

# **Rebuilding life:**

**A journey through the lives of women who have endured and been  
treated for obstetric fistula in Tanzania**

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**Centre for International Health**

**Faculty of Medicine and Dentistry**

**University of Bergen, Norway**

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This thesis is submitted in partial fulfilment of the requirements for the degree of Master of  
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*Love, strength and beauty were revealed when I began this journey...*



*... asante sana!*

## **Abstract**

### **Introduction**

Obstetric fistula is a birthing injury which leaves a woman leaking urine and/or faeces from her vagina. This occurs when there is prolonged obstructed labour, and emergency obstetric care is unavailable. It disproportionately affects poor, uneducated women from rural areas and makes them even more marginalized after they have suffered the injury. The constant smell from leaking subjects them to rejection from society, they are unable to work, and are ashamed of their condition. Obstetric fistula can be prevented by early intervention of obstetric care, and can be cured usually through surgery. Currently there is little or no follow-up of fistula patients after being treated, in Tanzania.

### **Aim**

This study aims at exploring the experiences of fistula patients after repair in Tanzania.

### **Methodology**

A qualitative approach was adopted in this study using in-depth interviews, a focus group discussion and observations. With local collaborators, this study was primarily conducted in four regions of Tanzania; Dodoma, Mbeya, Mwanza and Singida.

### **Findings**

The women who had endured obstetric fistula and received treatment also faced some challenges after repair. Out of 30 women with whom we conducted in-depth interviews, 10 remained with some incontinence and the problems attached to leakage continued. How they experienced and coped with the challenges after repair was closely connected to their experiences before treatment. How the women made sense of fistula also influenced their perception and feelings about their situation and their future. Oftentimes, their experiences before treatment involved struggles with their personal identities as women, their roles as wives and their acceptance as daughters-in-law, which affected their experiences after repair. They commonly experienced loss of womanhood, sexuality, family life and self-esteem and many returned to financial debt and dependency on family or community

members. The duration spent with fistula before repair and the success of repair greatly influenced their experiences after repair as well. Almost all who received treatment quickly and were completely dry regained their social lives, however most were financially strained.

### **Discussion**

The discussion draws upon concepts in medical anthropology and existing research to make sense of the findings.

### **Conclusion**

Obstetric fistula is an inequity issue and most of the challenges can be prevented with increased awareness, better referral between hospitals and quality care. Treatment of fistula must go beyond the closing of a physical hole, but address physical, psycho-social and economic challenges to completely rehabilitate the individual affected after repair.

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## **Acronyms and Abbreviations**

VVF	Vesico-vaginal fistula
RVF	Recto-vaginal fistula
CCBRT	Comprehensive Community Based Rehabilitation in Tanzania
MUHAS	Muhimbili University of Health and Allied Sciences
DHS	Demographic and Health Survey
WHO	World Health Organisation
GBD	Global Burden of Disease
TBA	Traditional birth attendant
AMREF	African Medical and Research Foundation
UNFPA	United Nations Population Fund
NGO	Non-Governmental Organisation
NFP	National Fistula Programme
MOHSW	Ministry of Health and Social Welfare

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## **Chapter 1: Introduction and Background**

*“When I sat with my friends I was always unhappy because urine was leaking, so instead I used to stay at home alone.”*

These words were spoken by Saphia, a 36 year old woman living in rural Tanzania, who suffered from urinary leakage for three months after her eighth childbirth. Hidden behind the global estimate of 3,000,000 women suffering from obstetric fistula (Wall, 2006: 1201), are women like Saphia who are silently suffering from leakage, social exclusion and extreme poverty as a consequence. This thesis documents the experiences of women who have lived with obstetric fistula, acquired treatment and have returned to their communities primarily in four regions of Tanzania, namely, Dodoma, Mbeya, Mwanza and Singida.

### **Global burden**

Maternal health and making pregnancy safer has been on the global agenda to address the fifth Millennium Development Goal (MDG), of reducing by three quarters the maternal mortality ratio from the baseline in 1990 to 2015 and to achieve universal access to reproductive health (United Nations, 2000). For every woman who dies from a pregnancy-related cause, another 20 suffer from serious but non-fatal health problems and long term disabilities such as vaginal tearing, severe anaemia resulting from haemorrhage, and obstetric fistula (FIGO, 2009: 38). Accurate prevalence rates of obstetric fistula are unavailable due to inaccurate reporting, underreporting, and shame, which prevent women from speaking about it openly (Miller et al., 2005: 287). There has also been some discussion about the difficulties in calculating estimates (Stanton et al., 2007), however, according to the Global Burden of Disease (GBD), the incidence of obstetric fistula in sub-Saharan Africa is 18.8 per 100,000 women and the prevalence is 184 per 100,000 women aged between 15 – 44 years (Murray and Lopez, 1998 : 260). Obstetric fistula was prevalent world-wide, but now, it is almost completely eliminated in high-income countries through improved availability and accessibility to emergency obstetric care. It now, disproportionately affects poor girls and women, especially those from rural areas with limited or no access to obstetric care and health services (Lewis and De Bernis, 2006 : 2). To address this, the UNFPA is focusing on four key interventions in countries with high maternal mortality

through the Maternal Health Thematic Fund. These interventions are family planning, emergency obstetric and newborn care, human resources for health, particularly midwifery and prevention and treatment of obstetric fistula (UNFPA, 2011: xii).

### **What is it and why does it occur?**

Obstetric fistula is most commonly a birthing injury due to neglected obstructed labour (Muleta, 2006: 962, Wall et al., 2001: 898). Although a proportion of fistulas can be caused by trauma during sexual abuse like in the Democratic Republic of Congo (Onsrud et al., 2008), coital injury in child brides, infections, traditional practices like female genital cutting or other forms of unnecessary surgery, most obstetric fistulas worldwide occur due to prolonged, obstructed labour (Wall, 2006: 1202). It is a hole that is formed between the vagina and bladder, or vagina and rectum, or both, during a difficult childbirth (Bangser, 2002 : 4). When there is prolonged and obstructed labour, where the head of the baby cannot pass safely through the birth canal of the mother, the foetal skull presses the soft tissue of the vagina and bladder and/or rectum against the pelvic bone. Due to this, the blood supply to the tissues is restricted, causing them to disintegrate (ischemic necrosis). This necrosis leaves behind a hole between the woman's vagina and bladder, or vagina and rectum, or both. As a result, the woman uncontrollably passes urine and/or faeces continuously into her vagina (EngenderHealth, 2006 : 1). When a woman is leaking urine through her vagina, she is said to have a vesico-vaginal fistula (or VVF) and when she passes faeces through the vagina, it is called a recto-vaginal fistula (or RVF). RVFs are mostly seen in the most extreme trauma cases, and it usually occurs in addition to VVF (Bangser, 2002: 4).

### **How can it be treated?**

When obstetric fistula occurs, different approaches can be used for treating it. According to Muleta (2006), treatment of obstetric fistula can be conservative or surgical. A large majority of women will need surgical management; however, in some cases, obstetric fistula formation can also be prevented by placing an indwelling urinary catheter for all mothers who have survived obstructed labour. Also, newly formed obstetric fistulas can heal spontaneously in 60% of cases if the margins of the obstetric fistula come together and continuous urinary drainage using a



Foley catheter is used (Muleta, 2006: 964). Midwives can be trained to assist in and/or perform obstetric fistula repair surgeries, as well as to counsel, re-educate, and participate in the preoperative and postoperative rehabilitation of obstetric fistula survivors (Miller et al., 2005: 293).

### **How can it be prevented?**

Obstructed labour can occur due to various reasons. One reason is when the foetus is larger than the space available in the woman's pelvis, and the woman is unable to deliver the child through her birth canal naturally. Other reasons for obstructed labour could be due to malpresentation, and malposition of the baby (Konje and Ladipo, 2000: 291, Neilson et al., 2003: 192) or when there are ineffective uterine contractions, which could be the case in women who have had multiple children (Neilson et al., 2003: 192). When there is obstructed labour, a caesarean section is needed to save the mother and the baby (Creanga et al., 2007:151). According to Wall (2006) trained birth attendants can reduce maternal deaths, prolonged labour and even decrease operative intervention (by allowing normal labour to proceed without unnecessary interference) by the use of simple graphic analysis of the progress of labour (the partograph); yet even this level of basic obstetric care is absent throughout most low-resource countries of the world (Wall, 2006:1206).

### **A socio-cultural and socio-economic phenomenon**

Tsui et al. (2007) mention that the reproductive health of women in general, appears to be affected by the age at which they bear children, which is linked to socio-cultural norms. More specifically, these trends are associated with poverty, low status in the community, low educational level, and rural residence, which additionally leads to malnourished girls who are likely to turn into women of stunted stature (Tsui et al., 2007, Miller et al., 2005, Wall et al., 2001, Chong, 2004, Cook et al., 2004). Obstetric fistula is common in countries where there is malnourishment and early marriages which result in pregnancies before full pelvic growth is achieved (Wall, 2006: 1203) or where access to emergency obstetric care is usually limited and contraception is culturally restricted or unavailable (Creanga et al., 2007: 151-153). Neilson (2003) states that ultimately, what is required to prevent obstructed labour is universal

adequate nutrition intake from childhood and accessibility to adequately equipped and staffed clinical facilities to cater to problems that may arise during labour (Neilson et al., 2003).

Obstetric fistula is a public health problem of low-income countries and it is also a clear indicator of a failed health system for addressing women's reproductive health needs (Bangser et al., 2010: 91).

Not only is this inequity between high-income and low-income countries, but obstetric fistula is widening the socio-economic gap between marginalized groups and others within a country. It is the current day example of gender and health inequity within a country. Women's wealth status is also one of the determinants of receiving skilled care. Women living in the poorest households were 2.8 times less likely to have a skilled birth attendant during childbirth as compared to women living in wealthier households (WHO, 1992-2004: 3). Another study suggests that 11% to 13.1% of pregnancies likely to end in prolonged labour in Niger, Nigeria, and Tanzania could be prevented merely by ensuring that girls 17 years or younger do not bear children. An explanation for this was that adolescent girls who delayed marriage and/or childbearing would benefit by completing their own growth first, thus avoiding putting themselves and their offspring at risk for nutritional deprivation and serious health consequences (Tsui et al., 2007). The lived experiences of women suffering from obstetric fistula are complex, with several aspects that influence their quality of life and their perception of life. The layers of social implications of obstetric fistula include gender inequity, sociocultural norms, government inadequacy in priority setting, lack of resources, lack of awareness, and above all, poverty. Special care is needed to heal not only the physical injuries, but also to mend the social and psychological trauma associated with obstetric fistula (Donnay and Ramsey, 2006).

### **Consequences on lived experiences of those affected**

Living with obstetric fistula means living with incontinence. This implies living with the stench, the inability to control one's urine or faeces as an adult, and often the inability to play the expected role of a woman, a wife or worker combined with misconceptions within the community about the cause of obstetric fistula. It brings with it acute and chronic social,

economic and psychological consequences. The smell of urine and faeces that surrounds these women along with strong community misperceptions about the cause often results in isolation and ostracism. The psychological consequences of obstetric fistula have as yet not been fully explored, but there is evidence that they may be severe. Accordingly, comprehensive treatment and rehabilitation necessarily includes mental health services, but reflection is required on what can be provided in low resource settings (Donnay and Ramsey, 2006: 259 - 260).

### **Rationale of the study**

Research shows evidence of discrimination towards women with obstetric fistula, however, there is a knowledge gap in understanding women's experiences after treatment, when they are reintegrating into their communities. This is because follow-up of women after treatment has been limited. Locating women after they have left the treatment facility has proved to be difficult and many NGOs have not been very successful with follow-up. This inhibits our understanding of what women require to fully reintegrate into society (Donnay and Ramsey, 2006: 260). Zheng and Anderson (2009) also state in their review article that a knowledge gap exists and an evaluation of obstetric fistula prevention programs with attention to post-repair issues is needed (Zheng and Anderson, 2009: 89).

Some needs assessments for women after receiving treatment have shown that there is a concrete need for rehabilitative care. NGOs are playing an important role in shedding light on what aspects need to be addressed. Some NGOs in Niger, Chad and Bangladesh, provide skills training e.g. in textile production, with the aim of improving the socio-economic situation of women with obstetric fistula. Some NGOs are now focusing on spreading awareness and following up with past patients, in order to avoid reoccurrence of obstetric fistula in following pregnancies (Donnay and Ramsey, 2006: 260).

In Tanzania, Pope et al. (2011) did a study on reintegration on a small island in Lake Victoria and found that awareness about treatment was increasing and they were reintegrating into their communities. Some were also re-marrying and having children. They found that time, social support and means of earning an income, especially immediately after surgery were important

in helping women reintegrate. Also stigma was reduced when treatment was sought quickly which eased reintegration (Pope et al., 2011). Research shows that if surgical repair was done less than three months after the occurrence of obstetric fistula, the success rate increased to 93.9% as opposed to 87% if treated after three months (Raassen et al., 2008: 77). According to Wegner et al. (2007: 110) it is imperative that more be understood about how community members can best be integrated into the schemes developed toward obstetric fistula prevention and the care. From the results presented by Pope et al. (2011), it seems imperative that the experiences of women before treatment have to be understood in order to get a more comprehensive understanding of their experiences after repair. This study aims at adding to the limited body of knowledge regarding reintegration of women who have undergone obstetric fistula surgery in Tanzania.

## **Research objectives**

### **General Objective**

- ❖ To explore the experiences of women reintegrating into family and community life after obstetric fistula surgery in Tanzania

### **Specific objectives**

- ❖ To explore how women who have endured obstetric fistula make sense of the condition and how this has affected their future hopes and plans.
- ❖ To explore how obstetric fistula affects a woman's identity and social roles
- ❖ To explore the social and economic challenges endured and coping strategies adopted, before and after obstetric fistula repair
- ❖ To document stories of women who have lived with fistula, undergone surgery, and their lives after surgery by means of digital media

## **Chapter 2: The national context of obstetric fistula in Tanzania**

It is estimated that for every 1000 live births, four or five women die during delivery in Tanzania. However, this number is suspected to be grossly understated. (National Bureau of Statistics and ICF Macro, 2011: 265) The 2010 Tanzania Demographic and Health Survey (TDHS) showed that nationally only 50% of births were assisted by health professionals. However, 80% of all births occurred in rural areas, where only 42% of the births were delivered by a skilled provider. In contrast, 83% of births were delivered by a skilled provider in urban areas. Additionally, only 5% of births were delivered by caesarean section, most of which were in urban centres (National Bureau of Statistics and ICF Macro, 2011: 137). The TDHS report stated that within their sample, less than 1% of the women reported having obstetric fistula and so it was concluded that obstetric fistula was not a public health issue of concern. The report did acknowledge, however, that to be able to draw a meaningful conclusion on the occurrence of fistula in the population, a survey with a very large sample was required with more detailed methods for probing (National Bureau of Statistics and ICF Macro, 2011: 142). It is safe to assume that the prevalence of fistula in Tanzania is also grossly understated considering the high maternal mortality and the low availability of emergency obstetric care.

Since the early 1960s, hospitals in Tanzania have been doing obstetric fistula repairs, however, on a limited scale. The service has not been accessible and/or affordable for many women who have been living with the condition for many years. Obstetric fistula has gained more attention internationally in recent years, particularly in addressing the MDG five to improve maternal health. International and local organisations are working together to address this public health problem. The two key international agencies involved in addressing obstetric fistula in Tanzania, are the African Medical and Research Foundation (AMREF) and the United Nations Population Fund (UNFPA).

In a needs assessment report by Bangser (2002), it was stated that Tanzania depended greatly on visiting doctors from other countries to cater to the need for fistula repairs. There was a need for an increase in capacity of local doctors to perform these repairs. The report also

suggested a need for a national referral system for fistula prevention and treatment, for increasing availability of care in underserved areas, for providing treatment at highly subsidized rates or free of charge, and to raise awareness in communities and among health providers about causes, impact, treatment and costs of treatment for fistula (Bangser, 2002: 19-20).

AMREF addressed these needs by improving service delivery, capacity building and raising awareness. They did this by coordinating and funding training of fistula surgeons and organizing outreach visits. A map of locations where obstetric fistula services are provided in Tanzania is attached in the Appendix.

The National Fistula Programme (NFP) was established in April 2005 with the Ministry of Health and Social Welfare (MOHSW) and Women's Dignity Project (Raassen, 2006: 26) which was funded by the International Federation of Gynaecology and Obstetrics (FIGO, 2009: 15). The NFP is involved in dissemination of information about fistula services, supporting local referral systems that link women to treatment, training of fistula care providers, reimbursement of hospitals for services and conducting advocacy on fistula (Bangser et al., 2010: 97). Under this program, hospitals performing fistula repairs in Tanzania are paid USD 200 for each operated woman. This money is used to provide free treatment to women, pay the women money for their transportation, buy essential supplies for the hospital and in some cases also used for some allowance for the staff (Raassen, 2006: 26).

Women's Dignity is a Tanzanian NGO established in 2001 in Dar es Salaam with the aim to influence health policy and address the inequities towards women within the health systems of Tanzania. The organization is actively involved in sensitising communities by raising awareness about reproductive health including obstetric fistula at the grass-root level. Due to a lack of donor funding, Women's Dignity was closed down in June 2012 but has now reopened as UTU Mwanamke after more funding was acquired.

The Tanzania Fistula Surgeons Association was inaugurated in June 2011. The purpose of the association is to have a group of surgeons, who can offer their time to repair obstetric fistulas, listed under one entity. In locations where there are no obstetric fistula surgeons, a group of

patients can be gathered over time, and an outreach visit by these surgeons can be organized. Although capacity is increasing, hospitals are understaffed, lack skilled surgeons and/or nurses, lack surgical equipment and/or ambulances, and face challenges developing partnerships with neighbouring hospitals for successful referrals (Women's Dignity Project, 2011).

In Tanzania, there is a hierarchy of health facilities within the public sector with increasing level of expertise and services. There is the village health service, the dispensary service, the health centre services, district hospitals, regional hospitals and finally the referral/consultant hospitals that operate at the highest level of services in the country. All four referral hospitals in the country have the capacity to perform obstetric fistula repairs along with several regional and district hospitals.

