreated from OF for long time make women endure severe physical complications. A woman in one of the FGDs mentioned, ***"fistula prevented me from walking. If the doctor see me he will find out that my thighs are ulcerated. It [treatment] is getting longer and we are exhausted. Fistula is the worst thing that can happen to you because you cannot walk, this wetness cause me lacerations. What if the fistula was there for three or four years more? This is like death sentence isn't it?*** (FGD2-W2)"

3.2. Role and Identity Disruption

The women involved in this study talked about their value in their communities and among their family, including their husbands. They explained that their value as women come from being able to produce babies. A woman in one of the FGD's explained ***"You are not valued if you didn't give birth to children, people tell the man that you have to leave her if she didn't. Women's value comes from the delivery".***

Zeinat 27 years old from West Sudan described how she felt bad when her grandmother was mocking her about her lack of ability to have a child again due to her condition.

She said ***"I was having a bad time and people kept talking about my condition, my grandmother kept saying that you won't be able to conceive nor deliver again. She made me feel bad, she used to tell my husband that "this girl is done, she will just make you lose your money and won't give you a child, divorce her and marry a healthy girl"".*** Zeinat was married to her first degree cousin that's why her own grandmother was siding with her husband. The grandmother even advised the husband to leave Zeinat and marry a girl that can give him a child because this the easiest option for men, leave and marry another woman.

When women discussed issues related to their value in their communities and to their husbands, they talked about the importance about being able to do house shores to be seen as a valuable woman. One of the FGD participants mentioned "… ***If you are home doing your duty related to house chore***" and another said "***The man value you when you cook and clean for him, if you are not able to or ill he wouldn't care about you***". Women used terms like defective, deficient, incomplete to describe how other would think about them. on the other hand some were tired of been seen as incompetent. Maysa 23 years old is living with OF for seven years said "***I swear I can do it but people wouldn't allow me to do anything especially at our house, now I can't cook because they don't allow me to cook, I clean and wash clothes but they don't allow me to cook***" She continues ***"Nothing is difficult and it is not related to work but the community doesn't leave us rest, someone who has fistula is being seen as incapable of doing anything but she actually can."***.

The Sudanese girls are raised to be wed and have children so being different than the community norms such as being divorced is highly stigmatizing too. Sakeena, 24 years from a village near Nyala said ***"Of course they do not educate us as girls because they say that a girl should get married, have kids to raise them.".*** Majority of the participants therefore were furtherly stigmatized for being divorced or abandoned by their husbands. A woman in one of the FDGs said ***"they see us different than them. they***

say that we are ill. Because our men divorced us because of this illness, people talk about us" (FGD2-W2). In addition, having a husband as a male guardian is seen as important in the Sudanese community. Some of women lived in a different state for treatment which put a strain on them because according to their community "they are living there without a guardian". Ensaf expressed how living so long for treatment in another state (Khartoum state) away from her family has caused her problems. She said ***"People don't leave me rest. People talk about me they say that I am not ill, I am just walking around in Khartoum without a guardian."***

Being attractive to men was another issue that the women expressed their concerns about it. Maysa 23 years old is living with OF for seven years and she is divorced twice because of OF, she said ***"Because in the current time no man will accept a woman with such issue. No one will accept to have a woman who has a problem and she can't sleep with him anytime he wants, he see it as if he wasted himself".***

3.3. Mental and Emotional Disruptions

Feeling Sad and Worthless

Having urine leaking uncontrollably caused women so much sorrow especially if they were not familiar with this situation or didn't know about it before. Sitana 50 years old who is originally from Zalengi, west Sudan but she moved to Omdurman for treatment speaking on how she felt about being incontinent ***"I used to think at that time [15 years ago] that I haven't heard about this thing [OF] before, I used to cry the whole night and not to eat. I told my mother that I want to die and my mother tried to encourage me by saying that there is a girl she knew was like me and she was treated, so I shouldn't be afraid".*** Ensaf 33 years old from Aldindir said ***"I didn't want to live anymore"***. Ensaf talked about how she lost her appetite for life and how her life is no longer enjoyable, she said ***"I swear I don't feel like doing anything, I just eat because of hunger. I lost***

interest in everything." She continued ***"I don't want anyone to visit me and I don't want anyone."***

In addition to the OF, majority of the women interviewed also suffered the death of their babies too which was also painful to them. Sara 20 years old from AbuZabad, West Sudan described how she felt ***"I was sad and tearful because my baby died, I waited for him nine months and he just died, not only that, I was so ill and my legs was hurting day and night and the wound down there [means perineum area] was large. I cried the whole day, even without a reason I cry. What upset you the most? What I am up to, my pain and losing my child".***

Losing a child and the feeling that her life stopped here, she won't be able to conceive or work again caused a tremendous pain to Tahani where she said ***"I felt that I won't be well again and I can't deliver and have a baby again. I can't work again and my life will stop here. I reached a point that I told my husband that I don't want to live with you anymore, I don't want him to suffer with me"***. Women during FGDs conducted agreed that their value in their communities comes mainly from being able to deliver a baby. FGD-W5 said ***"Women are important just because of the delivery. If you are ill and you have the money of the world, nobody will care about you".***

The women living with OF suffered from low self-esteem. FGD2-W1 said ***"before the fistula I can deal with anyone but after it I myself feel ashamed. If someone say hi to me, I lower my head and don't respond. They tell me that you shouldn't be ashamed because this thing is not caused by you, this is written and destined from above."***. In addition, they feel that they weren't a priority in their families and community. Ensaf 33 years old from Aldinder lived with OF for 17 years sadly mentioned ***"All my brothers money is gone and my father married another woman and nobody cared about me anymore".*** Everyone's life in Ensaf's family is going on except hers. Her husband looked for treatment with her for four years and then abandoned her for years without even sending her divorce papers. Ensaf continued sadly ***"My mother died ten years ago***

and my father died eight years ago, I have no one now. I came here [fistula ward] alone, I told them [her family] just let me go.". she felt that nobody cares about her.

The participants used expressions like "***you [meaning herself] feel like you are not existing***" , "***People do not see me***" , "***they don't even notice her and don't care about her, they don't see her important because of this illness*** " to describe themselves and how their status changed after getting incontinence. In addition, Haleema 32 years living with OF for four years described the struggle she has inside because she want to accept her fate and at the same she can't help it that she is envious of others when they look good and she is not "***I swear I say that this is my destiny but when I look to other people wearing nice things and walking nicely and if you sat with them you feel like you are not existing***". Mona 18 years from Sudery, West Sudan living with OF for one year mentioned that ***"I feel myself incomplete, and I am inferior to people. I see all people better than me because I have this illness, nobody had it before I got it***"**.** Mona felt that she is different than others because nobody had OF before her which aggravated her low self-worthiness. Mona continued ***"I don't want to go out because am shy because of my condition I say to self that I have fistula where would I go, 24 hours at the bathroom or changing my clothes***". She described how her situation prevented her from visiting others because she is shy of her condition and she has to spend the whole day cleaning herself from urine.

Khadeeja, 33 years old from West Sudan, says ***"I am never like I was in the past, I see myself as if my status is lower now. When I look at myself now I see myself different. Another thing is the fear from the community that I live in, when I join people conversation nobody listen to what I say like before, they see me as a weightless person. No one says that to me but this is how I think***"**.** Khadeeja suffered from a distorted self-image after what happened to her. Khadeeja's feeling is worse than other women because she is a midwife. Midwives have a respected and valuable position in a community like hers that why having OF for a midwife has a huge effect on her self-

image. Maha 18 years from Alginaina talked about how she felt defective when she couldn't work like the others, she said ***"I used to cultivate and now I can't, they told me that you had an operation do not work, I feel myself deficient not like other people because I see all of them work in farms and I sit there doing nothing I feel myself useless and ill."***.

3.4. Spiritual Disruption

Some women believed that having OF was punishment from God for something they did. Altaya 17 years old from Almanagel described how sad she was during the first period when she got OF ***"I cry when the urine flow uncontrollably, I think how could this happened to me.***

Interviewer: Do you blame someone for that?

Altaya: I blame myself for that, I ask myself why Allah is punishing me for. I might have done something to get that".

Tahani (30 yeas old from Atbara North Sudan) explained the guilt associated with self-blame and questioning God' will when she said ***"I am all the time thinking about it and I ask myself whether Allah is punishing me for something that I did, I went so far. I hope Allah will forgive me for it"***.