The bulk of obstetric fistula repairs in Tanzania are handled by the Comprehensive Community Based Rehabilitation in Tanzania (CCBRT), a private NGO in Dar es Salaam, and Bugando Medical Centre, a referral hospital in Mwanza. Complicated obstetric fistulas are referred to these two hospitals. CCBRT also hosts the trainings of obstetric fistula surgeons and nurses, and raises awareness with regular radio broadcasts about treatment for obstetric fistula. CCBRT has also introduced an innovative strategy to mobilize patients through the recruitment of 'ambassadors'. These are commonly relatives of obstetric fistula patients, obstetric fistula patients who have been treated, health officers at various health facilities, religious leaders or doctors. The ambassador's task is to refer the patient to CCBRT. When that is done, CCBRT uses Vodafone's M-PESA system to transfer money for transportation to the ambassador's mobile phone. CCBRT partnered with Vodafone in January 2011 to develop this program (Vodafone, 2011). The ambassador then uses that money to buy the bus fare for the obstetric fistula patient and sends her to CCBRT. After the patient is admitted at the hospital, the ambassador is paid a USD 3 incentive payment for mobilizing the patient. This strategy has proved very effective and the number of patients treated for obstetric fistula at CCBRT rose from 168 surgeries in 2009 to 338 surgeries in 2011, an increase of over 100% in two years (Vodafone, 2011).

With the aim to ease the transition into society after surgery, CCBRT has established the Mabinti project which teaches women treated for obstetric fistula, income generating skills like sewing, beading and how to manage a business (CCBRT, 2011). Similarly, in order to give them a skill for income generation after recovery, patients at Bugando Hospital are taught how to knit while waiting for treatment or recovering from treatment. Currently there is no follow-up for obstetric fistula patients on the community level after surgery. Psycho-social support and general medical follow-up for dealing with stress-incontinence is severely lacking throughout Tanzania.

At the fistula stakeholder's meeting in 2011, it was strongly suggested that MOHSW should move obstetric fistula under Reproductive and Child Health so that it can have a continuous source of funding and be within the priority areas rather than under people with disability and elderly persons section where it stands currently. As obstetric fistula is a morbidity issue, the national road map strategic plan to accelerate reduction of maternal, new born and child deaths in Tanzania 2008 – 2015 (Ministry of Health & Social Welfare, 2008) does not address the problem of obstetric fistula at all.



## **Chapter 3: Methodology**

### **Collaboration with local partners**

This study had a strong local collaboration. First, I was enrolled as an exchange student at Muhimbili University of Health and Allied Sciences (MUHAS) in Dar es Salaam, under the co-supervision of Professor Thecla Kohi. Professor Kohi was also supervising Lilian Mselle, a PhD candidate at the time, who conducted research about women currently living with obstetric fistula in Tanzania. One of my supervisors at UiB, Prof. Karen Marie Moland, was also co-supervising Mselle's work. This study was intended to add to Mselle's work and expand on the understanding of reintegration after obstetric fistula repair in Tanzania.

In Dar es Salaam, I also worked as an unpaid intern (June 2011 – January 2012) at a local NGO, Women's Dignity, which has been actively involved in community sensitization about reproductive health and obstetric fistula. This was one of the main organizations in Tanzania that was conducting active outreach and sensitization about obstetric fistula in rural villages across the country, and also in some parts of Uganda. Their knowledge and experience in fieldwork and particularly in reproductive health in Tanzania was immense. Coincidentally, Women's Dignity was also planning to conduct a research study regarding reintegration and rehabilitation of obstetric fistula patients when I contacted them, and so the partnership was a very natural process. All the fieldwork for this study was jointly conducted with Women's Dignity. This included Women's Dignity staffs conducting interviews with me during the entire study, using their vehicle and experienced drivers to travel to all the villages, at their expense and it was the strong local community knowledge of Women's Dignity staff that made this study possible.

As an intern at Women's Dignity, I had the opportunity to attend the National Fistula Stakeholder's Conference that was organised by them in Dar es Salaam in June 2011. At this unique event, I was able to get a good overview about the problem of fistula in Tanzania through presentations from donors, fistula surgeons and several hospital representatives across the country where fistula repairs were being performed either by resident or visiting doctors.

This was also the event where the Tanzania Fistula Surgeons Association was inaugurated and a valuable forum for networking.

For this study, there was a need for collaboration with hospitals conducting obstetric fistula repairs in Tanzania. This was necessary for two reasons; firstly, in order to get the names and addresses of women who had been previously treated for obstetric fistula, and secondly, to interview health professionals involved with obstetric fistula, for the study. For this, we partnered primarily with Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) and Bugando Medical Centre. I was able to make the contact with CCBRT at the Fistula stakeholder's meeting, while Women's Dignity made the connection with Bugando Medical Centre and several other district hospitals on my behalf, during the course of the study.

### **Recruitment and training of Research Assistants**

As this study was conducted with Women's Dignity, research assistants were recruited from within the organization. Women's Dignity's field coordinator, Catherine Kamugumya, who was responsible for the reintegration and rehabilitation study, acted as co-researcher and translator for me. She is a nurse and midwife by training, who has also completed a Master's in Public Health. She has worked in the field of reproductive health in Tanzania for over 30 years, first with the Ministry of Health and later with Women's Dignity and conducted several qualitative and quantitative research studies. The consent forms and interview guides were reviewed by her and we worked very closely together as a team.

In addition, we recruited assistants through personal references and interviewed eight candidates. The first two candidates recruited quit before starting or just after starting the research because better offers came their way. After that, the next candidate recruited was required to sign an official contract and was hired as an intern at Women's Dignity, to improve retention and accountability.

Two female note-takers were used during the study. One was a current university student, studying community development. Her curriculum required her to do an internship at an NGO. The other was an administrative assistant to the executive director at Women's Dignity, and

had been on previous field visits with the group. It was organization policy to send all employees for field visits at different times to expose them to the purpose of the work they do.

I presented the note-taker with a thorough overview about obstetric fistula and the consequences of the condition. I reinforced this by showing her a documentary about experiences of women with obstetric fistula from Ethiopia entitled, "A walk to beautiful". I also briefed her about qualitative research, methods of questioning, and the importance of observations and recording notes about the surrounding area, body movements, silences and long pauses, emotions and so on. We practiced with a bit of role playing and showing by example. She was also trained on how to operate the audio recorder and to ensure that it was working correctly during the interview. After each interview, we debriefed and shared constructive criticism with each other. One note-taker accompanied us during our field visits in Dodoma, Iringa, Singida, Mwanza and Shinyanga, with the other accompanied us to Mbeya.

One of the note-takers also transcribed almost all the interviews of the study in Swahili. Another person was recruited to translate all the interviews and also transcribe a few of the interviews. The translator had a master degree in Sociology and had worked previously for several research projects for health and community development and also had experience with translations. She signed a work contract that clearly stated all the necessary details necessary for the successful completion of the task.

## **Study design**

A qualitative approach was used in this study. As public health has evolved over the years, it has now widened its scope and also explores how a disease is experienced by the individual, and how social, economic and environmental factors influence health. Qualitative approaches are a good compliment to quantitative approaches that have been traditionally used in health research, while at the same time, also being a good tool on its own, for certain health research projects.

There are three domains where qualitative approaches are most frequently used in public health research. These are studies which explore how economic, political, social and cultural

factors affect health, or studies aimed at understanding how people make sense of their experiences of health and disease or studies of interaction between different actors participating in public health activities (Dahlgren et al., 2007: 1 - 2).

Qualitative researchers also start with a certain common perspective of the world, which is that realities are subjective, multiple and socially constructed, that it is not possible for the researcher to be separated from the informants because they both influence each other, that qualitative research is value-bound, inductive, time and context bound and follows an emerging design. Based on these perspectives, qualitative researchers prefer to pursue a holistic approach so that all parts are interpreted within the overall context, understanding the inseparability of the researcher and the informant and the pre-understanding, expectations and biases of the researcher must be openly debated. These perspectives influence the entire research process from selection of research questions to interpretation and presentation of data (Dahlgren et al., 2007: 12 - 13).

A qualitative research design was used in this study because we wanted to understand, from the perspective of the informant, how life after treatment of obstetric fistula was experienced, within their individual contexts. Qualitative research is flexible and inductive. It uses reality mirrored in the data, as a starting point. Based on the data, with an open mind, new concepts, hypotheses or theories are discovered (Dahlgren et al., 2007: 13). In the case of understanding reintegration after obstetric fistula repair, not much research has been conducted, and so, it was necessary to have a flexible approach so as to explore the lived experience of the women, after repair. Obstetric fistula is also a sensitive topic, where the affected have experienced some stigma, at least in the past. Flick (2009) suggests that in order to understand a complex, multi-layered phenomenon, it is most effective to adopt qualitative methods (Flick, 2009: 15-16, 25).. In this study, the complexity of experience after treatment, incorporating the physical, social, psychological, and economical challenges within a specific context was too complex for quantitative methods.

Different qualitative research tools were used in this study. A combination of in-depth interviews, a focus group discussion, observations, and documentation using film and photography were used in order to effectively capture the data and have a better means to disseminate information after the study. The video and pictures were used to give another dimension to the data collected, and allow the voices and faces behind these stories to emerge with their messages.

### **Study setting**

As this was a collaborative study with Women's Dignity, the regions for conducting research were decided on jointly. Study locations were chosen based on the largest clusters of possible informants, feasibility of travel, and covering a wide geographical range of the country. Refer to the map in the Appendix.

Tanzania is divided into thirty regions (*mkoa*), four of which were added in March 2012<sup>1</sup>. Regions are subdivided into districts (*wilaya*), divisions and wards, villages (*kijiji*) and hamlets (*kitongoji*). This study was carried out primarily in the regions of Dar es Salaam, Dodoma, Mwanza, Mbeya, and Singida, however some informants very close to the borders were interviewed in Shinyanga, and Iringa as well, covering a wide geographical area within Tanzania.

There were two kinds of study settings, one was hospital based where we interviewed obstetric fistula surgeons and nurses, while the other component was community based where we interviewed ambassadors and women who had been treated for obstetric fistula. For the hospital component, we interviewed at CCBRT in Dar es Salaam and Bugando Medical Centre in Mwanza. CCBRT is the largest provider of disability and rehabilitative care in Tanzania. Annually it provides care to 120,000 people with disabilities and their caregivers. It serves a total of 3 million people in Dar es Salaam and 7 million people in the surrounding regions (CCBRT, 2012).

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<sup>1</sup> Four new regions, namely, Geita, Katavi, Njombe, and Simiyu were added to Tanzania in March 2012. <http://allafrica.com/stories/201203090225.html>. For this thesis, we will use the map of Tanzania as it was during the time of the study. Geita, for example, was a district in Mwanza region at the time.

Bugando Medical Centre is a consultant and teaching hospital for the lake and western zones of Tanzania. It has 900 beds and approximately 900 employees. It is a referral hospital for six regions, including Mwanza, Mara, Kagera, Shinyanga, Tabora and Kigoma and serves a catchment population of approximately 13 million people (Bugando, 2012). Doctors and nurses from the obstetric fistula wards were interviewed at both hospitals.

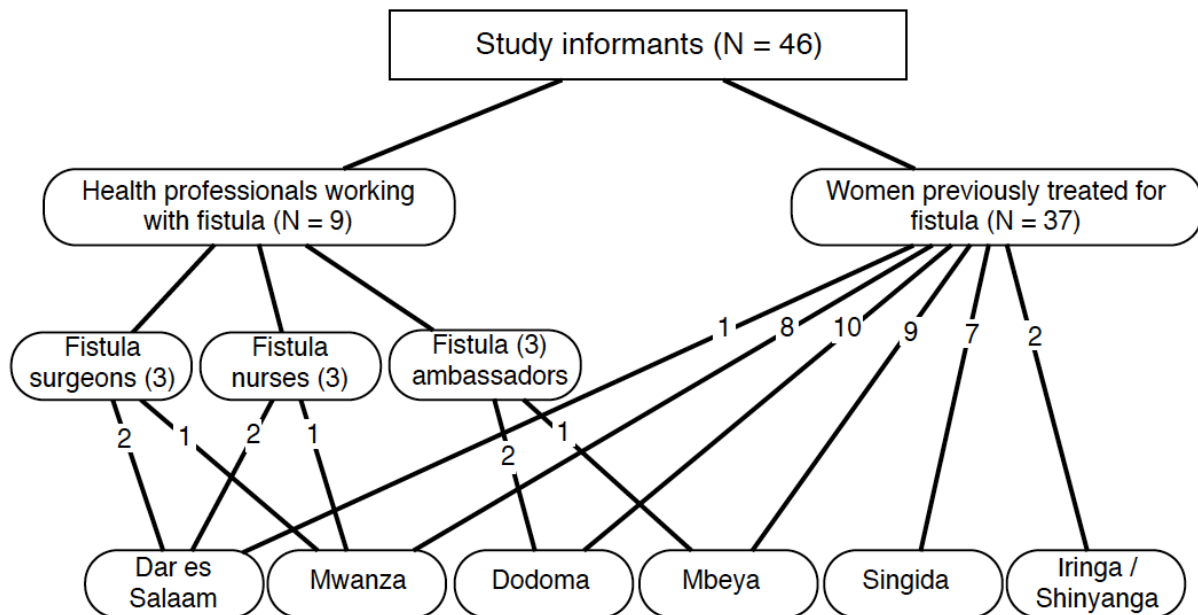
For the community based component, the women who had undergone obstetric fistula repair came from 4 districts of Dodoma, 3 districts of Mwanza, 4 districts of Mbeya, and 1 district each in Shinyanga, Iringa and Dar es Salaam and all except one were interviewed at their homes. The women in Singida region were called in at the hospital for a focus group discussion. For those informants, we did not collect information about the districts that they came from but they were also scattered across the region. Throughout the study, there was never more than one informant from the same village. In addition, four ambassadors were interviewed in three different districts of Dodoma and one in Mbeya. Most of the women came from a rural setting, except for one informant from an urban setting and three informants from an urban-rural setting. Ambassadors were usually located at district centres.

## Characteristics of informants and recruitment

### Characteristics of informants

Study informants were of two types; health personnel working in the field of obstetric fistula, and women who had already been treated for obstetric fistula. A total of forty-six informants were recruited for the two components of the study as shown in the flow chart below.

Refer to the Appendix for an informant profile table. Two obstetric fistula surgeons and two obstetric fistula nurses were recruited from CCBRT and one head obstetric fistula surgeon and one head obstetric fistula nurse at Bugando Medical Centre. The CCBRT ambassadors were



interviewed during community visits in Dodoma and Mbeya. One ambassador was an employee at a local hospital, one was a relative of an obstetric fistula patient, and one was a social worker employed with an NGO working on prevention of female genital mutilation.

Thirty-seven women who had previously been treated for obstetric fistula were interviewed and they varied in age from 17 to 75 years spread evenly across the spectrum. Twenty-two of the informants were treated within one year of getting obstetric fistula, eight were treated after one year and we do not have this information for the seven informants from Singida. All

informants had reintegration time of at least six months after treatment except for one informant who got treatment only three months before the interview. The distribution of informants by ethnic affiliation is shown in the table below. The informants for the focus group discussion were a convenience sample. These were women who had previously engaged with Women’s Dignity, had been provided skills training or financial assistance to help during reintegration and some were now advocates within their communities spreading awareness and mobilizing others with fistula to get treatment.

### Recruitment

A combination of purposeful and convenience sampling was used in the recruitment of informants.

Regarding health personnel, we interviewed doctors, nurses and ambassadors from CCBRT and Bugando who agreed to be interviewed for the study. Women who had been previously treated for obstetric fistula, was a greater challenge. The first step was to get details of patients from the hospitals. First, we got an overview from CCBRT showing what regions, the bulk of their obstetric fistula patients came from, in the past year. The highest concentration of patients came from Mbeya, followed by Morogoro, while Dodoma and Ruvuma had the third highest concentration. After speaking to surgeons at CCBRT, we learned that the ambassador in Mbeya was also very active, and would be a good informant. So we selected Mbeya as one region. Women’s Dignity was already planning a health worker training in reproductive health in Dodoma and so it was more feasible

Ethnic Group	Informants (N = 37)	Region	Type of Interview
<b>Nyakusa</b>	9	Mbeya	In-depth
<b>Sukuma</b>	8	Mwanza/Shinyanga	In-depth
<b>Gogo</b>	7	Dodoma	In-depth
<b>Nyaturu (most likely)</b>	7	Singida	Focus Group Discussion
<b>Hehe</b>	2	Dodoma	In-depth
<b>Bena</b>	1	Dodoma	In-depth
<b>Maasai</b>	1	Iringa	In-depth
<b>Sumbwa</b>	1	Mwanza	In-depth
<b>Ethnic Affiliation unknown</b>	1	Dar es Salaam	In-depth



to continue this research in Dodoma after that training was completed. So, Dodoma was selected as the second region. Bugando Medical Centre had most patients from the Mwanza region, and so that was selected as the third location. Women's Dignity had previously mobilized and worked on rehabilitation with a group of obstetric fistula patients in Singida. Due to this contact, a focus group discussion with these women was arranged in Singida.

After the regions were selected, patients treated at CCBRT were recorded from their VVF operation register. This showed the patient ID number, the region they came from, the date of surgery and whether they were 'cured' or not. Cured in this case was defined as the successful closing of the hole or fistula. I was advised by my supervisors and Women's Dignity, that it is common that individuals relocate after repair and it would be much harder to find patients who were treated several years before. We also wanted to interview individuals who had at least 6 months to reintegrate, for us to get a better picture of their experience. For this reason, all patients who had undergone VVF surgery at CCBRT from a year to 6 months before the interview (August 2010 – February 2011) were recorded. Later, these patient IDs were looked up in the hospital computers to find some details about their name, address and/or contact numbers. Similarly Women's Dignity, through their contacts, got names of past patients from Bugando medical centre, and other hospitals in Dodoma and Mbeya. The informants recruited for the focus group discussion, however, were contacts of Women's Dignity and we knew they could be located even though they were treated several years earlier. Therefore, we did not stick to the above mentioned criteria for the focus group discussion.

### **Tracing informants in the field**

Tracking down past patients at their homes was one of the most challenging tasks in this study. As mentioned above, patients often relocated after repair. Many did not have clear addresses or contact numbers. Or if they had contact numbers, oftentimes the number was not reachable or the phone was switched off. Many contact numbers given at the hospital were of relatives or others who helped them reach the hospital. Innovative approaches had to be used to overcome this challenge.

First, we called the patients for whom we had contact numbers. If reachable, oftentimes this would lead us through a chain of contacts before we were able to reach the individual. Sometimes we would also find that the location given at the hospital was different from where they were currently located. If we were in a district that had a CCBRT ambassador, they would sometimes know where the patient lived or how to contact them even if a contact number was not provided at the hospital. For others, if we had the name of the district and their village, we would drive to the general location, and ask people in the area to guide us to their village. At the village, we would meet with the village executive head that would help us locate their home. Sometimes, after arriving at a village, we would still be unable to locate the person's home. It could be because they had relocated, or had given a different name at the hospital than what they were commonly addressed as in the village. Twice, we visited the primary school at the village, and asked the principal to see if any of the students knew of the person we were looking for. Once, I had to make a brief speech to all the students with words of encouragement, and then they were asked about the informant we were looking for. To the best of my knowledge, the disease was not mentioned, and the students were just asked if they knew someone by that name. This helped us find the informant in two different locations. Sometimes we spent over eight hours driving on dirt roads, without successfully locating the informant.

## **Data Collection**

Data collection for the study was conducted from 19th August 2011 – 17th January 2012; however I stayed in the field from June 2011 – January 2012. Other activities included fieldwork planning, obtaining ethical approval, transcription and translation of data. A table showing the times and locations for data collection are attached in the Appendix.

For this study, semi-structured interview guides (attached in the Appendix) were used for the in-depth interviews. For the focus group discussion, a formal interview guide was not used but similar topics were addressed. The interview guide evolved as the field work went on, based on some of the answers we heard. Also, the interview process developed along the way. We started by introducing ourselves and the project, and then going straight into the questions

from the interview guide. I would ask the questions in English, and the co-researcher would translate them for the informant and so forth. After every interview we would debrief and share constructive criticism with each other. We found that informants were not always elaborating on answers as much as we had hoped, even when we tried to probe them. We constantly brainstormed on how to improve the interviews.

In order to get “thicker” stories from the informants, we tried to start the interview with a very open ended question, asking the women to speak of their lives from when they were children, what they liked to do, when they got married, when they got obstetric fistula and so on. After the informant spoke, and got stuck, then we would turn to the interview guide and start probing based on previous responses. This worked for some informants, while others were still less chatty. I struggled with developing a connection with the informant due to my lack of language competency. In order to develop that connection, we decided to try starting the interview by sharing with the respondent, my own story. I would speak of my childhood, when I developed a stutter, social stigma and social support that I experienced, relationships that I had, how I coped with it, what my fears and interests were and what I hoped to do in the future. This was a chance for me to develop some familiarity with the informant, and to show by example, how they could speak about their own lives. This approach worked quite well for most of the interviews. As the fieldwork went on and the familiarity with the questions increased, Catherine Kamugumya would do some of the probing herself. Also, in some interviews when we felt that the constant translating was interrupting the flow, Catherine Kamugumya would continue the interview in Swahili, and I would hear the transcription and translation later. We changed our approach slightly with each informant, depending on the situation. The earlier interviews were approximately 30 to 40 minutes, while the later interviews lasted between 60 to 90 minutes.

All in-depth interviews had at least three people with the informant, which included the co-researcher/ translator, a note-taker and me. In some cases, the local health worker who accompanied us would also sit through the interview. For two interviews, the local health worker assisted in translating Swahili into the local language for the informant and vice versa. In

this case, I stepped away and the co-researcher conducted the interview. At all times, there were only females in the room, with the informant, during the interview. If the local health worker was a man, he was asked to wait aside with our driver. Similarly, other relatives of the informant were asked to step aside. This included husbands. In order to do this in an acceptable way, we would speak with the husband, if he was there, and explain why we had come, and that we would be interviewing him as well afterwards and so we did not want him to hear the questions just yet. In this way, the husband was not offended, felt included and waited patiently for his turn. The discussions with husbands were brief, and were used as observations for the study.

The focus group discussion was conducted entirely in Swahili and lead by the co-researcher. Almost all the informants in the focus group discussion had interacted with the co-researcher in the past as Women's Dignity had provided them with some skills training and start-up capital to help them get back on their feet financially. They were also used by Women's Dignity to help mobilize other obstetric fistula patients in their communities. This was also an older group of women who had been treated many years before. The focus group discussion was held in a room at the district hospital in Singida.

For every interview, we had a note-taker who ensured that the audio recorder was working, and took hand written notes about the surroundings, emotions expressed, and body language during the interview. Also, most informants agreed for their video and photograph to be taken. For the video clip that was made, audio visual content was selected based on the findings. The aim was to present a few case stories that represented the effect of the experiences before repair to the lived experience after repair.

## **Permissions and Ethical Approval**

### **Legal Permissions**

To conduct research in Tanzania as a citizen of another country, a minimum of two permits are needed; a residence permit and a research permit. As I was enrolled as an exchange student at a local university, I was granted a student visa/residence permit, class C<sup>2</sup>. In order to get a research permit, I first needed ethical approval from the appropriate ethical review board. As a student at the university, I got ethical approval from the MUHAS Ethical Review Board after making minor reviews to the proposal. This approval, along with the proposal was then submitted at the Tanzania Commission for Science and Technology (COSTECH), which later issued the research permit. Both documents are scanned and attached in the Appendix.

### **Informal permissions**

For each region that we visited for conducting research, we first reported to the regional hospital and notified them that we were in the region for research purposes. Often this meant that we spoke with the regional medical officer, and signed in the hospital's guest registry. This time was also used to brief the medical officer about obstetric fistula and where things stand. Catherine Kamugumya, the field coordinator at Women's Dignity and the co-researcher, would use the opportunity to speak of community sensitization, and reproductive health in general. She would also distribute Women's Dignity's brochures and calendars, and get an overview of where things stand within the region regarding reproductive health. Then we would move on to the district hospital, and do the same at the district medical officer's office. At this stage, we would often ask for a local health worker to accompany us on our field visit. This was done for a few reasons. It allowed us to have a local who often spoke the local language if the need arose, they would help us locate villages, if the police stopped us for any reason, it was better to have a local with us, and finally to educate the local health worker about obstetric fistula, how community research is carried out and for them to know about the situation of obstetric fistula

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<sup>2</sup>Issued to foreigners such as missionaries, students, volunteers, researchers or retired persons:  
[http://www.moha.go.tz/index.php?option=com\\_content&view=article&id=38&Itemid=137](http://www.moha.go.tz/index.php?option=com_content&view=article&id=38&Itemid=137)

patients in their area and raise awareness. On arrival at the village, we first met with the village chairman, and we signed in their guest register after explaining why we were visiting their village. Then they would assist us in locating the informant. After completing all the interviews within a district or a region, we re-visited the district medical officer and the regional medical officer to report about the work we did, before leaving the area.

### **Ethical considerations**

Informed consent was taken from all study informants. There were two written consent forms; one was for the interview and another for taking pictures and video. The consent forms were translated from English to Swahili and were given to every informant in the study. If they were able to read themselves, they were asked to read the forms, and were free to ask us any questions. For those unable to read, the contents of the form were read out and a thumb print was taken as a signature. For all informants, the main points of the consent were verbally restated, to ensure that the contents were understood. We also stressed that their participation was completely voluntary, and that they were free to decline or withdraw without any explanation or consequence whatsoever. All informants were happy to conduct the interview and for it to be audio recorded, but some did not want their picture or video taken. Also one informant agreed for her video to be taken provided that her face is not shown so a clause was added to the consent form to state this preference before consent was given. All the consent forms were kept confidential. Both English and Swahili versions of the consent forms are attached in the Appendix.

Additionally, the principles stated in the World Medical Association's 'Declaration of Helsinki' (WMA, 2008) were followed by the research team throughout the study. Respondents were also compensated for their time after the interview. There was a minimum amount of TZS 10,000 that we gave to each informant individually, and the husbands of informants were also paid separately. Many informants received a much larger sum depending on what they said they needed to improve their socio-economic status, however the respondent was not at all aware about any compensation during the interview. Women's dignity plans on following up with informants whom we provided some start-up capital.

Multiple backups of audio files, video files and pictures were made on a daily basis. Backups were securely stored, password protected and confidentiality maintained. Confidentiality of data was also maintained when transcriptions were given to the translator. The translator was required to sign a contract which clearly states the payment for each task, when the payment would be made, and confidentiality of the data. The translator was allowed to work from home, but was asked to delete all the data after the translations and transcriptions were submitted from all sources of data storage which included flash drives, personal computer, and email. Names and other identifiers of informants were deleted from the transcripts before they were given to the translator. A few weeks after all translations were submitted, I cross checked by asking the translator to re-send certain translations, to which she responded saying she no longer had them as she had deleted them as per the agreement in the contract. In this thesis, all names of informants have been changed to protect their confidentiality.

The video accompanying this thesis will not be posted online. It will be separately handed to the examiners for evaluation and will be shared at meetings and events for the sole purpose of advocacy and dissemination.

### **Data analysis**

Data analysis for this study has been a continuous process throughout the course of the research. As mentioned earlier, preliminary analysis was done during fieldwork. We roughly transcribed the interviews and debriefed after each interview. Based on the responses, we added some questions to our interview guide and changed our interviewing approach in order to get the best data quality. I also continuously asked my research collaborator and the note-taker, both native Tanzanians, their interpretation of what the informant said in order to make sure I was not misunderstanding anything. A more thorough and systematic analysis of the data was done after all the interviews were transcribed and translated.

### *Transcription and Translation*

All interviews were digitally recorded as audio files. These were transcribed in Swahili as that was the language used in the interviews, except for the interviews with the obstetric fistula surgeons and one of the obstetric fistula nurses, which were conducted in English. The note-taker at most of the interviews transcribed all interviews. Some of the field observations and notes were included within the transcriptions in parenthesis. These transcriptions were then given to the hired translator, and we received these documents in a Microsoft word format with an English translation below the Swahili text, line by line.

### *Preparation for analysis*

First, all the transcriptions were read thoroughly ordered by region and a broad mind map was sketched showing some of the different areas covered in the data. These broad topics were similar to those in the interview guide, for example, social, socio-economic, physical, and psychological perceptions of the informant regarding life with obstetric fistula and after treatment. While reading through the transcripts, a general informant profile table was made. This included demographics, some relevant behavioural and social patterns, awareness levels, and the success of the treatment as perceived by the informant. All the transcripts were then converted from word documents into text documents and imported into the software, "OpenCode" version 3.6.2.0 (Umeå University Dept. of Public Health and Clinical Medicine, 2012). Graneheim and Lundman (Graneheim and Lundman, 2004) describe the steps of qualitative analysis which include identification of meaning units, condensation, coding, developing categories and finally themes. This was used as a guideline for my analysis.

### *Condensation of meaning units and coding*

A *meaning unit* is defined as "the constellation of words or statements that relate to the same central meaning" and the label of a *meaning unit* is referred to as a *code* (Graneheim and Lundman, 2004: 106 - 107). Meaning units were condensed while preserving the core. In my analysis, text were condensed, coded or both. There was not always a clear distinction between



condensation and codes, and so this was grouped together as the first phase of my analysis. For simplicity, I shall refer to this as coding. All the transcripts were coded in this way, using the software, OpenCode.

### *Reflection*

After coding a few interviews, I would take a step back and reflect about the bigger picture. I would skim through the codes, write them out on paper, thinking about possible categories or emerging themes. I did this about three times during the coding process.

### *Categorizing the codes*

After all the interviews were coded, I grouped them into categories. Categories are defined as “a group of content that shares a commonality” (Graneheim and Lundman, 2004). In order to do this, I printed out all the codes from OpenCode as a list. Due to the previous reflection process, I had a few categories in mind already. I started with my initial list of categories and colour-coded them within the list of codes. In that process, I also added more categories. Some categories were, ‘understanding disease’, ‘stigma’, ‘emotional support’, ‘financial constraints’, and ‘hiding’.

### *Finding patterns*

After grouping ‘common codes’ into categories, I looked at the emerging themes and patterns that brought light to the research questions. How do women understand and perceive obstetric fistula after repair? What have they experienced before treatment that influenced their experience after treatment? What were the challenges that they were facing after treatment? How do they cope with the situation? This process required finding some trends in the experience before obstetric fistula that could affect their experience after. Some of these questions were put into a table, to count the frequency of answers, in an effort to determine what the dominant theme was. For example, if the husband had abandoned his wife because of obstetric fistula, I looked how soon after getting obstetric fistula was she able to get treatment. What was her understanding of the cause of her obstetric fistula? And so on. I counted answers

in order to make sure not to focus on the 'exotic', and that I gave the women their rightful voice. Throughout the writing process, original transcripts were re-checked to make sure that context of statements was maintained and that the findings are representative of the study informants.

### **Reflections on researcher's position**

As soon as I arrived in Tanzania, I lived with a Tanzanian family. The daily interaction with native Swahili speakers helped me work on my language skills and exposed me to the Tanzanian culture. As an intern at Women's Dignity, I made a point to interact with all my colleagues and participate in social events. I tried to integrate as much as I could by taking local transportation, interacting with street vendors and so forth. I knew I was an 'outsider' in Tanzania but I used my time during the planning phase to immerse myself into the culture. Even though I could not speak Swahili, I was getting some Swahili lessons from friends I had made, and my vocabulary did increase over time. By the time I left Tanzania, I knew my greetings, I could bargain and I was able to communicate with a combination of hand gestures and strategically placed words.

I have a Bachelor's degree in Anthropology and have grown up in a low-income country. Pakistan and Tanzania are in some ways different, however, in many ways, they are also very similar. I have previously worked for three years at a not-for-profit health research organization, coordinating public health research projects and implementing health informatics in both rural and urban locations in Pakistan. I have participated in both quantitative and qualitative research projects and learned the challenges of each method in practice. I have also travelled to several international conferences in Uganda, Kenya and South Africa. During my time in Uganda, I also made a short film about mobile technology being used for an education project there. All my experience combined, gave me an advantage despite being an 'outsider' in Tanzania.

Also, in Tanzania, there is a prominent second or third-generation Indian population who control a sizable portion of its economy. There is an underlying animosity between the Indians

and the Swahili people, in general. However, fortunately for me, I was perceived to be European rather than having an Indian heritage, which worked to my advantage at times.

## **Theory and concepts**

In this thesis, a few theories and concepts will be used to understand and discuss the findings from this study. These concepts are described below.

### **Illness Causation and health seeking behaviours**

Susan Whyte, in her book, *Questioning misfortune*, speaks of how an illness is understood and how that understanding influences the actions that follow it. She speaks of the symptomatic idiom versus the explanatory (aetiological) idiom. Symptomatic idiom, as the name implies, is when treatment for the symptom is sought while the explanatory idiom is when the treatment for the cause of the symptom is sought. In life, she explains, problems are common. A disease or illness, can be thought of as a problem and when it occurs, its symptoms are addressed. When the symptoms do not disappear, or they persist for an extended period of time, perhaps even years, then an aetiological perspective is adopted and treatment of the cause of the symptoms is sought (Whyte, 1997: 25-26).

Within symptomatic treatment, one starts with the simplest form, for e.g. each family will have a home remedy or an herb, or a local traditional healer that they trust over the years. The problem is initially tackled in that way, before seeking further help (Whyte, 1997: 25). Kleinman describes the three social arenas within which sickness is experienced and reacted to - the popular, folk and professional arenas. The popular arena involves healthcare by family, social networks and the community. It is within this arena that decisions about when to seek additional care, whom to consult, the efficacy of care and whether to comply or not, are made. The folk arena includes non-professional healers that could be grouped under sacred and secular groups by ethnographers. The professional arena includes professional scientific (western) medical doctors and professional indigenous healing traditions like Chinese, Ayurveda, Yunani and chiropractic (Kleinman, 1978: 86-87).

When the illness or problem persists, there is a shift in perspective. Then, the causes of the symptoms are considered pivotal in order to alleviate the illness. There is then a belief that there is another agent or cause behind the symptoms, which must be addressed in order to gain relief. This shift in perspective is described as the shift towards the explanatory or aetiological idiom (Whyte, 1997: 26).

Symptoms do not exist in isolation but instead are seen in the context of other symptoms and social and ritual relationships. In order to understand an illness, symptoms are therefore continually assessed in relation to what has already been tried. Hence, the perspective of understanding disease can shift from natural to supernatural, symptomatic to aetiological and back again. All illness is assumed to have a cause; however, that perspective is only acted upon, in the situation when an illness is not cured by addressing the symptoms. In that case, it is imperative that the aetiological perspective is adopted for healing to occur (Whyte, 1997: 27-28).

### **Dirt and pollution: a deviation of perceived order**

Mary Douglas, in her book, 'Purity and Danger' speaks of the concept of dirt and impurity having roots in religion or hygiene, and explains that the concept of dirt at its core, is associated with matter being out of place. If that holds true, it suggests that dirt is never a unique isolated event, but rather part of a system or order which can get out of place. This idea of dirt leads to the field of symbolism and the symbolic systems of purity. Culture, in the sense of the public, can create perceptions of order. These perceptions are developed by taking in some cues and rejecting others. The uncomfortable facts that are rejected are either ignored or distorted so as not to disrupt the established and accepted order of things (Douglas, 1966: 36-38).

An anomaly, she describes, is an element which does not fit a given set or series. These anomalies can either be treated negatively, where they are ignored, just not perceived, or condemned or they can be treated positively, where it is confronted and there is an effort to create a new pattern of reality in which it then has a place. When a particular sense of order is created as part of a culture, it has authority, and mediates the experience of the individual.

Cultural categories are public matters and they cannot so easily be subject to revision. Anomalous events can be labelled dangerous and oftentimes the individuals sometimes feel anxiety when confronted with an anomaly. Therefore, if uncleanness is matter out of place, it must be approached through order (Douglas, 1966: 38 - 41).

## **Findings chapters 4, 5, and 6**

In this section, I will present the findings of this study in three chapters. The findings are presented with the perspective of how women who have suffered from obstetric fistula experience it with a focus on reintegration. As presented earlier, there were two groups of informants. One group represented women who had undergone obstetric fistula repair and the second group included health professionals who have worked with women who had obstetric fistula. From the interviews, it was evident that health professionals did not know much about what happened with their patients after repair because of a lack of follow-up, and so the focus of the findings is primarily based on interviews with women who have undergone obstetric fistula repair.

In the following chapters, I refer to the concept of a misfortune. A misfortune can mean many different things to different people. In her study of the Nyole in Uganda, Susan Whyte identifies four kinds of misfortune. Misfortune can be a 'failure of health' where there is some sort of sickness, or a 'failure of prosperity', where there is some reason for reduced income or food supply, or a 'failure of gender' where problems of marriage, reproduction and sexuality are experienced, or lastly, a 'failure of personal safety' where a natural hazard could destroy or hurt people and/or property (Whyte, 1997: 16-18). I will use her concept of misfortune in the analysis of the findings.

## **Chapter 4: Making sense of obstetric fistula**

A sudden onset of illness causes feelings of uncertainty and anxiety for the patient and their families. There is a desire to explain such an event. What happened? Why did it happen? Why did it happen to me? Is it dangerous? These are the type of questions that arise in such situations. (Helman, 2001: 165) In this study, the misfortune faced by the informants is a birthing injury, obstetric fistula, and the challenges that accompany it. It is anticipated that how obstetric fistula is understood, i.e., what caused it and why it happened, influences how the informants experience the condition, how they go about seeking care, how they feel about themselves, how they cope with the situation, how they are able to reintegrate into their communities, and how they would think of the condition in the future. This chapter aims at exploring how the misfortune of obstetric fistula is understood, and how that understanding influences their lived experience and future planned behaviours related to childbirth.