3.5. Relationship Disruptions

Disrupted marital life

In majority of cases the relationship with their spouse worsened after having OF. Maysa 23 years old is living with OF for seven years compared how her relationship with her first husband was before OF. She said ***"My first husband was very good with me, he didn't even like to be outside the home after he is back from work. We used to chat, bath together, sleep together and we were so happy but fistula ruined everything and all these problems were caused by it [OF]"*** she continued ***"Before the fistula we were***

very good with each other, we would go out together and I would go with him to visit his friends. But since the fistula happened we were just like strangers, to the point that I felt that the problem is not only the fistula maybe there was something else". Majority of their husbands wanted to have nothing to do with them. FGD2-W1 said ***"The man wouldn't accept you after fistula, if I sat beside my husband he tell me to move away of him."***

Women were divorced or abandoned by their husbands as a result of getting a OF. Haleema 32 years is living with OF for four years said ***"I told him after we got back to village, he left us at the hospital. He didn't say anything to me, he just came after a week and said that I divorced you. What can I say, he just divorced me because of what has happened to me."***. Marwa 20 years developed OF ten months ago "***He treated me fine. After we came here [fistula center] and returned back home without doing the operation, people said that this sickness will not be treated and that's why he left me"***.

Zeinat 27 years old from West Sudan felt betrayed when her husband took the money collected by her family for her treatment and married another woman. She said ***"Everyone gave him money because he is responsible of me then he took the money and married another woman. He considered me dead"***. Maysa was angry because her husband blamed her for getting pregnant after having OF and stopped talking to her, she left the house to her family house because she felt unwelcomed by her husband and his family. He didn't even come to hospital when she delivered her baby. Maysa said ***"After 15 days I got pregnant with my second son, since he discovered that am pregnant he stopped talking to me. He blamed me for the pregnancy saying that am sick and I have to be careful."*** She continues ***"What can I do? That was Allah will; so I stayed there and he didn't talk to me or even say hi. I got angry and I went to my mother house, he didn't even come to hospital when I delivered his second son"***. Maysa had to live with feelings of helplessness and powerlessness due to lack of support from the husband and her own family. When she asked her husband about their situation he

answered ***"I don't mind you staying with me but with this illness I don't want you and I can't treat you, if you can work in tea selling or anything else do that and treat yourself"***.

On the other hand, some women expressed their worries about ending up being alone if they didn't get treatment for the incontinence. Maysa said ***"If I didn't have the operation most likely it will affect me, I might just stay like that; alone and no woman can stay without a man that is impossible. Even if I had a man the end result will be divorce, even if I got married every year, I don't think that there is someone that can tolerant to what I have, which means that I will just be like that, this is what I expect."***

Minority of women showed resistance and refusal of to the usual scenario that men would leave women untreated and go and marry another one. ***"this thing [OF] has happened because of him [the husband], he brought me healthy from my father's house so he should wait till I am treated then look for another woman. How can he just divorce me? Whose responsibility is this? This illness has happened to me at his house, if he want to get married he should treat me first and don't get married with the money that should be used for my treatment. Why would I just stay to explode alone without a child. If they found the woman weak then they will go over her head. The man [the husband] said to me "let me send you to your father to treat you" I told him [the husband] that this is your responsibility not my father's"*** said FGD2-W1.

Women' sexual life has also been disrupted after OF. Some women reported that they didn't have sexual intercourse after OF. Sakeena, 24 years from a village near Nyala, West Sudan living with OF for four years said ***"This [sex] I forgot about since I become sick, I didn't sleep with him since"***. Sit Albanat 45 years old from Eldoweim, Middle Sudan living with OF for 15 years said ***"I do not sleep with him I refuse to unless, when am treated. I sleep alone. He wants it but I am the one who refuses"***. Samia 58 years old from Kaddam, West Sudan described how OF affected her appetite for sex, she said ***"he***

never ditched me but I used to say no to him,
interviewer: Why?

Samia: Just like that, I think if the woman is healthy she prepares herself for sex by perfumes or by smoke bath* or clothes but how is it when she is ill?" she continued ***"I just didn't want to hurt him but he never changed the way he treats me"***. Women described how OF made sex no longer normal and enjoyable. Asma 47 years is having OF for seven years said ***"It is OK [sexual life] but I see that leakage increase when we are together and am psychologically not comfortable"***. Maysa is 23 years old and she is living with OF for seven years, she mentioned that the primary cause of the failure of her second marriage is their challenged sexual life. She said ***"I guess it is because of the fistula, I never fought with him. When we were together these opened areas affect when we have sex. That's why I am sure that it is fistula because we cannot be normal".*** Maysa continued "***I told him about it [her condition] before the marriage but he thought it is a normal thing and it is possible for me to be with him [have sex with him] 24 hours a day. But after marriage I wasn't able to sleep with him all the time [when he wants], sometimes just two or three times a month" .. "I didn't like it when we sleep together because this thing [sex] affect me and make ulcers***."

Beautifying Sudanese women's bodies is part of the Sudanese culture, this is done to please the husband. Women use hinna and smoke baths to beautify themselves after marriage. However, women living with OF reported that they lost their interest in such rituals. Asma 47 years old living with OF for seven year said ***"I used to make hinna and smoke bath all the time but I don't after the fistula because of my feelings".***

Disrupted Relationship with Family Members and Friends:

Majority of women interviewed gained the support of their families, however, some suffered disruption of their relationship with their family members after they got OF. Maysaa described how was her relationship with her mother and siblings before getting

OF, she said ***"When I was heathy and nothing wrong with me they [her siblings and mother] used to treat me well but now they don't. I keep asking myself is it is my illness or what? Or is it because they are tired of saying that I am going to hospital and please do this and that to me? They don't deal with me. When I say that I am going to hospital nobody cares".***

Relationships with friends were also affected by OF. According to what was stated in the FGD ***"all my relationships with my friends are not existent now. They don't visit me because I don't go out, I used to visit them but since this fistula happened I couldn't go out. They just visited me the first time and then they didn't."*** FGD-W3. Tahani 30 yeas old from North Sudan is living with OF for 2 years, she mentioned ***"I feel that I want to stay away from people because I have nothing good to tell if I want to chat with them, all of it is related to my illness."***

Women living with OF are victims of verbal insults from their relatives due to their condition. Zeinat from West Sudan said ***"Even if a small discussion happened they name you by it [urine] and say to you "the one with urine" or stinky one. No respect for you and they don't consider you a human. You have urine then you are unvalued in the community"***. Similar sentiments were expressed in the FGD, ***"since I had this fistula I have had problems with my husband and his family. They told me that I am useless 'you become useless because you can't have normal labor, you can't sit with other people even food you cannot cook it. You rush to bathroom every now and then while cooking'"*** FGD-W1. This woman continued describing how her in-laws treat her ***"When I cook my in-laws tell me that "you are ill maybe you didn't wash your hands or you didn't have a bath so we cannot eat what you cook" they say that to me all the time. I just gave up"***. Maysa explained her feelings after her in-laws told her that it doesn't matter whether she got treated or not, they don't want her anyway, she said ***"I felt that I cannot do anything again and even if I got married again the same thing will occur".***

To be treated from incontinence, all participants had to travel to the capital "Khartoum" to have the operations which detached them from their families and social networks. Sakeena from a village near Nyala, West Sudan *said* ***"I cannot live with my mother since I got the fistula for years now. They are far away and I can't go back to my village until I complete treatment.*** Zeinat 27 years old from Ed Alfirsan, West Sudan said ***"I don't know anything about them [her friends] now because of being far and I can't contact them because I don't have a phone now".***

Social Lives Disrupted

Women suffering from OF were too afraid to attend social gatherings. Aisha 16 years from Abujbaiha, West Sudan reported that she cannot participate in social gatherings or weddings because she is afraid that someone will talk about the smell. Haleema 32 years from a village near Kosti, Middle region Sudan living with OF for four years said, ***"I didn't hear but when I walk by someone I say to myself what if that person can smell an odor on me, I have to think like that, I just tell you the truth".*** She continued, ***"I heard also people talking about the woman who has fistula. They say, 'this woman smells bad. Why doesn't she go to treat herself?' They cannot sit with her and if they did you find them agitated as if they cannot stand her anymore."***

Interviewer: ***How do you feel when you hear them talking about her?***
Haleema: ***I say to myself that if I walk by them they will say the same thing about me.".*** Another reason for lack of participation in social gatherings that women that they found it easier to act according to the their communities expectations. FGD participants agreed that community expect them to stay home when one of them said ***"they say that, 'look at this woman her urine is there and still she is roaming around, she better stay home.'".*** Some women stopped going to social gatherings because they encountered an unpleasant attitude from the others. Ensaf 33 years old is living with OF for 17 years said ***"If I sat with people like how we are sitting now [referring to FGD],***

the person who sits after me starts to feel the bed to see if it is wet or not, my niece who was six years old heard them saying that I wetted the bed, she told me not to go visit them ever again"..."A small girl of six years old said that! I said OK. I gave up going out after what she said. This happened eight years after I had fistula."