### **Perceptions of the cause of fistula**

All informants had their own personal experiences with obstetric fistula, and had developed an understanding of why it happened, based on the specific circumstances surrounding the birth and their life in general. All had been treated for obstetric fistula, and so had eventually come to learn that it is a treatable condition. However, only four of the informants said they had heard about obstetric fistula before they got it themselves. Even though they now knew that it was a known condition, very few had seen others in their village experience the same. This could be because it was not common, but it could also be that, those who got it, often hid it from the community at large. This unfamiliarity with the condition led to uncertainty and speculation.

### **Is it a 'normal' disease?**

If a woman had not seen or heard of another woman with a similar problem or heard about it on the radio, she felt that the condition was unique to her. The common perception was that if a disease was 'normal' or familiar, then it was curable. Ruby said,

*“Generally I thought I was bewitched and many people said this disease used to attack old women and that they were dying from that disease, as there was no cure. They were saying that ‘either you are bewitched or when you were operated, they made a mistake and did something wrong on the urine vessels’. Therefore I was asking myself, ‘what disease was it?’ I was not sure whether I was bewitched or if it was just a normal disease ... frankly speaking I had never heard about it. It is my brother-in-law who told me that he went and asked some people about it. He explained to them how I was suffering and they said that this disease is curable and that I should not get worried and that later on I will be treated. Then I started to get hope. Then they said, ‘let us go, it is true, the disease is curable’. Then I got God’s blessings.” (045, Age 29, Mbeya)*

Amina also questioned if this was ‘normal’. She said,

*“They [my husband and in-laws] thought it was because of child bearing ... I thought maybe it was because of child bearing or because someone has bewitched me also because it is not normal to start leaking urine from nowhere. Others deliver and they do not get any problems” (050, Age 32, Mbeya)*

After receiving treatment and learning about obstetric fistula, Amina continued to hold on to the belief of also being bewitched. Her community members were saying that it was because she was living at her mother-in-law’s compound that she got obstetric fistula, and so she relocated to another house with her husband after treatment.

In contrast to Amina, Gladys changed her perception after learning that it was curable. She said,

*“After treatment they [community members] said, ‘you are cured, we thought you have been bewitched by your mother in law’. When I reached Bugando hospital [for treatment] I noticed that we are many, then that idea [of being bewitched] disappeared. Then I believed it was a disease. But when I was here in the village I thought I was bewitched [laughing]” (036, Age 40, Mwanza)*



### **Delay in experiencing symptoms**

Many of the informants reported that they began leaking urine some days after delivery. From their stories, there seemed to be a delay between childbirth and the symptoms appearing, which in some cases, caused confusion about whether it was childbirth related or not.

*“Others said it was just a normal disease. And that time when I was crying they told me that I should not cry because I did not cause it myself. If it is curable it will be cured ... I thought it was because the baby stayed for a long time on the outlet which was painning me so much. They were telling me that it happens when you deliver. So I was asking myself ‘what has happened to me?’ As I have spent one week in the hospital and when I came back home is when the problem happened. So I was confused because some people were telling me that the problem happens immediately after you deliver.” (043, Age 33, Mbeya)*

Throughout this process, the informants found a way to make sense of their misfortune. Some explained it with biological or symptomatic reasons for their misfortune as something that occurred during childbirth while others gave an aetiological understanding about why it happened to them, specifically.

### **A misfortune during delivery**

Most women associated the cause of their obstetric fistula to be birth related. The reasons mentioned included childbearing, long labour, delay to the hospital, the baby being too large, or an accident by a medical professional or birth attendant during delivery. In the focus group discussion, there were varying opinions of what actually caused the obstetric fistula and it was evident that even after being treated for obstetric fistula, the cause of it was not very clear to them.

Some attributed it to prolonged labour pains and delays in going to the hospital

*“It is a disease that women get during delivery if you delay to go to hospital or if you deliver in the street. That is when you get that problem of urine leaking nonstop” (FGD, Singida)*

Janeth blamed her delay on her family members. She seemed to not have any decision making power about her own health during delivery. She said,

*“My husband was preventing me from using herbs in order to increase blood. He was saying that it will delay my delivery, which is why I got fistula” ... “my relatives did not take me to the hospital because they did not know that I was sick, but when I told them they said I had not yet reached the climax of labour pain. Later, my mother-in-law noticed that I was really sick and they took me to hospital” (O30, Age 18, Mwanza)*

Others felt strongly that it was the birthing attendants who caused it.

*“Once you call a person to assist you to deliver, and she inserts her arms, then urine starts leaking and you get fistula” (FGD, Singida)*

*“It is a disease that people get when the traditional birth attendant has long nails and she pinches the bladder.” (FGD, Singida)*

*“To me it was because my mother pinched the baby while getting it out and the baby came out with blood on its head”. (FGD, Singida)*

While another refuted,

*“Myself, I do not think that the birth attendants are the ones who caused the problem. It was the baby, it was big” (FGD, Singida)*

Most informants, after experiencing prolonged, obstructed labour, eventually found themselves at a health centre or hospital where they underwent a C-section or an abortion. Sometimes when the cause of obstetric fistula was uncertain, they wondered whether the doctors made a mistake during the operation.

*“When I started labour I went to hospital and I was not late. When I reached there, after a short time I was operated. After operation, I was discharged to go back home. After two days urine started leaking. I came home and waited for seven days and I went back to remove the stitches. When urine started leaking I was not feeling comfortable because I didn’t know what its source was. So it was a problem to me and I was crying all the time. I didn’t know what to do. When I tried to ask my peers, they said, ‘we do not know what type of disease this is’. They said, ‘maybe they made a mistake when they operated you and they destroyed the bladder’” (045, Age 29, Mbeya)*

Others who were still unsure had their own explanations

*“I went to hospital early but I think there are hospital rays that caused the problem ... I still do not know” (FGD, Singida)*

Some informants like Mariamu described a very long and painful delivery over a few days and being taken from the village dispensary to a health clinic and finally to the hospital. Mariamu’s account of her delivery spoke of health worker’s negligence and their blaming the difficult delivery on magic. She said,

*“When I was pushing, she [health worker] said with surprise ‘this baby’s head is already out, what is holding it back?’ My mother suggested increasing the outlet, but the nurse said we should wait until the baby comes very close. She [health worker] inserted something to increase the passage, yet it was impossible. Then the nurse said there are witches who have probably magically held the child back. My father suggested taking me to a hospital, but the nurse said to wait. Some people brought traditional medicine for me to drink and when it was midnight the nurse went to sleep. She said you have to push strongly. I remained alone and I started pushing.” (044, Age 20, Mbeya)*

Her baby was finally pulled out by force, after which Mariamu’s legs were paralysed and her baby had died. In this case, the symptomatic and childbirth related reasoning was tied together with the supernatural beliefs from medical professionals and family members.

### **Supernatural beliefs**

Some informants gave complex accounts of how magic, spells and sorcery, or the evil eye had caused them their misfortune<sup>3</sup>. At times, these explanations were tied in with spiritual healing. I will present some of these accounts as examples of different ways of understanding this misfortune.

#### ***Magic and spells***

Returning to Mariamu's story, one month after getting obstetric fistula, she was taken to the traditional healer, a certain old woman who lived in the village. The healer told her that her (vaginal) 'passage' was still enlarged, and so they inserted traditional medicines. Slowly, the 'outlet' was shrinking but urine continued to leak and her legs were paralysed. She was then sent to another traditional healer who massaged her legs with hot water. After that she said she could walk again but was still leaking urine. Her father took her to hospital, and her obstetric fistula was repaired; however she could still not urinate without a catheter.

*"After treatment my parents and my in-laws thought the baby was held back by magic."*

She narrated a story of how she experienced a few incidents after treatment, where she started behaving strangely, and spoke words she did not know she was saying.

*"My conscious was not there. It was like, I was mad."*

Her family suspected that she was bewitched by a lady in her neighbourhood.

*"They used to say 'why is this person bewitching her? What has she taken from him/her? If she has done anything, she/he should wait so that we can pay.'" (044, Age 20, Mbeya)*

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<sup>3</sup> Within this study sample, such beliefs seemed more common in the Mbeya and Mwanza regions, where the informants associated themselves with the Nyakyusa or Sukuma ethnic group.

Similar incidents occurred a few times, so she was taken to traditional healers for treatment again. Eventually the suspected witch's house in the neighbourhood was burnt down and the woman was driven out of the village. Mariamu said she had been normal after that.

### ***Evil spirits and evil eye***

Another perspective on the misfortune is the belief in bad spirits. This usually stems from social tensions between people. During the focus group discussion, there were several comments about traditional birth attendants causing obstetric fistula. When we asked why they felt birth attendants caused the problem, one informant said,

*"Birth attendants always have evil spirit" (FGD, Singida)*

Veronica, on the other hand did not feel negatively towards the birth attendant but rather her mother-in-law. She had lived with obstetric fistula for thirty years and her husband abandoned her because of it. She believed that it was God's will for her to get obstetric fistula, but at the same time felt her mother-in-law, whom she was not on good terms with, also contributed to her misfortune.

*"It is God who gave me the problem. I did not expect I could get this problem. I was shocked. I asked myself that God created me nicely, he also made me his creature and today I have this problem, and I have also lost a baby... everyone was surprised, they did not know why I got that problem...I think it was because of my mother-in-law. We were not on good terms and when I was delivering she came and stood there and then she said 'this child is too harsh and has refused to come out of the stomach'. The birth attendant told her 'go away from there'. After a short moment, I fainted and the nurse told her, 'Do you see now?' After that we remained not in good terms" (017, Age 63, Dodoma)*

The suspicion of the evil eye could also arise without a specific individual in mind. It could be perceived as something that exists without accusing a specific individual. Gloria had been

through seven pregnancies, one being a pair of twins, and currently had five children alive. She explained that she had lost every other child that she conceived and because of the pattern in her misfortunes, she wondered whether there was an unexplained supernatural cause for her children's deaths. When asked why she thought the baby died, she said,

*"Frankly speaking I was asking myself why that (baby came out dead) happened! Why is always every second child dying?" (028, Age 39, Mwanza)*

Similarly, when we asked Eva who had lost all four of her children either through miscarriage or shortly after birth, how she felt and she said

*"Sometimes people's eyes can cause miscarriage" (016, Age 43, Dodoma)*

She told us that if she got pregnant again, she would move and live away from her village when she reached seven months of pregnancy, to avoid other people noticing and talking about her pregnancy. She would do this in order to protect herself from the evil eye that caused her problems in the past.

### ***Religious healing***

Sometimes informants began the explanations of their misfortune to have roots in evil spirits, while their healing is explained through the power of God. Tina was widowed and had lived with obstetric fistula for 15 years. Her husband had two wives and she was his second wife. Her second pregnancy caused her the obstetric fistula, and she described different incidents during her pregnancy, like sharp stomach pains, and the occurrence of a hurricane, that built up her understanding of the evil spirit being the reason for the challenges in her pregnancy. She visited a few traditional healers during her pregnancy to undo the workings of the evil spirit on her. She believed that the evil spirit wanted her to die with her child, but because of the healers that she went to, her own life was saved, but her child had died and she was left with obstetric fistula.

*“When I delivered, the baby was already dead. After two weeks, I noticed that urine was leaking when I stood up. Then after one month I got a sudden fever and my body turned grey and when I passed urine, it looked dark yellow in colour. I continued to pass urine and although it was leaking, it was not as much as others. When I saw others, I was feeling sorry for them. But in my case it was because of craftiness of the evil spirit. One day my husband and my brother took me to the healer because they saw that my condition was deteriorating and whole of my body had turned grey. The healer removed a piece of flesh and a piece of charcoal from my body.”*

Then she returned home with her husband and soon became a born-again Christian. Since then, she called on God to be her healer.

*“I told God ‘God because you are a healer and I heard that you heal people, if this problem is supposed to be treated in the hospital and it is your will that I go there then I will go to hospital and you use those doctors in the hospital to heal me, let your name be blessed and if it is your will that I get cured through a miracle, let your name be blessed.’ I decided to involve God.”*

She continued to live with the leaking for several years and she continued doing daily activities. She said her relatives had even forgotten that she still had the problem. She said,

*“Even the pastor was not aware. When I became a born again, I did not tell the pastor about my problem. I only told him that I had stabbing pain and when they prayed, I was healed from stabbing pain instantly, but urine continued to leak”*

Several years later, she was widowed and a fellow born-again Christian told her that she had heard about a cure, and gave her money to go to the hospital. She was operated at CCBRT and when the nurse removed the catheter after 14 days, she was still leaking.

*“So, they inserted a catheter again and on the third day I had a dream. It was like we were in the hostel sleeping and a white man asked me ‘who has told you that you are not yet cured?’ I told him ‘but they have said I still had too much urine and I am*

*confused'. He said 'you are cured completely. Just lie down in the bed gently'. Behind that white man, there was an African. Then he took my catheter and he was taking urine little by little and pouring it in a certain container. When he finished, he said lie yourself in the bed gently again. I lay down again and then he tied me with something in my genitals. Then holding a cloth in hand he said 'this is what has been afflicting you' but now you are cured completely.' After he removed that cloth, I woke up and I started to thank God and that is when I realised that I was dreaming. I did not tell anybody. It remained my secret. In the morning when the doctors were making a ward round they said 'Tina, you are already cured. Why are you not discharged?' ... when they withdrew my catheter, they found that I no longer had urine." (038, Age 36, Mbeya)*

For Tina, her dream confirmed that she was held back by magic and her faith assured her that God was her healer. She returned home and gave her testimony at church as an example of God's miracle of healing.

### **Social acceptance and care seeking**

The notion of a normal or common disease verses something unexplainable also impacted how quickly the informants sought care. When they thought the disease was normal, they had hope and sought out care; otherwise they surrendered to the problem and felt helpless and sad. The community's perception of the condition was similarly important during social interactions.

### **Disbelief about cure and acceptance in society**

The ease of social reintegration is challenged by the disbelief that obstetric fistula was, in fact, a treatable condition. Nitike explained,

*"I heard about it (fistula) when I got it. Only then I heard people talking about it. They were saying this disease cannot be cured. (When I came back cured) they were just looking at me, they do not believe up to now that I was cured."*



When asked about what her neighbours and relatives said when she returned cured, she said

*“They said because God has helped you and you have been cured we thank those who cured you.” (046, Age 20, Mbeya)*

For Nitike, some had accepted her, while others were still suspicious. We got a little insight into why some communities may believe that an obstetric fistula cannot be cured from the head obstetric fistula nurse at Bugando Hospital, in Mwanza region. She explained,

*“They (fistula patients) are comparing the bladder of a dead goat and our bladder. They usually see the bladder of a goat as if it is plastic or glass, they compare a bladder with a plastic ball, once it is broken, it’s gone. They think a bladder does not have blood circulation or muscles. Muscles, if you cut it, you can stitch it but not a bladder, so they think fistula can’t be cured”*

When obstetric fistula is not completely understood, sometimes hope was lost and feelings of helplessness emerged amongst the women. Rodha who got obstetric fistula after her third pregnancy said,

*“I felt bad I even cried (after I saw that I started leaking after 1 week). I felt bad because of leaking because I didn’t expect that could happen and I thought that I will be disabled completely.” (043, Age 33, Mbeya)*

When informants believed that they were the only ones inflicted with obstetric fistula, they felt different from others in the village. There was a strong desire to be ‘normal’. They would rather stay away from the community or prepare them that she had found treatment for her condition to minimise being ostracized during reintegration. Joyce was taken to the hospital for treatment, where the doctor asked her to return after a few months because he was going for training to repair obstetric fistulas, after which he would be able to treat her. She said,

*“I refused, I told him I cannot go back home because even children were avoiding me and the whole community was avoiding me because they were perceiving the disease as not normal because here in the village I was the first to get this problem ... the whole*

*village was aware about my problem, when I was at the hospital I phoned them, as you know in the village if one person gets the news it will spread to the whole village. I phoned them that I was getting treatment and that I am now cured. Therefore when I returned, many believed that I am now cured ... they [community members] came, some of my relatives came to prove whether I am cured or not” (009, Age 28, Dodoma)*

After being cured, Nitike, in her own mind, felt reintegrated. She said

*“Now I feel comfortable. I am now like other women. I was not comfortable, I thought I was destroyed completely but now I am back to normal like other women and when I am with other women walking around I feel like them. I am happy and I am also comfortable.” (046, Age 20, Mbeya)*

The informants in the focus group discussion, who stayed with obstetric fistula for at least one year before being treated, said that they waited so long because they were not aware that treatment was available or where to get it.

### **Avoiding traditional birth attendants**

Some informants, who had prolonged labour and blamed the traditional birth attendant for their obstetric fistula, said they would never go back to them in the future. Frida was married when she was only 12 years old and got obstetric fistula during her first pregnancy soon after marriage. She stayed with obstetric fistula for 13 years before getting treatment. When we asked her what caused her the most pain during the entire experience, she said

*“One was labour pain that I experienced because they [TBAs] were inserting their hands and pulling and they were telling me to push and I was feeling terrible. I will never go back there because they destroyed me.” (049, Age 26, Mbeya)*

## **Lack of awareness**

The women's experiences with obstetric fistula, in their specific communities, with their belief systems, their level of access to health care, and quality of health care, influenced how the condition was perceived in the future. It also revealed the level of awareness about obstetric fistula despite having lived through it themselves. At the end of each interview, we asked the informants whether they had any questions for us. One informant who had difficulty conceiving again after treatment asked,

*"I have a question ... once a person gets this problem why does it cause poison in getting another pregnancy [prevent from conceiving] until you are moved out from your compound? (R7, FGD, Singida)*

It is interesting to note that some of these questions arose after the women had been treated and have had some time to reintegrate. This implied that they had been treated, but had not managed to conceive again and were trying to make sense of that phenomenon. From these questions, it was evident that a more thorough explanation of obstetric fistula, its causes, and future consequences needed to be instilled when they received treatment and reinforced during follow-up visits. This questioning was also tied to the cultural importance of childbearing, which will be portrayed in detail in the next chapter.

## **Reflections**

From this chapter, we learn that there is a significant influence on the experience of a woman who has lived or is living with obstetric fistula, depending on how the condition is perceived by the informants and their community members, both before and after repair. It affects their self-esteem, their social position and role in society, their ability to seek care, and how they cope with the circumstance. In Susan Whyte's terms, the women affected by fistula experienced a 'failure of health' and a 'failure of gender' in as much as they were not able to bear children. When the informants could blame someone or something else, seemingly outside of their control, for their misfortune, there was a shift in responsibility. They perceived themselves as

victims of an external force. This influenced their emotions, be it feelings of resentment and anger towards others, or feelings of hope that cure could be sought and recovery was possible. Making sense of illness within different contexts of individual life experiences, for example, timing of events, human relationships and their involvement in the informant's life, the social belief systems of the communities and their own perceptions of different aspects of life, helped capture the complexity of experiencing life with obstetric fistula and conversely, assessing the transition after repair.