Women do not feel comfortable going to gatherings due to anxiety linked to the frightening idea of people seeing that they were wet. Therefore, feeling wet is not as important for women as looking wet, in other words, other people could see the wetness on her clothes. Haleema 32 years from a village near Kosti, Middle region Sudan living with OF for four years said ***"Before, I was clean around the clock I do not feel wet; but now, if I sat with people for some time I start thinking if my clothes look wet now. I worry about that, I swear".*** She continued, ***"Your inside must be busy thinking about something."*** Haleema reported that when she participate in social occasions, she had to be worried all the time about people seeing her wetness in addition, she had to anticipate it before it happen and visit the bathroom and change her clothes. Asma 47 years old is having OF for seven years said ***"I am not like the past, when I go out I come back as fast as I can so I don't get wet. I don't really feel comfortable, I visit my neighbors for example if one of them had a baby I visit her but I don't sit."*** She resumed ***"I am anxious about my condition and I am never comfortable like before"***

Women reported that they were being watched by others for signs of wetness or urine. Khadeeja is a midwife from West Sudan, she is living with OF for four years. Khadeeja mentioned ***"They watch you and look at you to see if there is something coming from you or if the bed is wet after you stood up, always observed...when I went back to the village and I was sitting in one of the rooms, women who heard about me were looking at my legs because they expected that they will see the urine coming down my legs"***.

Women living with OF were also undermined by other members of the community. People questioned their ability to work or cook or go out and participate in social

gatherings. Zeinat voiced it like this: ***"some of [community members] think that she is incomplete, she can't do her duty or anything else. There are people who even do not eat something made by her because she is considered dirty and not clean. If they saw her praying they ask her how come you are praying and your urine is flowing, they even come between her and her God. I agree that urine is dirt but what if it continued for a year or two what can we do then?"***.

3.6. Financial Disruption

The majority of women interviewed almost never went to school or had a primary school education which limited their options when it came to financial independence and work. They depended on the financial assistance from family members, such as brothers and fathers and their husbands if they were still around. The cost of living, drugs and transportation is extremely high let alone that they need to pay for the operation itself. Some of them tried to work while staying at the hospital to earn some money to help with their expenses. Zeinat 27 years old lived in Khartoum for years without her husband's support, he divorced her after a while because he didn't want to be bothered with her expenses. She said ***"I tried to work because I need money for living here. I used to tell the lady that makes tea in the hospital to leave her stuff so that I could use it at the evening. At the same time my mother was sick and I needed to send her some money too".*** Zeinat continued "***If I find a way to work is better that I ask others for money, I don't want a thing from anyone so he will say that I gave you this or that".***

Some of them stopped working due to OF which affected their income. That was due to physical reasons or because they were worried that someone would find out about their condition at work. Asma 47 years said ***"I also used to work but I stopped. Interviewer: Why?***

Asma: I said I might be wearing a diaper and urine break out in front of people so I decided that I stay home and this affected our income".

Moreover, the women were no longer able to live where they have better resources due to treatment. Sitana 50 years old, she is originally from Zalengi, west Sudan and she had to move to Omdurman for treatment, living with OF for 15 years. Her husband died few years ago which made her the main provider of the family, she said ***"When I was back in my village, I used to farm and cultivate wheat and beans and we had plenty of livestock. We were restful when my mother and father were alive, we had these troubles [their financial struggles] now because of the fistula."*** She continued ***"After the man [her husband] died I couldn't work a heavy work because of fistula, the worst thing is when you are in need and you cannot work***".

3.7. Dimensions of Stigma

Women encountered mostly self and enacted stigma as a result of leaking and urine smell. Felt-stigma rarely happened alone where in majority of cases felt-stigma was accompanied by enacted-stigma. Few women (three out of 19) encountered none of three types of stigma while three women have had all three dimensions of stigma. For details please see the table following (Table 3).

Table 3: The Dimensions of Stigma

Pseudonym	Number of ys living with OF	Dimensions of stigma			Notes
		Self (S)	Felt (F)	Enacted (E)	
Sakeena	4 years		X	X	F: Limited her social visits because she was worried that some people would treat her badly E: Some people didn't sit or eat with her at the beginning of her illness because she didn't know how to take care of herself
Aisha	5 months		X	X	F: She was afraid of people would talk about her. E: A neighbor was talking about her, her friends abandoned her
Haleema	4 years	X	X	X	S: she saw herself inferior to others F: worried all the time that people see wetness on her clothes or smell something on her or talk about her, witnessed people talking about other woman having OF that's why she was worried that the same will happen to her E: her husband left her
Fatima	7 years	X		X	F: she didn't sit beside people because she thought that she was dirty and smelly E: her husband left her
Marwa	10 months			X	E: her husband left her
Altaya	8 months				she had no signs of stigma
Sara	1 year	X		X	S: She felt that she is no longer the same person she used to be. E: she and her mother were not allowed to stay inside the room, they were staying in a shanty built outside the room at her brother's house, her sister-in-low didn't eat with them, and her husband left her
Mona	1 year	X			S: felt herself defective and everyone was better than her
Samia	18 years		X		F: worried that others would know about her condition and she loses her status because she is

					teacher
Sit Albanat	15 years				she had no signs of stigma
Maha	1.5 years	X		X	S: she isolated herself because she knew (accepted) that she is sick and not like the others. E: She was told that she is dirty and smelly, her husband abandoned her. *signs of stigma become better when the leakage reduced after she had two operations operation
Zeinat	6 years		X	X	F: she is worried that people would see her wet or the wet bedsheets if she spent the night in a relative's place. E: verbal insults, her relatives did not eat with her, and felt monitored at social gatherings (people touch the place she was sitting on to see if it is wet or not)
Asma	7 years		X		F: worried that people would see her wet during work
Sitana	15 years				she had no signs of stigma
Amira	12 years	X	X	X	S: She felt that she was inferior to others F: expected that people are talking about her E: her husband left her
Khadeeja	5 years	X		X	S: felt herself inferior to others and unheard by others E: being observed by others (looking at her legs to see urine)
Maysa	7 years	X	X	X	S: Felt something is missing in her and she was unable to do anything right. F: she was worried that her female friends will treat her bad if they knew about her condition. E: verbal insults from her in-lows, they didn't allow her to cook because she dirty, her family treat her bad, and her husband left her.
Ensaf	17 years			X	E: She was mocked by children, monitored at social gathering (women touched the bed she was sitting on), and her husband abandoned her.
Tahani	2 years	X			F: She felt that she is no longer the same person she used to be.

Section Four: Coping mechanisms

This section is about the different mechanisms that were used by the women to mitigate the consequences of OF. It comprises two sub-sections; first one tackling the emotion-based coping while the second addressing the problem-based coping.

4.1. Emotion-based Coping:

Concealment of their condition

Few women were able to conceal their condition which protected them from verbal insults and discrimination. Samia 58 years old from Kaddam is living with OF for 18 years mentioned ***"They [everyone around her] don't know nor they smell something so that they offend me" .. "If I said that I have fistula even if I don't smell people will pay attention but I didn't say"***. Samia is a primary school teacher so she used different techniques for concealing her condition from her colleagues. She said ***"When I go to school I put my dirty pad in multiple bags, I wait till 12 o'clock to go to bathroom because people are at classes at that time. So I go to bathroom and change, I wrap the dirty pad in a number of plastic bags so if someone saw it will think that it is a private matter. This was my biggest worry that other teachers open my bag to take a pen and see it that's why I wrap it that way."***. Samia was able to hide her condition even from her kids and siblings for years. Her husband was the only person who knew about her illness. She said ***"I wash my clothes in a distant place in my house away of people sights, I have a specific place to dry my clothes because of my children and guests"*** she continued ***"My daughter is married to her cousin , my brother's son, when I visit her I go to bathroom, wash the piece of clothes and I look for place away to dry it"***.

Silence and self-isolation

As reported earlier, participating women encountered unpleasant and sometimes very extreme reactions from others. Some of them chose to remain silent in order to cope with those events as described by Sakeena: ***"What can I do! I just be silent. If one treats***

me well I deal with him if not I just shut up. "Similarly, Maha said ***"I don't talk to them; I just sit in my place alone I don't go anyplace".*** Isolation could be both, a challenge that women have to live with it when people stay away of her and way of coping when she choose to. In a related manner some chose distance as mentioned by Maysa: ***"I just distant myself because I am afraid that someone might hurt me or embarrass me or say bad things to me."***. Zeinat mentioned ***"I consider the person who name me by an illness an idiot and I don't care about him or her"***.

Support from others

Support from husband, close family members and peers who went through the same problem helped women to survive OF. Samia had tremendous support from her late husband which helped her to cope. She said ***"My husband was supportive to the last moment of his life. He didn't let me down not even a second he never looked at me as a damaged woman till he died. He was my main support system he never abandoned me. If there was divorce or a hate problem, fistula would have affected me but I never encountered that. My husband, may Allah grant him heaven, never abandoned me not even a second, he used to tell me that I should never bother myself with this issue there must be a time for it to be treated. He also said maybe there would be a synthetic bladder and we go and have it. He had always encouraged me and that's what made me never to be afraid… I think if he abandoned me or did not support me I would have been hesitant or weak."***

Tahani 30 yeas old mentioned ***"He [her husband] was sensible more than me. He kept saying to me that am going to be treated and I don't need to worry. He is supportive, if he didn't stand by me the problem would have been bigger."***

Maysa who lost the support from her own husband and family found support from a friend who was treated from being incontinent. Maysa said ***"She is supporting me now, even when I give up she tells me that I didn't give up on her in the past".***

Religious coping:

Getting OF and losing the baby were adverse events with which women had to deal. The majority of women talked about this being their fate or that it was destined from Allah "God" and they had to accept it no matter how bad it was. This belief is expressed in the quotes below:

"Rabbana [Our God] gave it to me, what can I say?" said Sakeena.

Also Haleema said ***"I say that this is what Allah wants for me and there is no way out if I get angry or I cry; there is no way other than patience…If something is planned by Allah, Allah will never leave you, we just thank Allah for it."***. Relatives used to remind the women that what they have is their destiny as a way of support. Khadeeja mentioned ***"When I say to the man [her husband] that I will not be of use again, he tells me that this is gisma [her Destiney] … 'Allah is examining you with this exam for you to be tolerant and patient, and if you did he will forgive all your past mistakes, this is kafara [when God forgive mistakes because of having illness] .' Whenever I talk to him he tells me this."***

Haleema 32 years old ***"I have my eldest sister who asked me why are you crying Haleema, this is what Allah planned for you; if you got treated is fine and if you didn't we say that is destiny."***

Fistula Ward/Home as a Refuge

Some of the participants preferred to stay at the hospital or the fistula home because they felt more comfortable there; they made an alternative home and family. Amira is 27 years old from West Sudan is living at the fistula home for many years now, living with OF for 12 years, she said ***"I stay here because all the people here are ill like me, we are all the same here. There [she mean at home] I don't feel equal to others".*** Women also found the solidarity in the company of each other, they felt better that they were not alone. Amira said ***"Here is better because I have these women with me, I don't feel that I am ill or sad" .. "Sometimes I say that I shouldn't go anywhere, I become better***

after I came here.". Ensaf 33 years old from Aldindir, Middle Sudan living with OF for 17 years prefer to live at the fistula ward because doesn't need to worry about getting wet in from of the others. She said ***"I stay without a diaper here, am comfortable here, if my bedsheet get dirty I wash it"***. Women felt better by getting to know that they were not alone. Asma 47 years old and having OF for seven years mentioned "***when I came here [fistula ward] and I found these women I was relieved because I thought nobody else have this condition apart from me."***

4.2. Problem-based Coping:

Excessive washing and changing

Frequent changing of clothes, washing and putting pads made from pieces of old clothes were done by women to conceal their condition and mitigate the social consequences and personal discomfort associated with OF. In addition, they used scents to cover the smell as long as they can.

Asma does this: ***"... I bath a lot and use perfume and wash with soap a lot. If someone visits me at home he would never be able to tell that I have fistula unless I say so, because he won't find a smell."***

Amira also said ***"I put a piece of cloth and change and I always use a perfume so I cover the urine smell."***

Similarly Sitana explained what she does: ***"If I am wet I go wash that piece of cloth and put it again. I use a light one so it is easily washed and gets dry faster ...When you can organize yourself, and hide something like this, it is good.".*** In order to sleep restfully, women had to change bed sheets during the night. They also used a plastic sheet to cover the mattress.

Drinking less water

A few working women mentioned that they drink less water at work to minimize the amount of urine dispensed. However, drinking less water caused complications for

some of them such as infections and urinary stones. Khadeeja 33 years old from Sora' Aljamal who works as a midwife said ***"Drinking water annoys me because of wetness and this caused me urinary infections, when I came here this time they requested an image because I might have a stone because I don't drink water while working"***.

Smoke bath

Women used fumigation by sitting on wood smoke that helped them cover the smell and reduce the amount of urine leakage. Khadeeja mentioned, ***"I just use dokhan [smoke bath] (دخان) and diaper, then nothing would be on you. I use dokhan [smoke bath] morning and evening then the smell will be gone and no leakage. It makes the urine amount less even if it leaked the smell will be covered. When I go to the bathroom the smell will be like smoke"***. she claimed that smoking twice everyday made her live her life as normal as she can, especially that she can gets the wood she used easily from where she lived.

Persistently looking for a cure

The majority of women lived without treatment because they didn't know that OF can be treated. Some sought treatment late when doctors advised them to go to fistula ward and some were advised by the their relatives. Maha 18 years old said *"**They told me that I have fistula and I have to go to Khartoum for the operation because they don't have doctors to do the operation here".*** Also Asma said ***"My cousin told me that there is an operation to fix it. I was finally relieved, I thought that this condition cannot be treated. He gave me hope".***

Despite all the challenges they showed persistence and managed to get to the place where they can get a repair operation. Haleema 32 years from a village near Kosti, Middle region Sudan living with OF for four years said ***"Nobody told me that there is operation to treat it, they just said that I might be treated if God permit, if not we accept it. After three years, I went to Kosti again to seek help, I went to the same doctor who delivered me. My father accompanied me, we didn't find him the first time***

and we travel back home. We came again this time with my brother. My brother told the doctor that I delivered here with you three years ago and she can't control urine till that time if you know a doctor tell us. He told us that there is a doctor in Abu Hamama. We spent two months and then I came here with my eldest brother to doctor Hassan and the doctor told us to come after six months. We came to him after six months and he also told us to come back after two months and now I am here for a month." All those efforts and resources were spent just for them to be treated and become like the way they used to be before. Khadeeja 33 years old from Sora' Aljamal said ***"I want the treatment to become like I was in the past."***

Discussion

The objectives of this study were to explore the circumstances surrounding the delivery that caused OF in the Sudanese context, illustrate the women's perceptions on how their lives have been affected by OF and identify daily challenges they face and last but not least to identify and understand the coping strategies used to mitigate OF's effects. The women in our study endured a lengthy and a complicated childbirth from which, women ended up leaking and in the majority of cases, childless. As a result of urine leakage and its smell women lived stigmatized lives and suffered disruptions in their psychological well-being, relationships including their marriage and relation with friends and family members, social isolation, deepened poverty and being unemployable and being seen as a burden to the family and their husbands. In addition, women lost their dignity because they were dependent on others. The quotes of our study participants provide a vivid picture of the disruptions and suffering.

Circumstances Surrounding Obstetric Fistula

Delays in Recognition of Danger Signs and Taking the Decision to Seek Care

The majority of the participating women experienced the first delay i.e. delay recognition of danger signs and taking the decision to seek health care during childbirth, which is consistent with literature that implicates the first delay with contributing to complications during childbirth (63, 73-75). Our participants were kept by unskilled birth attendants or their families at home for days after labor pain started. It was also obvious from their narratives that the decision to go to the hospital was taken by someone else such as the TBA, husband, mother or other family members. Majority of women participated in this study had no or low literacy level and they were relatively young when they went through their labor experience. Lack of empowerment, illiteracy and age of the expectant mother at the time of delivery are factors that can affect the ability to take decisions related to childbirth such as choosing the place of birth (36, 63). The same factors listed happened to affect the vulnerability of

women to develop OF or other adverse outcomes of labor or in extreme cases maternal death (63, 75). A study conducted in Tanzania to explore childbirth experiences among women who developed OF found out that during the delivery time, other family members decided on the place of delivery (35). The same study showed that women themselves had plans for giving birth at the hospital but that was not up to them to decide since they lacked the financial independence to pay for the delivery and lack of the power to make decisions related to their health (35). Women had to wait until their husbands are back from work because they need their approval before taking any further steps such as going to the hospital (35, 76, 77).

Our findings suggest that the involvement of women in decision making was minimal although those decisions deeply affecting their own bodies and wellbeing which was consistent with the literature (16, 77). Lack of involvement in the decision making was observed to be deeply connected to the inferiority of women status in the community and their lack of economic autonomy which in turn, affected their access to the key and life-saving health services (16, 35, 74, 77). Furthermore, women's lack of negotiation power, as well as blind acceptance for others' decision and unequal power-relations were clear when women talked about their childbirth experiences which was observed in a study conducted in Sudan (16). For instance, the women were not consulted in the choice of health care they receive, instead a male guardian namely the husband or the father would be consulted by the doctors and thereafter signs the consent for getting the service. Deprivation of the woman's rights to decide the place of birth or the type of health service she wants is not an isolated incident, in fact, Sudanese young girls and women are deprived of the right to take major decisions related to their lives since their early years of life such as schooling, FGM/C, marriage and timing of and whether or not to get children (16). Lack of self-determination continues where the decisions were taken earlier by the father and later after marriage by the husband.