## **Chapter 5: Identity as a woman - Childbearing, marriage and family life**

In Tanzania, a woman's identity and status in society is very closely tied to childbearing (Dyer, 2007: 74). Childbearing is viewed positively and this is portrayed in different ways. It is depicted, for example, in how a woman is addressed after giving birth. After a woman gives birth to her first child, she is no longer referred to by her own name, but rather called mama followed by the name of her first born. For example, if a lady named Bakia gave birth to her first child, a baby girl named Rebeka. From that day on, her husband, family members, friends and neighbours will refer to her as 'mama Rebeka' instead of Bakia. From observation and casual conversations with women in Tanzania, particularly women in a rural setting, it was clear that most of the women wanted to have several children. Bearing children can be perceived as a success at womanhood, which leads to greater respect in society. In this chapter, I will explore the impact of having obstetric fistula on the informant's lives as women, as mothers, as wives and as daughters-in-law.

### **Being a woman**

#### **Childbearing**

In this study, women who had two or less than two children, wanted to have more children irrespective of whether the husband stayed and supported her or abandoned her during obstetric fistula.

#### ***"If I had a child it would not hurt me so much"***

Eva, a 43 year old informant had remarried twice after her first husband abandoned her. She got obstetric fistula when she was 27 years old, and she underwent two treatments. Her leaking had improved but was not yet cured. She had lived with obstetric fistula for 16 years, had four pregnancies, but they ended in a miscarriage, the child dying soon after birth or during the birth, which gave her obstetric fistula. While speaking of her second marriage, she said:

*"I was lucky I got pregnant but unfortunately the child died. After that incident the man deserted me and he said he could not live with a rotten human being who bears children that die".*

When speaking of her third marriage, she said

*"...I lived with this man for nine years and then he said he cannot live with a woman who does not bear children ... I told him that 'I have no capacity of bearing children therefore if you do not want me, tell me, so that I can leave myself. When I get pregnant the children die by themselves, so if you do not like me, just tell me, and I will go back home'".*

She wanted a child more than anything else, even a recurrence of obstetric fistula did not matter to her compared to not having a child.

*"I am eager to have a child...it hurts me when I see my fellows having children. When they come here, I wish I had my own... if I had a child it would not hurt me so much. I am not worried about becoming pregnant ... even if I get fistula, provided I have a child, I will not care" (016, Age 43, Dodoma)*

However, there were two informants who did not fit this pattern. Mary was 21 years old and had no children. She got urinary leakage (VVF) and faecal leakage (RVF) during her first pregnancy with her partner, who had abandoned her. Due to her traumatic experience, she was uncertain whether she wanted more children in the future. Her VVF was healed at the time of the interview but she was still waiting to go for surgery for the RVF. Amina also did not fit the pattern. She was 32 years old and had only one child. She had stayed with obstetric fistula for ten years and refused to have any more children.

*"I don't want to get another child, I am afraid because they (hospital staff) told me that if you get pregnant you will undergo a major operation. So that makes me feel worried to get pregnant. So one child is enough...they [hospital staff] told me what to do if I got pregnant, but I hesitate because I suffered a lot"*

When asked how she would handle this with her husband, she laughed and said,

*“I will use injection or pills...my husband also says he doesn't want [more children] because I suffered a lot”*

When asked what she would do if her husband decided to get another wife, she stated

*“I will leave him because when I was suffering, I was alone. If he decides to get married it is ok...I am sure I don't want [another pregnancy].” (050, Age 32, Mbeya, 1 child alive)*

In our sample, if the women already had three or more children, they no longer wanted to have more. Saphia said,

*“I would like my life to be good like it used to be in the beginning ... I will make my life better and stop bearing children...I have to stop as God has helped me. I have borne children and this is the eighth child who has caused me to get a problem ... but I am now cured and I thank God for that. I have stopped bearing children now. They assisted me to stop bearing children at Mvumi hospital”. (018, Age 36, Dodoma, 8 children alive)*

Neema was an exception, however. She had been through nine pregnancies and had four children alive and still wanted more children after obstetric fistula. Her husband had been very supportive while she lived with obstetric fistula for five months. During those five months, she used a catheter before she was treated. She was now completely dry and cured.

Childbearing is thus a primary task that a woman in Tanzania undertakes during her lifetime. When she 'fails' at doing so, she does not fulfil the expectation of her as a woman and it affects her feelings of self-worth, and her identity and status in society.

### ***Respect and identifying with other women***

Being a woman meant being a mother to most of the informants. Childbearing gave women a new and highly desired identity. It gave them a sense of fitting in and being like other women in

the community. Motherhood was thus identified with 'womanhood' and vice versa. Lucy expressed this by saying,

*"I felt very happy that I will be treated and be like my fellow women... what I want in my life is to bear children like what others do" (O29, Age 17, Mwanza, 0 children alive)*

Having children was important, and it raised the level of respect and social status a woman had in the society. However, being a woman also implied being an adult. Having control over your body was one aspect of being an adult. With obstetric fistula, a woman is stripped off this control, and she is faced with the embarrassment of being incontinent. For Saphia, despite having eight children, she had no respect because of leaking urine. She explained,

*"When I got a problem in getting a child, to be frank I was not feeling peace when I sat with my fellows. I was always unhappy because urine was pouring. I used to stay at home alone. I have children, but there was no respect because urine was leaking all the time...now I am cured, I am thankful" (O18, Age 36, Dodoma, 8 children alive)*

### **Being a wife**

From the sample of in-depth interviews (30), 11 women were abandoned by their husbands. In the cases where the husbands stayed (19), 13 were treated within one year and were completely dry after treatment except for one from Dar es Salaam. Six were treated after one year, some of whom were still experiencing some incontinence.

Fulfilling the expectations of being a woman also entailed being a wife among the informants. Obstetric fistula can put a strain on a marriage, both before and after repair. Initially, there was a sense of failure at childbearing, followed by uncontrollable leakage which caused smell and sores.



### **Lost sexual intimacy**

One informant expressed the physical pain and discomfort of having obstetric fistula. She said,

*“I developed sores in the genital parts. I was scratching until blood was coming out” (R5, FGD, Singida)*

This makes it physically unpleasant to have sex. Bakia had undergone two unsuccessful repairs. Although she had seen some reduction in leakage, she shared her challenges in being a wife.

*“I don’t want it [sex] because of leaking urine ... we use other methods until he gets satisfied ... no, I do not enjoy it, I only satisfy him ... if I don’t get cured, my husband will have to look for another wife...although he will be taking care of me but he will have to get married again [because] I can get a child but we cannot have sex”*

*I: “When he gets married do you think you will have peace?”*

*R: “It [peace] will not be there but what can I do?” (051, Age 25, Dar es Salaam, 1 child alive)*

Bakia felt inadequate as a wife and was uncertain if she would be accepted. She was interviewed again, after she went back to the hospital for a follow-up treatment. At the hospital, she was told that because she had already undergone a few surgeries, she could not go through it again. However, with regular bladder exercises, the leakage had reduced, even though she was not completely cured. She said that her husband did not want to remarry after all, and was very supportive even though she told him that he could get another wife. She said he was determined to find treatment for her, at another hospital. Bakia’s story was one of many women who had experienced rejection or an aversion towards sexual intimacy.

### **Sexual abstinence**

After obstetric fistula repair, the hospital usually advises women to abstain from sexual intercourse for up to four months in order to heal completely and prevent a recurrence of obstetric fistula. Most husbands, who stayed with the women, abstained from sex for the

recommended duration after they were shown the letter from the hospital indicating so. Some husbands were in fact very supportive of their wives before and after repair. Gloria said,

*“Some used to laugh at me; some could feel sorry for me ... My husband did not complain. He found me a rubber cloth to sleep on. He also bought me a powder and a perfumed soap because urine was pouring all the time” (028, Age 39, Mwanza, 5 children alive)*

However, others did not have the same kind of support. Eva shared,

*“When I was back he disturbed me as he wanted to have sex with me. I told him that I was instructed not to have sex with him until four months passed. He did not understand me. He said I was avoiding him and that I was not having such a problem. Then he continued to force me. So, I decided to leave and to go home because I could not go against the instruction I was given.” (016, Age 43, Dodoma, 0 children alive)*

Some informants, in order to comply with the hospital’s instructions, distanced themselves from their husbands immediately after returning from treatment. This also sometimes led to difficulties in the marriage. Ruby explained,

*“When I was going from one place to another looking for treatment I did not have a husband. By that time our marriage was shaken too much. It’s only recently when we have started to be on good terms again. He used to sleep outside the house with other women. When I came from there [hospital] I didn’t come directly here [husband’s house]. I went home [her parent’s house] first and I stayed there for four months. After four months, I came back ... so when I came back, I was like a guest in my own house.”*

She explained that because she did not have sex with her husband immediately after treatment, she did not get any financial support from him during that time.

*“I was already treated and cured but he could not use me [i.e. have sex with me]. So he was not even giving me care. I was living like a poor person. It is different now [eight months after repair] as I have my own money, I can make myself busy and get at least*

*Tsh. 2000 so I can get food and eat with my child ... I can also buy oil to use" (045, Age 29, Mbeya, 3 children alive)*

After relations with her husband improved, he gave her some money to buy a flask so she could sell tea. Similarly, Saphia who had been married for 17 years and had eight children with her husband, felt betrayed by him during her time of need. She said,

*"My husband did not accompany me to hospital because he was thinking that the problem I had will not get cured ... He used to tell my fellows that he will desert me if I am not cured. Now that I am cured, we are on good terms...after four months passed we continued to be in good cooperation but I felt bad. I was asking myself 'why should he desert me because of a problem that I acquired while living with him?' When I asked him why he said that, he denied it. I used to hear from my fellows that he had other women."* (018, Age 36, Dodoma, 8 children alive)

Despite feeling hurt, Saphia continued to live with her husband eight months after repair. Some informants were unable to abstain from sex after treatment and gave in to their husbands. They took the risk of obstetric fistula recurring, in order to maintain their relationship. Some informants, who conceived again, were still unable to go to the hospital for delivery, knowing that the hospital had recommended that they did so. One informant said,

*"I did not manage [to keep him away]. When I got home and when my husband saw me cured, we had sex and I got pregnant...I delivered at home because transport at our place is difficult to get."* (R1, FGD, Singida)

Another aspect that affects intimacy within a marriage or prevents an informant from remarrying in the future, is the fear of obstetric fistula recurring.

### **Fear of future childbearing: "it is like death"**

Half the informants mentioned that they had a fear of obstetric fistula recurring in the future. This fear often manifested itself as an aversion towards sex and childbearing which put a strain

on the informant's obligations as a wife and a woman. The duration the informant stayed with obstetric fistula before treatment affected her experience after repair; however this varied from informant to informant. Anna had a supportive husband and she was treated two months after she got obstetric fistula. Eight months after treatment, she said,

*"Yes, I am still afraid. It is like death. I am imagining that when I get pregnant I will get fistula again" (006, Age 22, Dodoma, 1 child alive)*

Neema waited with obstetric fistula for five months, with a catheter, until the doctor was available to continue treatment. She had a supportive husband who helped her with chores during that time. After treatment, they abstained from sex for longer than the time recommended by the hospital just to make sure that the obstetric fistula did not recur. Eleven months after treatment, she said,

*"Yes, I am afraid when I sleep with my husband ... I can get fistula again" (005, Age 39, Dodoma, 4 children alive)*

### **Resentment and separation - "I don't want to be destroyed anymore"**

Some informants felt resentment towards their husbands, or worse, towards men in general. Catherine was treated three months after she got obstetric fistula. She explained,

*"[after treatment], I went back to my husband. Sometimes my husband slept inside but sometimes he slept outside. Then my mother-in-law said she wanted to leave me alone with my husband [to have sex with him before months to heal were up], but I refused"*

She left her husband and returned to her mother's house. She was also subjected to judgment by the community because of her decision to end her marriage. It was more acceptable for a man to leave his wife; however, a woman risked being condemned for it. Catherine said:

*"... My relatives condemned me because my mother took me from my husband"*

Eight months after treatment, she was still experiencing some mild incontinence and found it difficult to do heavy labour as before. We asked her how she felt about remarrying in the future, she said

*“If a man approaches me I will refuse because I will tell him that I don’t want to be destroyed anymore. I do not want to get married again. It is better I stay home and cultivate. I am afraid if I get pregnant, the problem can recur. I don’t want another baby. The one I have is enough for me. I suffered a lot. I do not want to get married ... if I see a pregnant woman I will feel sorry for her...I have nothing to advise her except feel mercy for her. If I see a woman with the problem like I had, I will tell her to go and get treated”*  
(031, Age 20, Mwanza, 1 child alive)

Grace was 75 years old and had lived with obstetric fistula for more than 55 years. Her husband had abandoned her after she got obstetric fistula at the age of 16 years. We asked her if she had thought of remarrying after she got obstetric fistula, she said

*“No, who would agree to marry a woman leaking urine?”*

When we asked her who she lived with, she said

*“I live alone and my God is the second one.”* (003, Age 75, Dodoma, 0 children alive)

In the focus group discussion, informants experienced rejection in different ways. One said,

*“I got the problem when I was at our home. I told him [my husband] that I have a problem so he should help me. He said he has no money and did not give me any money. I was selling tomatoes and sorghum [to survive]. He said if I did not get cured he would send me back home [to my parent’s]”* (R3, FGD, Singida)

Others said resentfully,

*“Once you get this problem, the husband decides to marry another woman and leaves you without any assistance and he carries on with life as usual”* (R8, FGD, Singida)

*“I was about to be divorced because of this problem” (R2, FGD, Singida)*

The roles of women involve being adults, being able to work, being wives and childbearing, which is extended further to being daughters-in-law. Dealing with the social complexities of living up to the expectations of being a woman, was challenging for women who had suffered obstetric fistula.

### **Being a daughter-in-law**

In traditional, rural Tanzanian society, the mother-in-law is vital in the rearing of the children, and she has expectations of her daughter-in-law to work, produce children and take care of her son (Moland, 2002). Understanding this context, a woman with obstetric fistula struggles to live up to some of these expectations.

### **“Woman who has a problem”**

From the 30 informants with whom we conducted in-depth interviews, five informants’ mothers-in-law had already passed away. From the remaining 25, 14 informants did not receive any social or emotional support from their mothers-in-law. Some faced rejection and were not accepted well. Adeline said that her in-laws were back-biting about her. She explained,

*“They [my in-laws] were back-biting but they were not able to tell me openly that I had a problem, they could only speak against me with neighbours. They were saying that ‘our son is married to a woman who has got a problem’. They were saying a lot against me ... she [husband’s 1<sup>st</sup> wife] has never said a word against me openly, but one day she was saying that ‘my husband has married a woman who has a problem’ ... they [other community members] were not saying anything openly about bad smell but they were back biting about me” (042, Age 36, Mbeya, 2 children alive)*

Similarly, Eva was rejected by her mother-in-law and treated like she was impure and someone who had lost her ‘usefulness’ as a woman and a wife. However, her brother-in-law supported

her throughout. Her own parents were no longer alive. She had undergone three repairs and was still not completely dry. She said,

*“My husband told my mother-in-law and when she heard about it, she stopped coming to eat in my house. Currently we are not in good terms [with the in-laws], they are telling their son to divorce me and go back to the mother of his children [his first wife] because they say I am of no use...His relatives used to run away from me because I was stinking of urine. His mother did not want to eat my food and she wanted me to go against the instructions [of the hospital i.e. abstinence from sex]. My brother-in-law came here at [my husband’s] home and he did not find me there, he asked my husband where I had gone. They all [in-laws] found me at my parent’s house. I told them ‘I cannot go back because when I was sick, you all ran away from me’. They pleaded me to go back and that they would tell him [husband] to go to another place until I was recovered. Then I went back and after two weeks he [husband] left for casual labour. He has not returned until now [~2 months].” (016, Age 43, Dodoma, 0 children alive)*

Janeth, who was abandoned by her husband after obstetric fistula, blamed her mother-in-law for not believing that she was in labour and prevented her from going to the hospital in time. She said,

*“We were not in good relationship with my mother-in-law ... my husband loved me but he later changed after he was told by his mother that I was of no use” (030, Age 18, Mwanza, 1 child alive)*

However, some had support from their in-laws, most of who were treated within three months and were completely dry after treatment. Rodha who went for treatment only three days after she started leaking said,

*“I also showed it [letter from the hospital] to my mother-in-law and sister-in-law. After they read it, they were making follow up visits to us so that we adhere to the instructions” (043, Age 33, Mbeya, 2 children alive)*

Amina, who had suffered with obstetric fistula for ten years, said her neighbours and family had a party for her and her mother-in-law was overjoyed on her return. She said,

*“she [my mother-in-law] was even crying as she did not expect I could get cured” (050, Age 32, Mbeya, 1 child alive)*

## **Reflections**

The role of a woman and her personal identity is a complex blend of personal expectations tied tightly with the expectations that society puts on her. The informants in the study, having suffered obstetric fistula, have struggled with their own sense of self and womanhood, along with the social strains brought to marriage and family. The informants lose control over their own body, experience physical discomfort and a ‘failure of health’, while also facing emotional and psychological scarring due to their ‘failure of gender’. With early, quality treatment, the chances of husbands abandoning the women was lowered, they often experienced less rejection and they felt more positively about their future as women, as wives, as mothers or potential mothers.



## **Chapter 6: Life before and after obstetric fistula repair**

Grace was about 75 years old. She told us that she got married at 16 and her first child was aborted because she was beaten by her husband who returned home drunk one day. Then she conceived again, and went to her mother's to deliver the baby. After three days in labour, she delivered a dead baby and was left with obstetric fistula. Her husband divorced her because of her leaking, and she moved in with her mother, who was her only friend, she said. After some years, her mother passed away and she was on her own. When she thought of losing her mother, she said she cried even now. Her relatives stopped visiting her after her mother died. She stopped going to visit neighbours or to the church because she was scared of leaking. Her neighbours took her to hospital for treatment but they could not treat her, so she visited traditional healers. For most of her life, she did casual labour to earn money for food. She was now living in a mud hut, by herself. She stayed with obstetric fistula for 55 years and was finally treated eight months before the interview. She still had some leakage at night, however greatly reduced. She earned some income by collecting rocks, breaking them into smaller pebbles and selling them to construction workers – a laborious and unpredictable income dependent on when there is construction in the area. She is mainly dependent on her maternal niece who gives her some food.

Women who have obstetric fistula are suffering socially and physically as described in the previous chapters. After surgery, many return completely cured and dry while others return with some continued leakage. Although the ones who were completely cured felt relieved and regained hope and self-worth, they were sometimes deeply scarred by their experience of suffering from the social consequences of living with obstetric fistula and the financial depletion that it had caused. In this chapter I will explore the challenges faced by women who have suffered from obstetric fistula and how they coped with these challenges before and after surgery.

## **Economic challenges and coping**

One of the most prominent challenges that were revealed from the interviews was that of financial capacity. Most women interviewed, irrespective of whether their husbands were supportive or not, came from poverty and have sunk deeper into poverty because of obstetric fistula. This was due to the combined effect of physical inability to work, resources spent in seeking care, caretaker's inability to work, and returning to a financial state worse than before they got obstetric fistula without any support to build it back up. They often fell into the endless poverty trap and became financially dependent on friends, relatives, and the community at large. Their experience improved or worsened depending on different factors, including the duration they stayed with obstetric fistula before getting treatment, whether they were directly transferred to the correct hospital for treatment free of charge, and the availability of financial support from relatives and friends before and after treatment.

### **Inability to work**

For various reasons, earning capacity is hindered when a woman is faced with obstetric fistula and this affects many aspects of the quality of her life. Ruby emphasized this when she said,

*“Generally what pained me the most was that when I was sick, I was unable to sell tea and breakfast snacks at the market” (045, Age 29, Mbeya)*

Many informants explained that after they got obstetric fistula, they were unable to continue working, whether formally or informally.

*Neema: “[with fistula] I did not do any hard labour [for three months], I was just resting. I was unable to do any activity. If I stayed outside in the sun during the day, I would get sores at night and I had to wash my private parts with water.” (005, Age 39, Dodoma)*

*Shamira: “[with fistula] I could not even find firewood, when I bent my back like this [demonstrating] urine would leak. I could not even go to the farm to cultivate. I was not doing any work. I was only plaiting mats” (048, Age 57, Mbeya)*

*Joyce: “When I was sick, even if someone would give me capital, I would not be able to do anything. I could not even go to the farm because when I go to the farm there are some insects, small bees. They would follow me and sting me because of the smell.” (009, Age 28, Dodoma)*

After treatment, the women were advised at the hospital not to do hard manual labour for at least three months. During the study, we found that many informants had not completely recovered physically, in terms of strength, even six months after treatment. It took a significant amount of time, before some could resume doing the hard manual labour that is a part of village life. Gloria spoke of her physical limitations nine months after repair. She said,

*“I’m making good progress, I urinate in a normal way, but when I do hard work, my stomach [touching lower abdomen] aches” (028, Age 39, Mwanza)*

The leakage and the smell were perceived as dirty, and affected their ability to continue doing business. As most of the informants came from a low income and rural setting, it was common for them to engage in business that involved selling food and drinks. If she was leaking, people would perceive her as dirty and would be unlikely to purchase food from her.

*“I was selling vitumbua [breakfast snack] but I was leaking. I used to hide it so that people would not know. Now that I am cured I do my activities more openly. I do not hide myself.” (R3, FGD, Singida)*

### **Assets depleted in seeking care**

Many of the informants went to a number of hospitals and/or traditional healers before they reached the hospital that repaired their obstetric fistula. If they were not completely dry, this trend would continue even after repair. They were often referred from one hospital to the next

in search for treatment. The series of delays, wrong referrals and long distances to hospitals were quite expensive. Sometimes, one wrong hospital referral would limit them from seeking care for a few years because of their financial constraints. Also, at some hospitals that referred patients, the informants had to wait for weeks or even months until there were a sizable number of patients that the referring hospital could send, as a group, for treatment. Many lived in very rural areas and would have to travel for several hours, sometimes on foot, before they reached a town with a hospital. If they were asked to wait for treatment, informants would often choose to remain in the town for that duration. They would also incur costs for food and living in that case. As explained in the introduction and background chapter, obstetric fistula surgery is free of cost in Tanzania, and CCBRT and Bugando both provide support for transportation to the hospital, however, there are many costs incurred in arriving at a hospital or health clinic that can refer them to either of these two hospitals.

Nitike stayed with obstetric fistula for four months before getting treatment. She had support from her husband, and had returned to her community about eight months before we interviewed her. She explained,

*“We are [currently] eating the maize we cultivated last year ... it is a little...we are two [in the house] but we sold a lot of maize when I was sick, so that I could be taken to hospital. He [husband] was borrowing money from people so that he could take me ...he was going to customers and borrowing money with the promise of paying back after harvesting.” (046, Age 20, Mbeya)*

Traditional healers are also quite expensive and can exhaust a poor family of its limited assets that are usually in the form of harvested crops or livestock. Mariamu had visited traditional healers since childhood to care for different illnesses. When she got obstetric fistula, her family did the same. 11 months after repair, she said

*“We planned that after selling this paddy, some will be for food and with the remaining we wanted to buy iron sheets [for the roof of our house]. When I got the problem, that*

*money was used to send me to the healers instead. They gave the healer one goat and 20,000 shillings” (044, Age 20, Mbeya)*

Mariamamu had foot drop, and she said the traditional healer was able to help her with the paralysis in her legs. She later went to a hospital that referred her to CCBRT for treatment.

### **Dependency on others**

If the husband abandons the woman after obstetric fistula, in most cases, she returns to her parent’s home. In Joyce’s case, her father was not alive and her mother was the sole breadwinner. Joyce was unable to work because of the leaking, the physical weakness and the sores, so she became completely dependent on her mother and sister. She was wrongly informed that treatment would cost Tsh. 600,000 and lost hope because, as she explained, her family could not even afford Tsh. 20,000.

*“I lost hope and I said let me go home and die there because I had no way out ...” (009, Age 28, Dodoma)*

Joyce was completely dependent on her family for financial support. When we asked her what she was doing now, she said

*“I don’t do any activity, I always go to the farm to help my mother [...] When I go to my sister she buys me two or more clothes. When I come to my mother, I eat what she cultivates.” (009, Age 28, Dodoma)*

Catherine was similarly living at her mother’s when she had obstetric fistula for approximately three months before treatment. Her mother was the sole breadwinner and also became the sole caretaker for Catherine. Her mother was no longer able to work because she was seeking care for her daughter, and accompanying her daughter while they were being referred from one hospital to the next. We asked her how they survived for those months when she was not treated, she said

*“By that time we had food which we harvested last year”*

She left her husband soon after being repaired because she was being forced to sleep with him before she had healed completely from surgery. She moved in with her mother again. We interviewed her more than eight months after repair. She said,

*“The cultivation season passed, my mother did not cultivate [because she was taking care of me] so currently we do not have food, we are buying food...I can now cultivate but not hard cultivation... I dream to have money then my mind can settle”*

When asked how she wanted to get the money, she said

*“I will cultivate beans, groundnuts and sorghum if I manage, but I always get tired” (031, Age 20, Mwanza)*

Gloria, who had a supportive husband and was treated nine months before the interview narrated,

*“Now I feel alright...the condition I was in when I was sick, was not good. Even the village executive officer knew about it. My condition made people lose hope. I have made negative progress, frankly speaking. [Now] I have no food. I am being given [food] by my children and relatives. Sometimes I do casual labour. I borrow clothes... even during the [relative’s] wedding people helped me.... I have a child who is in kindergarten and her/his school uniforms are worn. They [husband and father] sold many ‘shamba’ [small farms] in order to get money for treatment”*

She added that her children were left behind at the village while she went for treatment. Her parents and her in-laws were not alive at the time and her sister had no money to support them.

*“They [my children] suffered a lot while I was away. My husband was living in Mwanza [town of hospital] bringing me food ... there is poor environment in the village, so no one took care of my children” (028, Age 39, Mwanza)*

Tina lived with obstetric fistula for 15 years. Her husband stayed with her, even though he had other wives. According to Tina, her husband did not prioritize her getting treatment because he could still have sex with her. He passed away and one year later, she managed to get herself treated by getting money from a church friend. She had been treated about nine months before the interview, and had no relative to support her.

*"...I was already renting a room in this woman's house. Some people help me to pay rent. Even now, I have a debt as I have not paid rent from October to December but if it happens that somebody gives me some money to buy food, I take a little amount of money and pay rent." (038, Age 36, Mbeya)*

### **Debt and no start-up capital**

When women return home after treatment, oftentimes, not only are they faced with a debt, but they have no capital to restart some form of petty business for income generation. They spend many months being dependent on family and community members, sometimes until the next harvest, which could be six months or more, before they can start rebuilding their socio-economic lives. Tina explained her financial situation after treatment,

*"I do not have any activity. As I have told you earlier, I thank God that he is taking care of me...[before] I was selling bananas because somebody had lent me money, but since I came back from hospital I am just staying home. The day before yesterday somebody brought me that maize you see there." [...] "What makes me unhappy is to have no job because God's writings say that 'he who does not work should not eat' and I have stayed without a job. Imagine. You are here to visit me, if I had a job I could have bought you soda to drink. Still this woman, the owner of this [house], is complaining that I have not paid her money for renting her house...I pay 15,000 after every three months...all the time I go to my fellow born again [Christians] for help" (038, Age 36, Mbeya)*

Tina felt she was being immoral and felt guilty for not working due to her spiritual beliefs. These feelings were a consequence of her being stuck in poverty and not having the start-up capital to

regain her financial stability after repair. As she was widowed, and had no immediate family to support her, she was dependent on herself. She had sent her only daughter to her sister's in the city because she could not support her.

Another informant had remained 10 years with obstetric fistula. She was treated nine months before we interviewed her. Previously she was part of a woman's saving group. It helped her get enough money to buy tomatoes and sell them in the market. She explained that to be part of the group, she had to contribute a certain amount of money every week, in order to get the larger sum to help in her business. She had not been able to resume selling tomatoes nine months after being treated due to a lack of capital.

*"I haven't started yet since June...I even haven't started to contribute [to the group] because I have no money."*

We asked if this group helped when she got sick,

*"We don't help each other ... they didn't assist me. When I went to Dar es Salaam [for treatment] I stopped contribution ... I can join again by paying 5000 shillings, but I am not settled [financially] yet."*

Her husband also did not have the money to help her re-join the group.

*"Now he is firing his bricks<sup>4</sup>. Therefore he doesn't have even a single cent. That is why I said that I have not yet started I will wait until this year passes then after that I will start because I don't have money. I am [physically] able to stay at the market, but capital limits me and when I ask my husband he says he doesn't have any" (050, Age 32, Mbeya)*

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<sup>4</sup>A common activity for the men was to make mud bricks for construction. Mud bricks need to be fired before they can be sold.



## Social challenges and coping

### Keeping the secret

Many women living with leakage, both before or after obstetric fistula repair, cope with it by hiding the leakage in different ways. The most common way was to wear thick padding, in order to prevent the leakage from running down her legs. Sometimes, if that was not enough, social seclusion was one approach that was adopted.

*Ruby: "It was leaking too much, I was not able to sit. I was staying in the bedroom and I didn't want people to see me. I was staying inside for the whole two months until I went back to hospital [for treatment]" (045, Age 29, Mbeya)*

Janeth explained that she feared being stigmatized.

*"I went back and stayed at home. I was making myself wet with urine. I was not doing any activities. I was not going [to visit neighbours]. I was living at home alone. I was afraid of going to people's houses. I thought they would laugh at me" (030, Age 18, Mwanza)*

Some informants remarried. Eva had remarried thrice and had been stigmatized by her husbands and in-laws for her inability to bear children. She felt a deep void. She had undergone two surgeries, but was still experiencing some leakage, however reduced. She wanted a husband but most of all, she wanted a child. In her attempt to make that dream a reality, she kept her 'leaking', a secret from her husband.

*"He [my husband] did not notice. When we slept, I used to lie to him that I was menstruating and he would ask me, 'are you menstruating every day?' Both of us have our own skin to sleep on. Later on when he was drunk, he was asking his fellows, 'why does my wife smell of urine?' He once asked me to tell him if I was sick and I told him that I have a problem of urine and I told him that if you are willing to stay with me I will live with you; if you are not willing, I will leave. ... Others were not aware [of my problem] but one day my husband got drunk and told people about it; that is how they*

*got to know. When I went to the church and to gatherings, I had to carry an extra kanga for changing. When I noticed I was getting wet, I would wash them and put them in the sun to dry so that people would not notice ...” (016, Age 43, Dodoma)*

Adeline got obstetric fistula from a pregnancy before marriage. That man left her before she got obstetric fistula, and she suffered on her own. After a few years, her leaking reduced and she was able to hide it. She married a man who did not know she had obstetric fistula. She was his second wife. She says,

*“When I got married here, they [in-laws] thought I was ok. They came to realize after I had stayed here for a long time...but I did not tell him [my husband] that I had this problem. I was not making the bed wet, urine only leaked when stood up ... I disclosed [to him] after we had lived together for many years [they already had 2 children together] and told him that I needed to go to the hospital...” (042, Age 36, Mbeya)*

Her husband was supportive and helped her get treatment. She is much improved now, but still experiences some incontinence. Similarly, some informants would avoid situations in order to hide their leakage. Amina explained,

*“I was afraid even to attend ceremonies. When my fellows said, let us go somewhere to attend a certain ceremony, I was afraid to go. I was afraid I would smell” (050, Age 32, Mbeya)*

Shamira masked her true feelings and personality from her community for 28 years in order to protect herself from the embarrassment and possible ridicule that would come with leaking publicly. In her attempt to retain her dignity, the personality that she revealed to her community was very different from her private reality. To her, being labelled as a proud and unsympathetic person was better than to publicly experience the shame of leaking. She explained,

*“I was feeling too much pain. I was too sick. Leaking is a burden. I was feeling so bad. I could attend funerals but I could not spend the night over there ... People used to speak*

*negatively about me ... that I am proud of myself because I did not spend the night at funerals and that I was saying the place is too dirty so I cannot sleep there. I prayed to my God. My God is the one who knows my secret. So even when they said negative words against me, I did not hate them because they were not aware of my problem..."*  
(048, Age 57, Mbeya)

Her husband had stayed with her throughout, and although her community knew that she went to get treatment, she said they were surprised because they did not know she was sick and they still did not know what she went to get treatment for. Similarly Tina, who waited 15 years before she got treatment said,

*"It was only me and my husband who knew, even my relatives when I told them they were surprised. They said, 'we were talking with you thinking you are Ok while you were sick! You can really keep secrets'. I thought I should disclose my problem to my God only because I thought even if I told them that I am like this ... they would keep discussing about me, therefore I decided to keep it to myself."* (038, Age 36, Mbeya)

The scars from the past remain with them, even after treatment. Even walking with friends was something Joyce appreciated and no longer took for granted.

*"My fellows did not know what I was suffering from. It is only three girls who were aware. On my return, my fellows received me well ... and we continued to live comfortably. We could even walk together"* (009, Age 28, Dodoma)

Lydia was still in school when she got pregnant and got obstetric fistula. Her lover had abandoned her and she stopped going to school because of her leaking.

*"Before I got the problem I could cultivate, I could go to school, I could do all the activities and after I got the problem I continued to do all activities as usual but I did not continue school. My teachers told me that I should go to school but I could not go back. I thought I would make the desk wet."* (033, Age 20, Mwanza)

Lydia's avenue for coping was marriage. She was proposed to by a man who promised her financial support and that he would help her find treatment for her obstetric fistula. She agreed and married him as his second wife.

### **The importance of social and emotional support**

The experiences of the women returning home after treatment were a blend of good and bad, challenging and smooth. Social and emotional support played an important role in the ease of transition. Lydia recalls how she lost her 'self' when she had fistula, even though she was supported by family and friends.

*"I was like a mad person. I could not sit with people, I used to sit alone. I was feeling very bad. I thought this problem does not exist and cannot be cured ... they [friends and relatives] perceived it as a normal problem but myself, I was feeling like a mad person. [Now] I feel ok. I am very happy because urine is no longer pouring" (033, Age 20, Mwanza)*

All informants, even though they were ridiculed by some, had support from someone else, be it a family member, a friend or church members. Support, however, is a relative term and the extent of support varied. One informant explained this blend of experiences by saying,

*"Some were laughing at me; others were giving me courage and saying that one day I will be healed. Some were speaking of me as 'this person is sick she is leaking urine ... she is giving birth every day while she is sick'. They also told my husband to divorce me ..." (R5, FGD, Singida)*

Many informants who were not able to hide their leaking knew that others were talking about them, and suffered in silence. Lucy said,

*"People were saying that I pass urine on myself, when I was going to the well [to fetch water]. I was just keeping quiet" (029, Age 17, Mwanza)*

Sometimes, Joyce explained, she was very sensitive to others' behaviours and felt that certain actions were directed towards her.

*"[before treatment] when I saw someone laughing I thought they were laughing at me and when they spat, I thought they were doing that because of me" (009, Age 28, Dodoma)*

Veronica said rather emphatically,

*"Life was bad. I was getting thin because of the sickness. I was in trouble totally... I continued to live without happiness. It is only in the last year that I regained my happiness. I can now regard myself as a human being" (017, Age 63, Dodoma)*

The informants often spoke about others feeling sympathy towards them. Sympathy from others was often well intentioned and could be very positive. For Rita, the sympathy was manifested as a joint celebration of her cure and a sincere sharing of happiness.

*"They received me well... there were a lot of people here because when I arrived, they gave me money, some gave two thousand... others gave me three thousand...they were saying sorry for your troubles" (032, Age 58, Mwanza)*

Amina shared,

*"They [neighbours] all come to see me, even my friends. It was like there was a party. When I was there [hospital], they used to phone me frequently asking me 'is it true that you are cured?' and I was telling them that I can even wear a pant only. They said 'really?' So when I returned my neighbours were very happy and they said 'we thought it was lies'" (050, Age 32, Mbeya)*

Some informants felt that community members felt pity towards them. This sentiment, in a subtle way, was more condescending towards the woman. Saphia expressed that despite having eight children, she got no respect because of the leakage. She said,

*“They used to see me when I sat and when I stood up...they were just looking at me and feeling sorry for me” (018, Age 36, Dodoma)*

Usually, if a woman was completely dry after treatment, she was happy to be dry. For Cindy, however, treatment was not enough. She was 19 years old when we interviewed her six months after her repair. She was very silent and looked very sad. Her parents were divorced, she was living at her grandfather’s house, and her husband had abandoned her. Her mother lived far away, and she could not visit her often and she was the eldest of her siblings. When we asked her if she had any friends in the village, she looked down, and said she did not have any. When we asked her what she enjoyed doing, she remained silent and looked downwards. She lacked emotional support, and lead a very isolated and unhappy life, even after a successful treatment.