The women in our study or their families chose to call for the TBA instead of rushing to the hospital when the labor started. A TBA was more attractive for women in labor and

their families because they are affordable unlike institutional care and in addition. Moreover, paying for a TBA has a more flexible nature (76, 78-80). In addition, TBAs were more trusted by women because they come from the same neighborhood, speak the same language and sharing the same culture (76, 78). The TBAs are always available and physically nearby unlike health care services for rural areas where it is most likely geographically inaccessible due to long distance or bad roads or other reasons (76, 78, 79). It was clear from the narratives of women in our study that TBAs didn't recognize complications and danger signs when they occurred until it was too late as well as they didn't have the ability to handle complications when they arose, which has been noted in a previous study (76).

Most women reported that the birth attendant decided that they go to the hospital when they found out that the baby was no longer alive or when they had developed severe complications already (81). Literature suggests that the smaller the period between identification of complications and reaching a health facility the better the outcome (63). Being kept at home for a long time made women reach health facilities in a poor clinical condition that was unsalvageable (63, 73, 81).

In a small number of cases, the cultural beliefs of the community affected our participants' health-seeking behaviors during long childbirth which was consistent with what was observed in Ghana (14). In contrast to what was observed in Ghana and Bangladesh, women were not directly blamed for the occurrence of obstructed labor (14, 38). However, women in our study who underwent labor for the first time were expected to have a lengthy labor which hindered taking the decision to seek health care immediately (14, 16).

Almost all women who were part of our study came from a poor household. Although the cost of health care services and the economic status of the household weren't mentioned by women in our study as hindering factors to use services it is suggested that they might affect their choice of the place of delivery as other studies showed (35, 76, 80). Although some emergency maternal health services are free of charge in Sudan

still women and their families need to pay other costs associated with transportation, items needed for delivery (gauze, IV fluids, antibiotics etc.) which are not taken into consideration (80). These costs increase the overall costs of institutional delivery and constitute a barrier to utilization of services by poor people such as our study participants (80).

Delays in Identifying and Reaching a Health Facility that Offers EMoC

The majority of women who participated in our study are coming from rural areas. According to other studies, living in rural places, with poor roads and limited access to transportation are associated with the second delay i.e. delay in reaching health facility (51, 63, 64). In addition, unpaved roads during the raining season made reaching health facility even more difficult. It is worth mentioning that it was not identified by women that the lack of emergency transport to the hospital as one of the reasons that caused the 2nd delay unlike others studies (35, 40, 51, 63, 74).

Some of the participants had to travel from a health facility to another because the first one they reached lacked essential EMoC services such as C/S due to the shortage of staff or equipment needed which was also observed in other studies (40, 51, 63). A study conducted in Sudan to analyze the causes of maternal death in Kassala state showed that 68% of maternal deaths during the study period occurred because women didn't receive medical care in the time when they reached health facility because all health facilities in rural settings were lacking basic EMoC services (57). The same study suggested that lack of availability of EMoC services at facility level led to the loss of trust of communities in health system which may explain why they do not rush to health facilities as soon as delivery starts which contribute to the first delay (57).

Delays in Receiving adequate Care at the Health Facility

Proper assessment of the quality of emergency obstetric health services provided was outside the scope of our study, however, there were some participants who gave sentiments that suggest that they didn't receive quality health services when they

reached the hospital. Women are advised over and over by having an institutional delivery. However, after all the struggling they endured to reach the hospital, some women in our study didn't get the care they needed and they developed OF inside the hospital (6, 35, 40). Negligence from health staff, improper monitoring of women during labor, incorrect diagnosis and delayed referral are defined as factors that are associated with the third delay (51). Shortage of trained staff as well causes the suboptimal quality of health care services provided (63).

It is worth mentioning that sometimes the third delay can be caused by factors that are related to the patient herself or her family members, as it came up in one of our cases. The C/S was offered by the health personnel but her husband refused. The same dimension i.e. delay in receiving health care due to patient-related factors was observed in a study conducted in Malawi and it suggested that a 3B-delay be added to the 3-delays model (51).

Consequences of Obstetric Fistula

The findings of our study were consistent with previous studies conducted in Eritrea, Ghana, Tanzania, Uganda, Kenya, Nigeria and Malawi in terms of the physical psychological, social and economic consequences of living with OF (2, 11, 14, 15, 26, 82-84). Having an OF was not barely having a hole that leaked urine and/or feces uncontrollably. Instead, it was a complex matter that literally changed every aspect of their lives. Women had to live with all dimensions of stigma due to leakage and the smell of urine. They encountered disruptions that made their lives difficult. Those disruptions involved their identity, psychological well-being, their relationships with others at all levels and worsened financial status. They lost their dignity and become dependent on others and seen as a burden.

Living a physically challenging life

The women who participated in our study had to live with continuous wetness from uncontrolled urine leaking. In addition, they had to live with the complications of

padding and excessive cleaning as well as what wetness itself caused which included bruises and sores for their groin area and thighs. Living with these physical challenges was difficult for them. These findings were consistent with what is described in previous studies (2, 11, 14, 84). Furthermore, as mentioned before, all of our study participants came from poor households which jeopardized their access to clean and hygienic diapers. They used pieces of old clothes as diapers which were harsh and unclean to their skin. The same was reported in a study among poor Tanzanian women who had OF (11). Sores in groin area and thighs are even worse when women have concentrated urine due to drinking less water to reduce leakage (2). It was a vicious cycle for the women if they drink water, they leak more, smell more, and are wetter. If they didn't drink water, urine is concentrated, burns the legs cause ulcers. The women think they are helping by not drinking while in fact they unwittingly make it worse. They are in a dilemma to try to choose between the lesser of two evils. This dilemma was observed among Ugandan women (2).

Leaking and waiting

Lack of knowledge about the existence of treatment and lack of financial means prevented women in our study from looking for treatment for OF. They stayed for years without treatment because of similar reasons reported in Ghana and Kenya (14, 26). In addition, lack of surgeons in health facilities where they can reach made it even more difficult to get treatment (14, 26). The same can be a reason that hinders access to treatment in our study since the vast majority of women came from states and treatment exist only in few centers in Sudan. Doctors in the Sudanese states tend to refer women who have complicated injuries to be treated in the capital, Khartoum. Other than that, repair operations in fistula clinics in Nyala and Alfasher are seasonal when a treatment campaign is there (59). Women in our study also reported that they had to go many times to hospital before getting a proper diagnosis and an operation which was observed in Kenya where women didn't get the treatment that they needed at their first contact with the health system (26).

During the period of waiting, some women reported that they were advised by their neighbors and family to use local remedies to reduce leakage which was also noted in Uganda and Kenya (2, 26). Some of them mentioned that they went to "*Sheikhs*" i.e. religious healers for treatment. Studies showed that women used herbs and traditional healing to treat their condition but it didn't work and it caused more injury to their bodies (2, 14, 26).

Mental and Psychological Disruption

The sorrow caused by losing the child and having OF was intense. Our study participants reported being sad, apathetic and loss of interest in life. Some of them wished to die at one point in their long journey with suffering of OF. The same finding was reported in Malawi (15). Although there was no scale used to detect and measure depression in our study sample, they showed some signs of having depression. A study conducted in rural Ethiopia showed that women living with OF had depression and suicidal thoughts (44). Another study conducted in Kenya to measure depression among women who lived with OF showed that 72.9% of study participants were depressed at the time of the study (18). Furthermore, 17.1% of them had the idea of committing suicide (18). The majority of our study participants were not employed. The study in Kenya showed that lack of employment was associated with a deeper degree of depression and it suggested that it might be due to lack of financial autonomy that women encountered (18). All of our study participants had OF for more than three months, the duration ranged from 5 months to 18 years which can increase the probability of them having depression. Having OF for longer than three months was associated with greater degree of depression in Kenya (18).

Disrupted Social Identity

Women in our study defined what is perceived to be "normal" in the Sudanese society to be clean around the clock, fulfilling her duties in terms of her doing house chores and satisfying her husband including his sexual needs, able to produce offspring, being attractive to men, and she is a social human being who takes part in social gatherings.

The same characteristics were described to give value to the women in Tanzania (11). As such, the smell of urine and leaking itself was severely discrediting and stigmatizing for women. For women, it was a source of shame, low self-esteem, anxiety, embarrassment and a cause of humiliation (2, 11, 14, 15, 26).

According to stigma theory by Goffman, those women failed to adhere to what the Sudanese society viewed as "normal" and therefore they were labelled as different with a spoiled identity (2, 11). They had a disruption in their role and identity as women in the Sudanese community as in the Tanzanian and the Ugandan community (2, 11). By leaking urine and feces, women were seen as dirty and smelly, unable to physically do house chores because they became tired faster or because others prevented them from contributing because they were considered unclean (2, 14, 15, 26, 85). Furthermore, many of women with OF (Nine out of 19) were left by their husbands as well as the majority of them were childless. Being childless made them even more vulnerable to be left by their husbands because the presence of children could be protective (16). Not only that, due to urine smell among other things, women were no longer attractive to their husbands (2). Women in our study couldn't attend to social obligations such as going to weddings and funerals due to anxiety, shame or past negative enacted stigma incidents. Socialization is an integral part of the Sudanese society, thus lack of participation in social gathering is considered a violation of social norms which was described in Tanzania as well (11). It wasn't observed in our study but in the Tanzanian context, stigma affected the family as well where the whole household wasn't included in invitations by the community to social events (11).