### **Believing in the power of God**

Some of the informants found peace through their spirituality and belief in God. Some found companionship in God, while others felt a sense of peace and security through their faith. Veronica felt strength and compassion through her faith which helped her cope with her circumstance. She had lived with obstetric fistula for over 35 years and had three partly successful treatments. Her husband abandoned her after obstetric fistula, and she conceived a child with another man. She avoided social events, and was mocked by her community. She narrates,

*“My relatives just took it simple but there are some people who were saying ‘why is this woman stinking of urine?’ I used to keep quiet because it is God who decided for me to be like this ... they are still talking about it until now but I do not listen to them because I am getting treatment. Those who are discussing about me let them discuss, because they are created by God and I was also created by God” (017, Age 63, Dodoma)*

Tina was able to accept her circumstance through blind faith in God. She said,

*“When I got a problem of urine I decided to involve God. I decided to accept it as a disability like what other people get, but I had hope that to God nothing is impossible. Therefore I knew God will heal me when he wishes to do that” (038, Age 36, Mbeya)*

### **Regaining freedom and mobility**

Travelling long distances or spending an extended amount of time at social events made it difficult to hide the leakage. Due to this, many informants limited their mobility to shorter periods and shorter distances. After treatment when the leaking stopped, there was a sense of freedom in terms of mobility. Freedom to travel without the worry of leakage, smelling, wetting the seat, having enough padding, feeling shame and embarrassment in front of others, or the fear of being ridiculed. It was a liberating experience. Amina shared,

*“... in the past I could not travel ... last week I was in Tukuyu to attend a funeral. I went there and I slept there. I am comfortable and I feel happy [to be cured]. I had so much trouble with this disease.” (050, Age 32, Mbeya)*

It is not surprising that treatment brought relief and comfort in many different aspects of her life. She regained her ‘self’ and felt happy. Shamira shared,

*“I felt good to be cured. I am completely cured. I was like a crippled person when I was sick, but after I got treated I felt relief in my legs. I can even stand up, because I was unable to stand up. I was even unable to walk, but now I can go to Itete [town nearby] ... When I go to sleep at 10pm and I wake up at 6am, that is when I go to pass urine but in the past I used to sleep with a container near me and I could make it full in a single night” (048, Age 57, Mbeya)*

## **Future hopes and expectations**

Women who have endured this scarring journey may have healed physically but the emotional scarring takes longer to heal. Repairing the obstetric fistula is of course the first step. Without this, they cannot even think about their future without pain. Mary, who had both RVF and VVF, was still recovering from her VVF treatment before she could go again to repair her RVF. She said

*“I cannot have dreams now. When I recover I will know what to do” (007, Age 21, Dodoma)*

Rita had remarried and moved on well with her life after having lived with obstetric fistula for 25 years. However, the trauma of her past still hurts her. She said,

*“Yes she [ex-husband’s other wife] comes to see me but I don’t go [to see them] because I got the problem at the place where they are living... so I do not want to go there...I hesitate to go there... I can go but it hurts me when I go there” (032, Age 58, Mwanza)*

A third of the informants interviewed still had some form of incontinence, either through an unsuccessful surgery or stress incontinence. When that was the case, their level of contentment depended on their ability to successfully hide the leaking or not. If they could hide it and the condition was better than before, they were still grateful for the improvement but hoped to be completely dry. If their condition was not improving, then they started to lose hope. Veronica had lived with obstetric fistula for 30 years with three treatments but was still leaking, although improved. She said

*“I was not born with it. God created me nicely. If I was born with it I could tolerate it.” (017, Age 63, Dodoma)*

We asked Amina what she would advise her own daughter in the future, she said,

*“I will tell her to study hard and that she should not be misled by men. I will tell her that she has to study hard because education will be her mother.” (050, Age 32, Mbeya)*



Joyce, even though she was still dependent on her family, regained hope after repair. She explained,

*“I feel well because I was afraid about my life, how could I live? Now I can do some work. If I get capital, I can do business.” (009, Age 28, Dodoma)*

All, except one said they would advise pregnant women to go to the hospital early and inform women about obstetric fistula and where they could get treated. Only one informant said that since she suffered alone, she wanted others to go through the same, and she would not advise them anything. After interviewing her, some of our team members felt she may not be mentally stable.

When informants were asked about their hopes for the future some said,

*Joyce: My dream is to get money in the future and sell clothes and cosmetics and after that I want to construct a house here at home” (009, Age 28, Dodoma)*

*Tina: “if God opened doors for me and I succeed to get capital I would like to do a business of selling rice. If God opens doors for me, I want to own a shop that is what I dream about. I hate staying idle without a job.” (038, Age 36, Mbeya)*

*Gloria: “I wish to have farms and a house so that I live a good life together with my children. I wish to get money so that I and my children could go and look for ‘mitumba’ [second hand clothes]” (028, Age 39, Mwanza)*

## **Reflections**

Informants in this study found ways to cope with their challenges socially, emotionally and financially. The hardships faced are overcome gradually after repair. Socially, most regain normalcy, however, their internal personal struggle continues in more subtle ways. This struggle is eased when they have support from their family and/or community. Depending on each narrative, most of them experience tremendous financial burdens and are finding it most

difficult to rebuild their financial position back to where they were before they got obstetric fistula. For some, it may be years before they can recover from that loss and some may never, particularly the informants like Grace, who were now elderly and had spent their lives suffering with obstetric fistula. These women have endured a failure of health, gender and prosperity and they are slowly rebuilding their lives, dealing with one misfortune at a time, in the best way that they know how.

## **Chapter 7: Discussion and Conclusion**

### **Discussion of findings**

According to the 'proposed reintegration needs' of women with obstetric fistula, which was presented by Data, Indicators and Research Group/Obstetric Fistula Working Group (DIRG/OFWG) in 2006, it was suggested that women's needs can be divided into four components; physical health, mental health, social well-being, and economic well-being. It stipulates that reintegration needs are fulfilled when women are physically continent, regain their fertility and sexual life as desired, and have safe deliveries in the future. Socially, they should experience reduced stigma, be able to participate in religious and social activities, receive social support and be able to marry or re-marry as desired. Economically, they should regain or improve their status, get family support or source of income and they should have the ability to support others. Lastly, their mental health should improve in terms of increased self-esteem and happiness (UNFPA, 2008: 31).

This model will be used as a backdrop for understanding reintegration after repair. During the follow-up of the 37 informants who had previously been treated for obstetric fistula, we looked at different aspects to understand their lived experiences, and challenges before and after obstetric fistula repair. The combined understanding of how obstetric fistula was understood, experienced and handled, physically, psychologically, socially and economically, helps reflect on their successes and challenges during reintegration.

### **Why me?**

The understanding of the cause of obstetric fistula varied across the study sample and it seemed to affect the informant's lived experiences and their planned actions in the future. The cause of obstetric fistula was explained either with a medical/biological reason, a supernatural reason, or a combination of the two. It was also interesting to note that some informants interpreted the question, "why did you get obstetric fistula?" to mean, why they physically got obstetric fistula, while others interpreted it to mean why this misfortune of obstetric fistula was

bestowed upon them specifically, moving beyond the symptomatic, towards the aetiological. This variation ties in with Susan Whyte's theory about symptomatic and explanatory idioms (Whyte, 1997: 25-28).

When obstetric fistula was considered 'not normal' or an unknown condition, it was an anomaly. When there was no one within the informant's social network who experienced the same condition after childbirth, or when the informant and community members had not heard about the condition, it became a misfortune that was often explained by a force beyond their control. There was a tendency towards the explanatory idiom, moving beyond the physical symptoms and wondering about supernatural forces to be the reason for its occurrence, for e.g., bewitchment, evils spirits or magic. Also, the 'blaming' of the occurrence of obstetric fistula on supernatural causes was not limited to the informants, her family members and her community, but it also came from the health professionals at times. Some informants held on to these explanations even after they had been treated and cured, while others changed their perspective after going for treatment and realizing that it was not really an anomaly and others were suffering from it as well. The etiological understanding of the misfortune was thus not limited to occasions where there was unawareness about obstetric fistula. It is suspected that such beliefs are rooted in culture and are a means to justifying social stresses within different relationships.

Douglas (1966) would speak of this anomaly as a deviation from the order created by culture and in this study was reason for condemnation or sympathy for those affected, often a combination of the two. The etiological understandings about the cause were in some ways, putting the blame of the misfortune on something external to them, which helped protect and preserve their psychological well-being to some extent. In the case of the health worker saying that the baby was held back by magic, she was also shifting the responsibility of the challenging birth to something external and uncontrollable. This shift in responsibility removes any feelings of guilt and instead, shifts the focus to coping with the circumstance in the best way they knew how.

Who or what the informants blamed for their misfortune influenced how they felt about themselves, their situation, and how they interacted socially. Sometimes when the blame was on a family member, a mother-in-law for example, the social relations with that person were turbulent. The beliefs about possible causes also drove behaviours like visiting traditional healers, or avoiding traditional birth attendants for future deliveries, or having feelings of resentment towards individuals.

The level of awareness about available treatment had a significant impact on the emotions of the informants. When they knew there was a cure, there was hope, and most felt positively about the future. However, if the solution proposed was unaffordable, feelings of helplessness would arise. All in all, knowing that their condition was curable and 'normal' was important for their psychological well-being.

How the misfortune was understood, also influenced health seeking behaviour. Using Kleinman's (1978) model, the first approach to understanding the 'disease' was through the popular arena, usually family, who would later refer to the folk arena, like healers, if it was considered an anomaly. As awareness about treatment increased, the informants eventually accessed health care within the professional arena, like hospitals. Depending on the level of success within the professional arena, this trend would continue in an effort to seek relief from the disease. For example, if the treatment was unsuccessful or partly successful, leaving the informant incontinent after repair, there was a trend to go back to the family and folk arena to gain relief, sometimes, a cyclical process.

Considering the proposed reintegration needs model, the physical needs have not been fully met, after treatment. Wall et al. (2007) speak of the 'continence gap' and how even though 85% to 90% of fistula repairs are successful, 15% - 20% of these still experience some degree of incontinence. They speak of the importance of a holistic approach towards addressing fistula, and not simply the clinical closure of a hole (Wall and Arrowsmith, 2007). A third of the women we interviewed were still experiencing some incontinence and their level of awareness was not strong enough to ensure safe deliveries in the future. One informant said she delivered another

baby at home, after she had already been treated for obstetric fistula, because it was difficult for her to get transportation from her village. There is a clear need for clinical follow-up of patients treated for obstetric fistula, to address residual leakage.

After treatment, if completely dry, how she felt about herself, was at times different from how others were towards her. When she was dry, she was happy and she associated herself with other women in her community. Pope et al. (2011) also found this in their study at Ukerewe in Mwanza region (Pope et al., 2011). When dry, the woman regained her womanhood, her self-esteem increased and her mental health improved. When there was disbelief from community members whether the condition was curable or not, the community still looked upon her with suspicion and may not believe that she was now completely cured. This could attach the label of the 'woman with a problem' for quite some time, even after repair. These circumstances, both before and after repair could strongly affect her psychological and social well-being.

### **Womanhood interrupted**

When a woman is faced with obstetric fistula, several things within the social and cultural order fall 'out of place'. She is unable to control her urine and/or faeces, she may be left with a failed marriage and she was most likely unable to bear a child. Mary Douglas (1966) speaks of the perception of dirt when things are not in their expected place. A grown woman is expected to have control over her excretion, a married woman is expected to maintain her marriage, and a pregnant woman is expected to deliver a child. When a woman is faced with obstetric fistula, her womanhood is interrupted and she becomes 'out of place'.

A woman suffering from obstetric fistula is stripped of her adulthood in the sense of an inability to control her bodily function of excretion. While urinating is normal, urinating without control produces 'matter out of place', and is dirty. A woman who wets herself with urine is considered unclean and is commonly subjected to rejection, and social stigma. This is often a 'dehumanizing' experience for the woman, causing shame and she feels out of 'order' with other women in her community and her family.

In a study among the Nyole of Uganda, Whyte explains that an individual is not complete as a social person, until he or she is married and can begin the process of creating a new family unit (Whyte, 1997: 54). This is relevant also in the Tanzanian context. Informants were sometimes rejected by their husbands due to the leakage and smell and their 'failure' at bearing a child. Before treatment, their sexual life was greatly affected by the leakage, the physical rashes, and the feeling of being 'destroyed'. It lowered the woman's self-esteem and put stress on the partnership. Some husbands showed support during this time, which was extremely important for the women. Other husbands expressed disgust, became unfaithful, brought on another wife, or sent her back to her parents. If the husband stayed, after treatment, when she returned home, she was required by the hospital to abstain from sexual intercourse for a few months. This was often possible, if she showed the letter from the hospital indicating so. However, a woman had no control over her husband's fidelity during that time.

Infertile women in Tanzania are more likely to be in polygamous unions, have higher levels of sexual activity due to marital instability, and be less certain about their sexual partner's fidelity (Favot et al., 1997: 416). Marriage and maintaining a marriage is also part of the social order and when it fails, using Mary Douglas' (1966) concept, she may be seen as 'matter out of place'. The woman faces a predicament if her husband has not left her, to either accept his infidelity, or to face the social consequences of a 'failed' marriage as well. She is often forced to accept the harsh reality that she is faced with.

Whyte also speaks of how women are valued more when they bear children. The less fertile women, bearing few or no children are unhappy when they compare themselves to their more fertile counterparts amongst the Nyole of Uganda. If a woman is unable to bear children, her husband will add on another wife. Even if the man is not keen on bringing on another wife, his family will put pressure on him to do so (Whyte, 1997: 54-56).

In Tanzania, the more children a woman has the more respect she earns in society (Dyer, 2007: 74). A woman who is faced with obstetric fistula is thus stripped of her womanhood due to her 'failure' at bearing a child. She loses her status in society, particularly if obstetric fistula

occurred during her first or second pregnancy. Even though with obstetric fistula, a woman is not necessarily infertile, until she bears children in the future, she has still 'failed' in her task of childbearing. Childbearing is thus not only something important from the perspective of the self, but also from the perspective of society.

Lilian Mselle, who had interviewed women with obstetric fistula and their husbands at hospitals in Tanzania got similar results in her study (Mselle et al., 2011). After bearing these circumstances, some are deeply scarred and have not been able to resume their sexual and reproductive lives, due to the fear of recurrence, up to one year after treatment. Many however, despite it all, want to have more children and resume their roles as women. Oftentimes, these were women who had been treated relatively quickly after the fistula developed and were completely cured after treatment. Some however, remarried, even with an untreated obstetric fistula, and brought back the 'order' in their lives.

### **Social and economic security**

Women who have endured obstetric fistula have faced physical and social challenges. Frequently, a consequence of that is also facing financial challenges. Most women who have suffered from obstetric fistula are already a marginalized group of individuals. They are oftentimes poor, less educated, women who have married young from very remote rural areas with little or no access to emergency obstetric care. Obstetric fistula is thus rooted in inequity. According to the global burden of disease report, obstetric fistula is weighted at .430 for disability adjusted life years (DALY). To give some perspective, blindness is weighted at .600 in the same report. (Lopez et al., 2001: 121-122) This is very significant considering that the years lived with disability (YLD) caused by obstetric fistula is 174,000 for sub-Saharan Africa where the age group affected is between 15-44 years (Murray and Lopez, 1998: 260). As these women already represent a marginalized group, they are further marginalized when they are unable to get quick, quality care for their obstetric fistula.



The most severe effects of the 'medical poverty trap' are felt by those living with untreated morbidity (Whitehead et al., 2001: 833). The longer a woman lives with an untreated obstetric fistula, the deeper she sinks into poverty, due to her inability to work, and her dependency on manual labour. If she is abandoned by her husband, she is suddenly completely dependent on other family and community members to support her. This dependency compromises her dignity, mobility and the ability to participate in society.

Studies show that the financial shock of seeking healthcare and living with an illness can put an extreme strain on a household that is already living at or below the poverty line (Russell, 2004: 147-153), and women are the most vulnerable of this group (Filippi et al., 2006: 1537). As shown in the findings, even when the husband is supportive, their assets are often depleted in seeking care, in fact, many return home deep in debt after receiving treatment for obstetric fistula. They commonly have no start-up capital to rebuild themselves and so automatically fall deeper into poverty and financial dependency. Most of the informants in our study were struggling to regain their socio-economic status after repair.

After the interviews, we asked what they would like to do to earn a living and how much money they would need to start it, oftentimes, the amount quoted was as little as Tsh. 30,000 (less than USD 20). For some, the physical recovery necessary to cope with the heavy lifting and hard labour done in the villages also took a significant amount of time, sometimes more than nine months. This added to their financial burden which seemed to be the more prominent cause for stress and worry during reintegration. Others, who were treated quickly and referred correctly to the appropriate hospital, were able to receive free treatment and resume their financial and social lives as before.

Socially, a very prominent coping mechanism was to hide the leakage. If they were successful at hiding the leakage, either before or after repair, almost all were able to engage in community gatherings and regain their social lives. Hiding the leakage was an effort to recreate the 'order' and control that was lost. All these experiences combined were easier to tolerate, when the women had some level of social and emotional support.

It was encouraging to find that despite being ridiculed or condemned by some, all informants had someone in their lives that supported them socially and financially. This support was immensely important for their mental well-being; however there was always a strong desire to recover completely and be self-sufficient.

A popular saying in Swahili is, “mtu ni watu” (a person is people) which means that no person is an island and every person needs the company and help of others to survive. This is also true for obstetric fistula survivors in Tanzania and it is this saying that also represents the philosophy within the culture which prevents obstetric fistula patients from experiencing extreme cases of exclusion and mistreatment. Most requirements stipulated in the reintegration needs model would be satisfied if there was increased awareness about treatment, better coordination and referral between hospitals, and quick and quality care.

### **Reflections on methodology**

The study sample included women who had visited hospitals for treatment of obstetric fistula, and it was likely that these were women who had some support from friends or family to be able to seek treatment in the first place. There may have been a selection bias while tracing informants. We started with those for whom we had a phone number, as we were often faced with a sample of informants without clear addresses. This could imply that these were informants who were more ‘connected’ and had better access to information. This however varied within informants. Oftentimes, the phone number was of a friend/relative/hamlet leader/ambassador, and so it was often through the grapevine that we reached the informant. Coincidentally, there was never more than one informant from the same village. In some cases, if we did not have a contact or a clear address, and if we were in the general vicinity, we traced informants through village schools which proved quite effective and allowed us to ensure a varied selection. In the cases where we had no mobile phone number or if the phone was unreachable, tracing informants was most effective if we had the village name and the name of the hamlet leader.