Also, women internalized their feelings of worthlessness and shame and saw themselves as defected and incomplete. Therefore, they had worries about people seeing urine on their clothes which prevented them from participation in gatherings and in some cases from going to work. Women in our study suffered from enacted stigma. Our findings on how women suffered from stigma both self-stigma, felt-stigma and enacted stigma were consistent with previous studies (2, 11). In addition, social

isolation, disrupted relationships with husband, family, and friends, disrupted financial situation were described in previous studies (2, 11, 14, 15).

Coping mechanisms

Leakage and the urine smell that was constantly haunting women living with OF constituted a stressful condition for them that they needed to cope with. As asserted by Lazarus and Folkman, women in our study used both emotion and problem-based coping (2). The choice for which coping strategy to use was dependent on the phase they are at, at that time. For instance, some women used concealment as a strategy for coping because they couldn't seek treatment at that particular period. Lazarus and Folkman suggested that the choice of the coping mechanism is dependent on the magnitude of the stressing factor and the perceived internal strength to stand against it.

Emotion-focused Coping Mechanisms

Some women concealed their condition to protect themselves from embarrassment and shame. In contrast to what was observed in Uganda, concealment of their condition was not widely used by women in our study although it was effective in protecting women from enacted stigma (4). Some of the participants used silence to cope with mocking and negative encounters because they couldn't do anything else (4). They also isolated themselves from society and chose not to participate in social gatherings because of anxiety and shame. This was consistent with what a study conducted in Uganda reported (2). Support from husbands and close family members gave women strength, financial, and logistics' capability to cope with the consequences of OF. This finding was consistent with what was observed in Ghana (14). However, some husbands and family members discontinued their support when they found out that the condition was chronic as described in Ghana (14).

Women found comfort in the company of other women living with OF. They reported relief when they knew that they were not alone and there are others who were also leaking. Therefore, they found it better to stay at the hospital or fistula home. A study

conducted in Kenya suggested that the company of other women with OF might have protected women from isolation and thereafter a worsened depression status (18). The refuge that women found in the fistula ward is threatened by the dismantling process of the Khartoum hospital that started in 2015 (59). Health authorities demolished the original AFC and relocated it to an existing old ward at the same hospital. Unlike premises for the other specialties, fistula ward was not transmitted to a peripheral hospital which put the fistula ward in continuous risk for destruction (59).

The use of religious coping was common among women in our study which was consistent with what was observed in Tanzania and Uganda (4, 86). All of our study participants were Muslims. Women used religious coping to deal with child loss and consequences of OF. Religion is one of the key aspects of the Sudanese society. Like the majority of the Muslim community, women expressed a strong reliance on God's will to cope with the consequences of OF which was consistent with what was observed in Tanzania (86). They prayed for treatment and strength to live the difficult life that they have. Adverse events such as losing a child or suffering from a serious disease are seen as an exam from God, as well as, people being rewarded if they showed patience (87). Many Muslims take the life of Prophet Mohammed (PBUH) as an example. For example, the patience he showed when he mourned and grieved the death of his only son who died as an infant (87). In contrast to what was described in the Tanzanian context, religious leaders 'Imams' didn't have an active role in women's journey to look for treatment (86). For instance; religious leaders in Tanzania helped identify fistula treatment centers (86). Lack of use of religious leaders by the health system is a missed opportunity to reach for women, their families and their communities.

Problem-focused Coping Mechanisms

The women in our study also adopted problem-focused coping mechanisms. Activities such as frequent bathing, washing their bodies and using scents were used by women to remove the urine smell where they were using pads to maintain their dryness. These mechanisms are similar to what was reported among women in Nigeria, Tanzania and

Uganda (2, 84, 85, 88). To cover the urine smell and reduce urine amount, Sudanese women used fumigation or smoke bath. This coping mechanism is unique to the Sudanese context because they are used as a beautifying activity that women in Sudan generally use (62, 89). There is a hole in the ground that is lined with Nile clay that women put sticks of wood acacia "*Talih*" of "Shaaf" and hot charcoal which produce dense scented smoke (89). Women sit naked on the mat surrounding the hole on the ground for about half an hour to expose their skin to smoke (89). A smoke bath is used only by married women which can be its use challenging for our participants since almost half of them are abandoned or divorced. Smoke bathing is believed to tighten the genital area, which they may perceive to help control the flow/leakage of urine.

As a way of coping, women also looked for treatment for their condition. As observed in our study, Kenya and Tanzania, women's motivation for looking for treatment because they want to lead a healthy life again (26, 47). Some participants who have had operations before reported lesser leakage and that positively affected their daily challenges and their social disruptions which was also observed in the Ethiopian context (44).

The activities that women used to cope with their condition sometimes made things worse. For instance; excessive cleaning and continuous padding led to an aggravation of their physical impairment because it resulted in sores and burning in their private parts which was also reported by women in Uganda (2). It is expected that since some women chose the silence to cope with their condition that might have led to internalization of feelings of self-worthlessness and aggravation of their lack of self-confidence. Self-isolation as a coping mechanism led to sadness and loss of contact with friends and worsened detachment from their social networks. Women travelled to another state for treatment which facilitated their social detachment further. The patience as a tool of religious coping might have made women less communicative about their condition and distant from others.

Methodological Considerations

Limitations of the Study

This study aimed at a rich description of the circumstances surrounding the occurrence of OF, the challenges that women faced due to OF and the strategies they used to mitigate those consequences. Although the study sample i.e. women who live with OF was appropriate to the aim of the study since women are central to the condition being studied, triangulation of other sources of information such as husbands, family members, and health workers would have strengthen the findings by providing a more comprehensive picture of the context of the other actors who play a role in either perpetuating or mitigating the consequences of OF. The story was one-sided. Women's reports were not checked against those other informants' reports. In future research, the views of partners, family members, and community members would be beneficial.

The study was a faculty-based study which might have caused selection bias where our study sample were women who managed to reach the treatment facility and in a way have support to do that. Lack of women recruited from the community may unintentionally overlook women who are less supported by their relatives and are likely to suffer from more severe consequences of OF.

The assistance of the health worker in AFC might have made it difficult for the women to refuse the participation in the study because they might have thought the participation in the study was linked to the treatment. However, the researcher was aware of this possibility during data collection and therefore she repeatedly reminded the participants the voluntariness of participation and it was not linked in any way to getting treatment or any other health-related services.

Strengths of the Study

The issue of OF was relevant to the research agenda in Sudan since the problem of OF is prevalent in Sudan and the region of Sub-Saharan Africa. There is little evidence published about the situation of OF in Sudan as well as the experiences of Sudanese women living with it. The researcher aimed at a deeper understanding of the accounts

of women living OF which was possible with the use of a qualitative design. The worthiness and contribution of this study are evident. The study gave a rich description of the lived experiences of women living with OF.

Triangulation of data collection tools i.e. the use of interviews and FGD enriched the quality of data collected. In addition, it was planned initially that only women who underwent the interviews would be invited to FGD sessions. However, that was not possible due to the time constraints. Instead, newcomers in addition to those who were available from women underwent interviews joined FGD sessions which brought new insights. Audio recordings and feedback loops from the participants on transcripts ensured that direct quotes used accurately reflected the voices of the women thereby improving the credibility of the findings and interpretations.

Because the experiences of Sudanese women living with OF provided rich text and because the study participants and settings were described in as great detail as possible transferability of study methods to other similar contexts may be easily determined.

Future Research

There are areas for future research that would help decrease the ambiguity of the situation of OF in Sudan. One of them is a country-wide prevalence study of OF and the associated risk factors with it. This would be used in advocacy and to enlighten the policy making and priority setting for budget allocation when they have actual figures about the burden of OF in Sudan. This study focused on the experiences of women living with OF. There is no doubt that men also encounter challenges when they have wives with OF so it would be helpful to shed the light on the experiences of these men. Experiences of women with OF in the community who don't seek or fail in their attempts to seek care was beyond the scope of this study, but such community-based studies are warranted if OF is to addressed throughout Sudan. Those women might have more severe consequences of OF. To my knowledge, there is no solid evidence yet that whether or not FGM/C has a causality relation with the occurrence of OF so this, too, is an area for future research. The current study suggests that TBAs had a role in

contributing to the adverse birth outcomes (e.g. prolonged, unresolved obstructed labor resulting in newborn death and development of OF). The role of TBAs, their practices and implications on OF reduction strategies should be researched further. Moreover, the role of community members in reducing OF and improving the reintegration of women with OF warrant further research.

Recommendations

Based on challenges narrated by the women in this study urgency of repair surgeries should be taken more seriously in order to alleviate unnecessary, preventable suffering. The issue of OF and women's wellbeing must also be prioritized in the national agenda and more resources allocated to strengthen the quality and coverage of reproductive health services. In addition, services for treatment and re-integration of women affected by OF are highly needed. Programs that promote the involvement of the community in the issue of OF is beneficial for detection of new cases, mitigation of stigma and improvement of support (be they moral, spiritual and financial).

The findings suggest that in order to implement an effective prevention intervention, special attention must be paid to raising community awareness about the detection of danger signs, what to do and the benefits of skilled birth attendance. In addition, raising awareness of the Sudanese people about the health risks of early childbearing and advocacy against child marriage is critical.

Long-term prevention measures to improve women's wellbeing and to prevent the occurrence of OF and other maternal morbidities are needed such as education of girls and empowerment and financial independence of women in Sudan.

Conclusion

This study aimed at a better understanding of the circumstances that surrounded the occurrence of OF in the Sudanese context, how the lives of women living with OF were affected by it and what they did to cope with the consequences of OF.

Having OF was not merely having a hole that leaks urine and/or feces uncontrollably. Women who live with OF encountered disruptions that made every facet of their lives difficult. Therefore, effective prevention, treatment and rehabilitation strategies must be comprehensive in nature and involve a multidisciplinary and multi-sectoral approach that will ensure their identities, psychological wellbeing, relationships with others and financial status are improved and protected.

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Appendix A – Consent form

***adapted from the Norwegian Regional Ethics Committee informed consent template**

Request for participation in a research project

"Experiences of Sudanese women living with obstetric fistula: A qualitative study in Khartoum, Sudan"

Background and purpose

This is a request for you to participate in a research study that intends to increase understanding of the experiences of women living with urinary/feacal leakage. We want to know how OF is affecting the lives of women.

This study is conducted by Salma Ahmed Eljailani Ahmed, a University of Oslo master student. You have been selected to participate in this study because you live with the condition.

Please read the information below or listen to the information provided by the researcher and ask if anything is unclear or confusing for you. You can consult your spouse or family member if you want. If you wish, the final results of this study can be shared with you upon completion. After you are given satisfactory information and answers to all the questions that you ask, you have the right to decide whether to enrol or not in the study in addition, you can withdraw from the study at anytime.

What does the study entail?

In this study, you will be invited to an interview conducted by the researcher which will take from 45 to 60 min. With you permission, this interview will be audio recorded. You are free to choose the time and place for the interview; the researcher will accommodate your preference.

Potential advantages and disadvantages

Disadvantages: Interview questions may trigger unpleasant memories or private issues that you can feel less comfortable discussing them. It can also cause emotional upset. It is very hard to expect how each respondent will react to such conditions. Some people feel that giving information to a study is a breach for their privacy.
Advantages: You may feel relieved to discuss you discussed your experience. You may also feel satisfied that you are contributing to generation of knowledge about this condition that will be useful.

What will happen to the information about you?

The data that are registered about you will only be used in accordance with the purpose of the study as described above. All the data will be processed without name, ID number or other directly recognisable type of information. A code number links you to your data through a list of

names. Recordings, list of names and data will be stored in a safe place and be accessible only to the researcher; they will be deleted upon completion of the study.

It will not be possible to identify you in the results of the study when these are published.

Voluntary participation
Participation in the study is voluntary. You can withdraw your consent to participate in the study at any time and without stating any particular reason. This will not have any consequences for your further treatment. If you wish to participate, sign the declaration of consent on the final page. If you agree to participate at this time, you may later on withdraw your consent without your treatment being affected in any way. If you later on wish to withdraw your consent or have questions concerning the study, you may contact
Salma Ahmed Eljailani Ahmed ~ Phone no. +249 9 12181877 ~ Email; salmaeljailani@yahoo.com

Consent for participation in the study

I am willing to participate in the study.

(Signed by the project participant, date)

Proxy consent when this is warranted, either in addition to or in place of the participant's consent.

(Signed by representative, date)

I confirm that I have given information about the study.

(Signed, role in the study, date)

Appendix B. Translated consent form –Arabic

موجهات إقرار موافقة الشخص الخاضع للبحث أو من ينوب عنه

أنا الباحث سلمي احمد الجيلاني نقوم ببحث أو دراسة عن الناسور التوليدي وتعتزم زيادة فهم تجارب النساء اللاتي يتعايشن مع هذه الحالة

لقد تم اختيارك للمشاركة في هذه الدراسة لأنك تعيش مع حالة أو تعرفهم أو تقوم برعاية شخص يعاني من الناسور التوليد. نتوقع بمشاركتك أنت والمشاركين الآخرين أن نتحصل على نتائج تفيد المجتمع وزيادة المعرفة عن تجارب النساء اللاتي يتعايشن مع تسرب البول او الغائط

في هذه الدراسة، سيتم دعوتك للمقابلة مع الباحث والتي سوف تستغرق 60-45دقيقة. بعد موافقتك سيتم تسجيل هذه المقابلة صوتيا. أنت حر في اختيار الوقت والمكان للمقابلة .الباحث سوف تستوعب الوقت والمكان المفضل لديك .سوف تسأل بعض الأسئلة عن الاسباب المتعلقة بحالتك والنتائج المترتبة على ذلك ، وجهة نظرك عن نفسك، السلوكيات طلب العلاج، واستراتيجيات التأقلم .كما سيطلب منك أن تعطي معلومات أساسية مثل سنك، والمهنة والحالة الاجتماعية، والخلفية التعليمية، وعدد اطفالك.

الإجراء الذي سأقوم به تجاهك به بعض من المخاطرأو الأعراض الجانبية مثل توارد ذكريات غير سارة أو التدخل في خصوصيات التي يمكنك أن لا تشعر بالراحة عند مناقشتها .كما يمكن أن يسبب اضطراب عاطفي .ومن الصعب جدا أن نتوقع كيف أن كل المدعى سيكون رد فعل لمثل هذه الظروف.

الفوائد :لا يوجد فوائد مباشرة لك؛ ولكن قد يشعر بالارتياح لمناقشة تجربتك .قد تشعر بالارتياح أنك مساعدتنا تعلم المعارف الجديدة حول هذا الشرط من شأنها أن تكون مفيدة أيضا.

ونحن إذ نأمل فى مشاركتك معنا فى هذا البحث , نؤكد لك على سرية المعلومات و الوثائق الخاصة بك , و أنه لن يطلع عليها إلا الباحث المعنى و لجنة أخلاقيات البحوث الصحية القومية.

كما نؤكد لك إمكانية الإنسحاب من البحث فى أى وقت تشاء , و دون إبداء توضيح لأسباب الإنسحاب , ويتم ذلك بالتوقيع على طلب الإنسحاب , و لن يؤثر ذلك أيضاً على حقك فى الإستفادة من البحث .

سنقدم لك الرعاية الصحية فى حالة حدوث مضاعفات من إجراء هذا البحث.

إذا كان لديك أى سؤال أو إستفسار يخص البحث , المشاركين معك فى البحث , أو حقوقك كمشارك أثناء تنفيذ البحث يمكنك الإتصال على سلمى أحمد الجيلاني تلفون:0912181877 ايميل: salmaeljailani@yahoo.com:

إقرار موافقة الشخص الخاضع للبحث

لقد إطلعت على المعلومات الحالية والتي تم شرحها لي وأتيح لى طرح الأسئلة عنها كيفما شئت , و قد تلقيت الإجابات الوافية عن كل الأسئلة , و أنا أقر بالموافقة على المشاركة **طواعية** فى هذه الدراسة و أعلم بحقى فى التوقف عن المشاركة فى أى وقت دون أن يؤثر ذلك على حقوقى فى (مثلاً : تلقى العناية الطبية اللازمة فى أى وقت لاحقاً) .

رمز المشارك.....

إسم المشارك:

.....

توقيع المشارك

.....

.في حال عدم قدرة المشارك على قراءة الإقرار ويحتاج إلى من يشرح أو يترجم له :

إسم الشارح(االمترجم) .....

عنوان الشارح أو(المترجم): .....

توقيع الشارح أو(المترجم): .....

توقيع الباحث: .....

Appendix C Interview Guide

Women

Date:_____

Starting Time:_____ Ending Time:_____

Demographics

- Age: Religion:
- Marital Status: Number of years married:
- Area:
- Occupation: Occupation of husband/partner:
- Highest level of school completed:
- Highest level of school completed by spouse/partner:
- Number of children (alive, provided ages): Number of children (who have died, provide ages):
- How many people live in your household?
- How do you access water?
- Is there electricity in the home?

Icebreaker (questions to transition into main interview questions)

What motivated you to participate today, why are you interested in participating?

Could you tell me all about yourself?

Pregnancy that caused the condition

- Would you please tell me, during which pregnancy did it happen?
- Can you tell me what happened during the delivery?
- Do you remember the type of care you received during labor and delivery?
- For how long were you in labor?
- When you arrived; what care did the health care workers give you?
- Did the baby survive?

Knowledge & Health-seeking Behavior

- When you first noticed something was wrong, what did you think was happening?
- Did you tell anyone? (Who was the first person you told)
    - If no, why?

    - If yes, when and to whom?
- How did you feel telling them?
- What was his/her/their initial reaction?
- How do they treat you now as compared to the first time they heard the news?
- When did you start seeking help and from whom?
- If the hospital was one of the places where you sought help, what did the doctors say was the problem?
- What did they say was the possible treatment for your condition?
- What did/do you think about this plan of care?
- If you went to a traditional birth attendant (TBA), what did they say was the problem with you?
- if the husband is not the one told first about the condition
    - When did you eventually tell your husband? How did your partner initially react to your condition?
- Had you heard of this condition before or knew of anybody living with the condition?
- What did you think about it (or the person you knew living with the condition) before you had the condition?

Lived experience

- Please tell me what does it mean to you to constantly leak urine (or feaces)?
- Do you view (look at) yourself differently?
- How has your condition affected your social life? (probe: Meeting people in gatherings: e.g., funerals, marriage ceremonies, naming ceremonies, etc.)
- What are the attitudes of friends and family members toward you?
- Tell me about the family roles/responsibilities that you used to play/have as a woman before you were leaking?
- Tell me about your ability to do work while leaking.
- Tell me some of the challenges you face as a result of your condition, regarding:
    - Your work
    - You and your husband's sexual relationship
    - Your relationship with friends and family members
- Do you think this condition will affect your future life plans? How?

Forms & Manifestations of Stigmatization

- What do others think about women who leak urine or feces?
- What words have you heard people use to describe women who leak?
- How do these words make you feel?
- Have you experienced any negative reactions based on people's knowledge or suspicion that you leak?
    - Probes: Can you please describe some instances when this has occurred?
- By whom? What exactly did he/she/they do?
- How did it make you feel? Any other instances you want to share?
- Do you at times blame yourself for the condition/or feel guilty? **If yes, why**?

Context and Locality

- Are there places you avoid since you now have this condition? Is there any place you go (have gone) or live (d) where you experience the most negative reactions (or negative reactions most frequently)?
- Can you explain what happens (-ed)?

Responses & Coping Mechanisms

- What has been your response to the negative reactions?
- Is there anything or anyone who helps you deal with the negative reactions?
- Is there anything or anyone who helps you deal leaking or any other physical consequences of the condition?
- Do you attend any support groups?

Problems & Solutions

- What are you most concerned about now that you leak?
- What hurts you most about constantly leaking?
- What can the healthcare system do to help you cope with obstetric fistula?
- What can the community do to help you or other women cope with this condition?
- What can your family and friends do to help you?
- What can the mosque do to help you or other women cope with this condition?

Conclusion

Are there any other thoughts about you and/or your condition you would like to share?

Thank you for your participation

Appendix D FGD guide

FGD no_____ Location_____

Date:_____

Starting Time:_____ Ending Time:_____

Introduction of the participants, information about the study and obtainment of consent for audio recording

- What are the causes of obstetric fistula or uncontrolled leaking of urine/faeces
- How does the community view women who leak?
- Why do you think they are treated in this way?
- How has the leaking affected your life, relationships with others including your family, husband, friends and neighbours?
- What do you think the some of the reasons are for women who leak that won't seek help? What services are currently available to help women living with this condition?
- What can the community do to help make sure that women with fistula are happy and are still a part of the community?
- What do you suggest must be done to reduce the negative consequences of obstetric fistula?

Conclusion

Are there any other thoughts you would like to share with me?

Thank you all for your participation

Appendix E – Exemption letter from REK – Page 1

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Anne S. Kavli	22845512	29.06.2016	2016/952/REK sør-øst A
			Deres dato:	**Deres referanse:**
			03.05.2016	

Vår referanse må oppgis ved alle henvendelser

Viva Combs Thorsen
University of Oslo

2016/952 Lived experiences of Sudanese women living with obstetric fistula; a qualitative study – Khartoum, Sudan Norwegian title: Obstetriske fistler: levde erfaringer i Sudan

We are writing in reference to your Application for Preliminary Approval for the above-mentioned Research Project. The Regional Committee for Medical and Health Research Ethics, Section A South East Norway, reviewed your Application during its meeting on the 9th of June 2016. The Project was assessed in accordance to the Norwegian Research Ethics Act § 4 (2006), and the Health Research Act § 10 (2008), for Regional Committees for Medical and Health Research Ethics.

Institution Responsible for Research: University of Oslo
Project Manager: Viva Combs Thorsen

Project Manager`s project description:
Obstetric fistula (OF) is one of the devastating complication of childbirth that change women life dramatically. Fistula is abnormal openings between birth canal and bladder and/or rectum lead to involuntary leakage of urine and/or faeces. Women afterwards suffer the loss of the child and live with the physical, psychosocial and economic challenges due to incontinence. This study will look into the psychological, social impacts of OF on women lives and how they cope with these impacts through women narratives. Qualitative methods design will be used to describe the experiences of women living with fistula in Khartoum - Sudan. Data will be collected by semi-structured interviews and FGD with women and family members. Research outcome is to provide testimonies of the women living with fistula will be used to enlighten policy making in Sudan and community interventions to minimize the social consequences of fistula and to help women re-integrate back into their communities.

Review

The object of the project is to gain a better understanding of what life is like for a woman suffering from obstetric fistula and their perceptions of obstacles and challenges related to the condition. The project aim to provide information that may contribute in the process of developing solutions to help reduce the negative consequences of obstetric fistula and to influence policy making in Sudan. The object of the project is not to generate new knowledge about health, disease, diagnosis or treatment. The project is therefore not considered to be taken in under the substantive scope of the Act on medical and health research (the Health Research Act), cf. § 2. The project can be carried out without an approval from the regional committee for medical and health research ethics in Norway.

Besøksadresse:
Gullhaugveien 1-3, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

Appendix E –Exemption letter from REK– Page 2

Decision

The committee considers the purpose of this study to be outside the remit of the Act on medical and health research. The project can be carried out without an approval from the regional committee for medical and health research ethics in Norway. It is the responsible institutions' responsibility that the project is carried out with reliability and that local approvals are obtained.

Appeal process

The decision of the Committee may be appealed to the National Committee for Research Ethics in Norway. The appeal will need to be sent to the Regional Committee for Research Ethics, Section A, South East Norway, The deadline for appeal is three weeks from the date on which you receive this letter.

The Committee's decision was unanimous.

Yours sincerely

Knut Engedal
Professor dr. med.
Chair of the Regional Committee for Medical & Health Research Ethics
of South East Norway, Section A

Anne S. Kavli
Senior Executive Officer

CC :k.t.stokke@medisin.uio.no; - Management of Administration, University of Oslo ; Faculty of Medicine, University of Oslo

Appendix F – Approval from Ethical committee in Sudan

Republic of Sudan
Federal Ministry of Health

HEALTH RESEARCH COUNCIL

NATIONAL RESEARCH ETHICS REVIEW COMMITTEE

Date: 3/10/2016

Ethical Clearance Certificate

This is to certify that the proposal entitled ***(lived experiences of sundaes women living with obstetric fistula, a qualitative study – Khartoum , Sudan)*** *submitted by* ***Dr. Salma Ahmed Eljailani Ahmed*** *from* ***University of Oslo –Norway*** *has been approved by* ***the National Health Research Ethics Committee, Federal Ministry of Health*** *to be conducted in the Sudan.*

NB

The principal investigator is requested to submit the final report to the Research Directorate- Federal Ministry of Health.

3/10/2016
Dr. Iman Abdalla Mustafa
Reporter of the
National Research Ethics Review Committee

Appendix G – Authorization letter from FMoH to AFC – signed by manager of AFC as well

Republic of Sudan
Federal Ministry of Health
General Directorate of Primary Health Care
National Reproductive Health Programme

جمهورية السودان
وزارة الصحة الإتحادية
الإدارة العامة للرعاية الصحية الاساسية
البرنـــامج القـومي للصحة الإنجـــابية

التاريخ : 11أغسطس 2016م

السيد/ مدير مركز الناسور التوليدي

الموقر ...

السلام عليكم ورحمة الله تعالي وبركاته

الموضوع : بحث عن الناسور التوليدي

بالاشارة للموضوع أعلاه ، وفي إطار السعي الدؤوب لوزارة الصحة الاتحادية في خفض مراضة الامهات ، نرجو من سيادتكم التكرم بتسهيل مهمة الطبيبة **سلمي أحمد الجيلاني** في إطار بحثها عن تجارب النساء اللائي يعانيين من الناسور التوليدي .

ولكم جزيل الشكر

د. نهاء عبد الفتاح صالحين

مدير البرنامج القومي للصحة الانجابية

ص.ب: ٣٠٣ الخرطوم - تلفون: ٢٤٩١٥٥١٤٧١٠٠+ فاكس: ٢٤٩١٨٣٧٩٩٩٣٠+
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