In some locations, for example in the district of Geita in Mwanza region, informants were more difficult to trace. This was a district where the primary source of living came from working as miners at the gold mines. This also led to frequent relocation of informants and their families from one mine to another. There were two incidents which also left some doubts about whose stories we were able to get and whose we were not. One informant, whom we were unable to trace, had relocated. We had a chance to speak with her neighbours, and they said that they had seen her previously and that she was in bad shape. They said she was walking by herself on the streets and then she moved away in search for a better life. Others in the same neighbourhood said she had moved due to superstition that this area was bad for her. Another informant in Magu district of Mwanza also raised some questions in my mind. We asked a local villager if he knew of the informant and he led us to her home. He mentioned that he had seen her and that she was still leaking urine. When we reached her home, her mother said she had gone to another village far away to get treated for another disease. The villager felt that her mother was hiding her and that she was sent to traditional healers for treatment. Other informants moved to the nearby towns to earn a living, and since the populations were much higher, it was difficult to locate them.

The head fistula nurse at Bugando hospital also narrated a story of a fistula patient who had both urinary and faecal leakage when she came from treatment. After treatment, she said she had refused to go home, and had eloped with a brother of another fistula patient at the hospital. The fistula surgeon at Bugando hospital also mentioned one case of a patient who had attempted suicide by jumping out the window of the fistula ward. After the study, I was left wondering, what were the stories that we did not get?

A wide and diverse demographic of informants was targeted to ensure a varied sample. Our informant's ages ranged from 17 years to 75 years, their reintegration period was between six months to 18 months before the interview, and the years lived with obstetric fistula before treatment ranged from less than a month to over 55 years.

In-depth interviews from husbands and other family members and friends of the informant would have added value to our data but because we did not have ethical approval for doing that, we had to exclude it from this study. However, we did engage in brief casual conversations with husbands in order to make them feel included and comfortable, which were recorded as notes or observations added to interviews.

The local collaborators in this study were critical for its success and for the depth and extent of data that we were able to collect. On one hand it was advantageous also to have collaborators with several years of experience in the field of reproductive health to jointly conduct the interviews, while on the other hand, due to this, there could potentially be more pre-conceptions and assumptions during the interviews.

All in-depth interviews conducted had at least three members of the research team, namely, the researcher, research collaborator/translator and note-taker, were sitting with the informant. At other times, there was also a local health worker that joined the interview. This decreased the level of privacy available to the informant, and could have affected the depth of information that was shared. This could not be avoided because of the researcher's inability to converse in the local language. In two situations, the local health worker was required to translate some words from a regional language as well. It was also in the interest of Women's Dignity to make local health workers aware of obstetric fistula and its consequences, and to show them how we were conducting fieldwork. At times, the interviews were also interrupted by neighbours or relatives who were politely requested to give us some privacy. In villages where the homes were relatively close to each other, watching the Women's Dignity vehicle drive through attracted some attention as well. Perhaps this could have made the informant a little uncomfortable or it could be taken positively and perceived as something special to have visitors.

The informants selected for the focus group discussion were obviously a biased sample. It consisted of women who had previously engaged with Women's Dignity and had been provided

financial assistance and/or skills training to assist with their reintegration in the past. They had also been treated for obstetric fistula several years before the rest of our sample.

Data collection with each informant was limited to a maximum of two hours during the first encounter. Informants were dispersed over a wide geographic area which made it difficult to return with follow-up questions or clarifications. This also limited the time to develop a deeper level of rapport with the informant and may have affected the quality of data to some extent. We were only able to revisit one informant who lived in Dar es Salaam.

The analysis of the study was primarily done using the transcriptions and translations. There was minimal cross checking done for both the transcriptions and the translations. Eight interviews were transcribed in the field, while research was being conducted. We checked these and found that they were not word for word. The person transcribing was explained what was required and these were redone. After the initial check, I trusted that the transcriptions maintained quality. The translator was not present when the interviews were conducted. Some words may have meant something else if body language and circumstance were taken into account. Some gestures were recorded as notes within the transcriptions, but there could still be room for variation in interpretations. While analysing, by accident, some errors were also found in the translations. The strength however, was in the triangulation of data in all its forms and approaches. Combining in-depth interviews, a focus group discussion, observations and audio visual data put meaning and context behind the words and lives of these women.

## **Conclusion and Recommendations**

Obstetric fistula is a multi-layered, multifaceted experience for the person affected by it. On an individual level, treatment of obstetric fistula requires a holistic approach. Treatment goes far beyond the closing of a physical hole; it requires a complete system that helps prevent, treats and rehabilitates a person physically, socially, psychologically and financially. At the medical level, it requires follow-up for patients with residual incontinence and quality care. At the community level, it requires more awareness. Mobilizing obstetric fistula survivors to be advocates for treatment and community education would be one effective approach. At the

health systems level, it requires better management of referrals, and coordination between health facilities. All these recommendations should be catered to within the specific context that they are being introduced in, in order for them to be effective. Community follow-up visits would be expensive in terms of time, distances and accessibility. However, with generally good mobile phone connectivity, the use of innovative and sustainable solutions with mobile phones would be feasible. CCBRT's MPESA system for compensating patients for transportation could be easily scaled up for follow-up as well. At the research level, more studies are required to get a deeper understanding of the extent of the challenges that are touched upon in this thesis. Obstetric fistula is an inequity issue surrounded by stigma. Researchers must wonder whether we are just touching the tip of the iceberg and question, whose stories are we not able to get?

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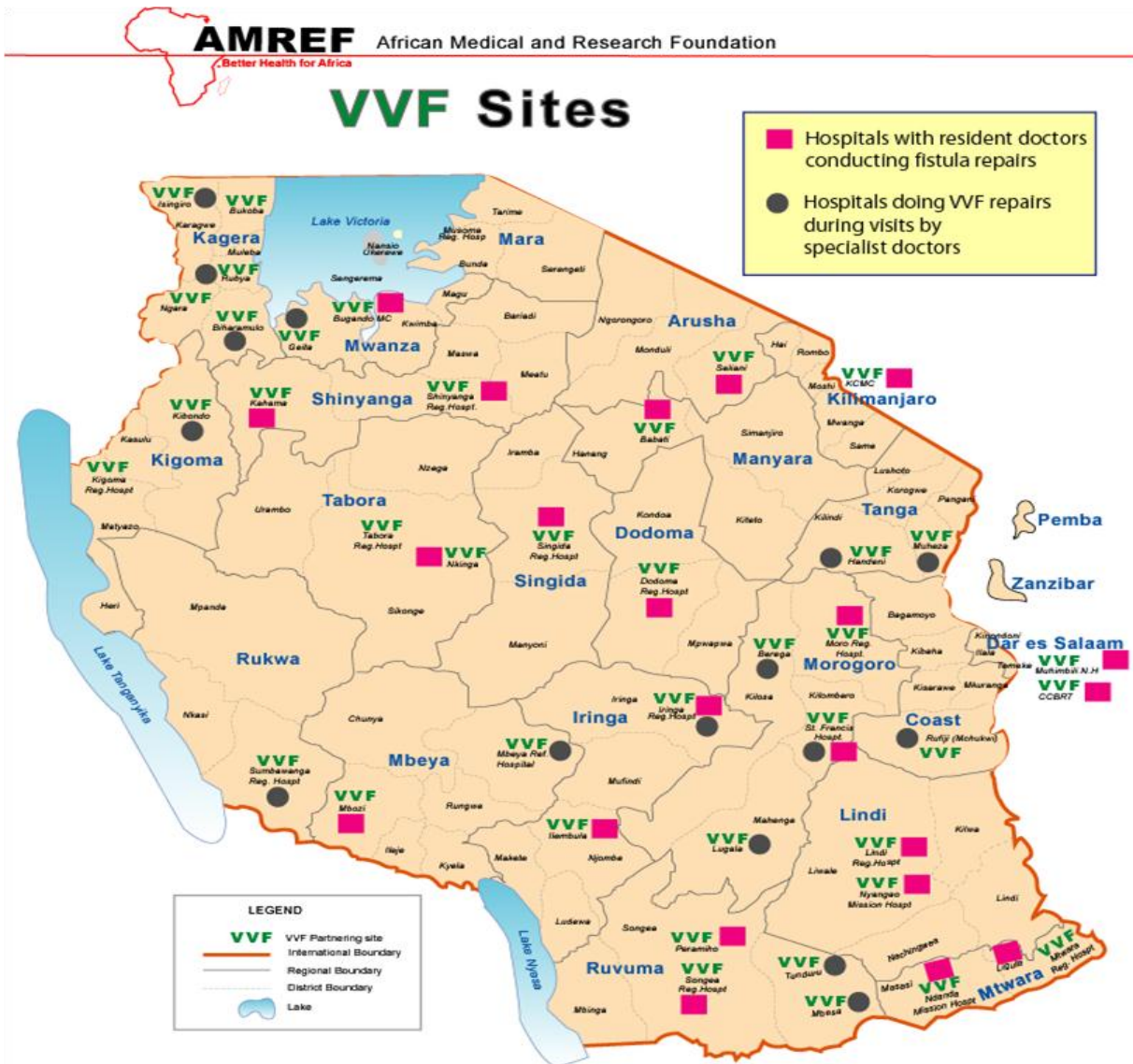
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# Appendices

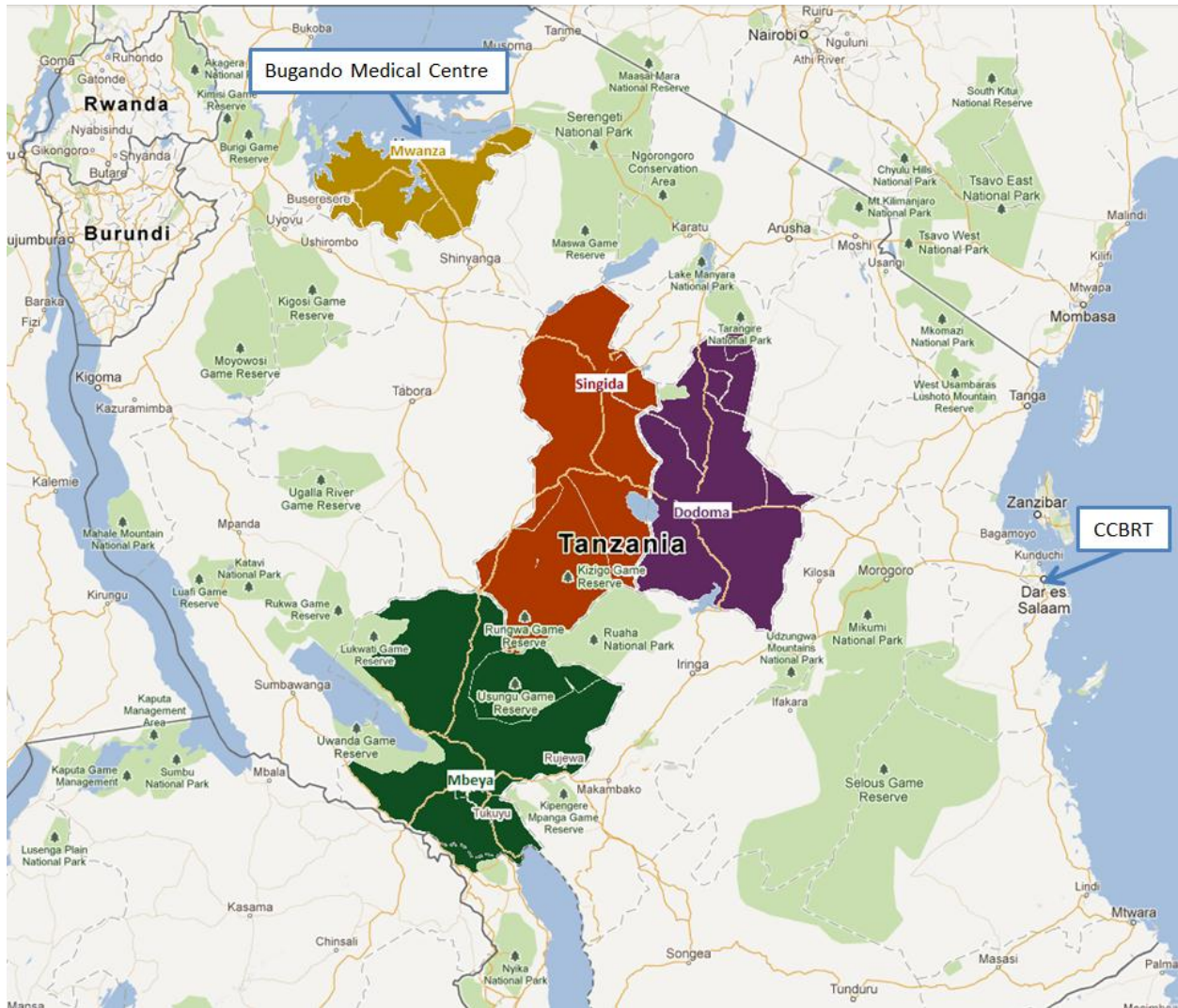
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# Map of hospitals providing fistula repairs in Tanzania, 2011



Map used with permission from AMREF Tanzania. Refer: Angela Mapunda 2011

## Map of study setting: Dodoma, Singida, Mbeya and Mwanza Regions



Adapted from Google maps

## Overview of women treated for fistula for in depth interviews

#	Ethnic group	Region	Age at interview	Married at age	Circumcised?	No. of pregnancies	Stayed with obstetric fistula (years)	Reintegration time (months)	Completely dry?	Education	Foot drop / paralysis?
1	Bena	Dodoma	21	Unmarried (preg @ 20)	yes	1	<0.25	6+	no	Std 7	Yes
2	Gogo	Dodoma	63	29	yes	2	1	6+	no	?	No
3	Gogo	Dodoma	36	18	yes	4	11	11	yes	?	No
4	Gogo	Dodoma	75+	~16	yes	2	55	8	no	None	No
5	Gogo	Dodoma	36	19	yes	8	<0.25	7	yes	Std 7	No
6	Gogo	Dodoma	22	17	yes	2	<0.25	8	yes	Std 7	Yes
7	Gogo	Dodoma	39	20	?	9	<0.5	11	yes	Std 7	No
8	Gogo	Dodoma	28	16	yes	3	> 1	9	yes	Std 7	No
9	Hehe	Dodoma	43	22	Yes	4	1	10	no	Std 7	No
10	Hehe	Dodoma	23	20	yes	2	<0.25	~12+	yes	None	Yes
11	Maasai	Iringa	18	17	yes	1	0	9	yes	Std 7	No
12	Nyakyusa	Mbeya	33	22	no	3	0	8	yes	Std 7	leg pain
13	Nyakyusa	Mbeya	20	18	no	1	0.25	8	yes	Std 5	leg pain
14	Nyakyusa	Mbeya	32	17	no	2	10	9	no	Std 7	No
15	Nyakyusa	Mbeya	26	12	no	1	13	8	no	Std 7	No
16	Nyakyusa	Mbeya	36	18	no	2	15	9	yes	Std 7	No
17	Nyakyusa	Mbeya	36	16	no	3	15	~12	no	Std 7	No
18	Nyakyusa	Mbeya	~57	15	no	10	28	9	yes	?	leg pain



#	Ethnic group	Region	Age at interview	Married at age	Circumcised?	No. of pregnancies	Stayed with obstetric fistula (years)	Reintegration time (months)	Completely dry?	Education	Foot drop / paralysis?
19	Nyakyusa	Mbeya	29	20	no	3	<0.25	8	yes	Std 10	No
20	Nyakyusa	Mbeya	20	18	no	1	<0.25	11	no		yes
21	Sukuma	Mwanza	18	16	no	1	0.5	15	yes	Std 1	mentioned leg pain
22	Sukuma	Mwanza	20	21 (conceived @ 17)	no	2	3	22	yes	Std 5	No
23	Sukuma	Mwanza	58	~	no	8	25	3	yes	?	yes
24	Sukuma	Mwanza	~40	18	no	6	<0.25	10	yes	Std 7	No
25	Sukuma	Mwanza	18	Unmarried (preg at 14)	no	2	<0.25	14	yes	Std 7	No
26	Sukuma	Mwanza	20	16	no	2	<0.25	8+	no	Std 5	yes
27	Sukuma	Mwanza	17	14	no	2	>0.5	15	yes	Std 7	No
28	Sukuma	Shinyanga	19	17	no	1	>0.5	6	yes	Std 7	yes
29	Sumbwa	Mwanza	39	16	no	7 (1 twins)	<0.25	9	yes	Std 3	No
30	Unknown	DSM	25	?	?	3	0	6+	no	std 7	No

## Timeline for data collection

<b>Dates</b>	<b>Activity</b>	<b>Region</b>
19-Aug-2011 to 25-Aug-2011	Health Personnel interviews at CCBRT	Dar es Salaam
08-Sep-2011 to 09-Sep-2011	Women's Dignity Health worker training	Dodoma
10-Sep-2011 to 25-Sep-2011	In-depth interviews w/ women + CCBRT Ambassadors	Dodoma/Iringa
26-Sep-2011 to 28-Sep-2011	Focus group discussion	Singida
29-Sep-2011 to 12-Oct-2011	In-depth interviews w/ women + Bugando Hospital health personnel	Mwanza/Shinyanga
Drive back to Dar es Salaam and mid study break		
23-Oct-2011 to 03-Nov-2011	In-depth interviews w/ women + CCBRT Ambassador	Mbeya
13-Nov-11	In-depth interview with woman	Dar es Salaam
17-Jan-12	In-depth follow-up interview w/ woman	Dar es Salaam

## **Interview guide for women previously treated for obstetric fistula**

### **GENERAL PROFILE**

1. How long did you have fistula before you got treatment?
2. When were you treated?
3. Did you return to your village immediately after treatment?
4. Did you get any counselling after treatment?
5. What is your education level?
6. When did you stop studying? Why did you stop?
7. How was it for you, in this society, to live with a fistula?
8. How did it affect your role as a wife, daughter, mother or friend?
9. How did it affect your participation in social life? (In family, productive activities, social networks/participation in community activities etc)
  - a. Did you live with your family when you had fistula?
  - b. Did you work when you had fistula?
  - c. Did you participate in activities with the community, like praying, dancing/singing, attending weddings? Etc If no, why not?
  - d. Did you eat with the family?
10. What can a woman with fistulae do and what is it that she cannot do?
11. How easy was it to seek for fistula repair?
12. Do you have any children?
13. Are you married?
14. Did you feel supported by friends/family/community?

### **EXPERIENCE DURING REINTEGRATION INDIVIDUALLY**

1. Now that you've been treated, how do you feel about being back at your village?
2. What do you usually do in the day? Probe about different activities – based on previous answers

3. Do you want to have a baby again? If yes, where would you like to deliver the baby?
4. How do you feel about yourself now, and what are your goals for the future?
5. What makes you happy?
6. What are your dreams? If you could close your eyes and wish for ANYTHING, what would it be?
7. What concerns you most after fistula repair?

**EXPERIENCE DURING REINTEGRATION WITH THE FAMILY**

1. How is your relationship with your family right now? (probe based on answers)
2. How is your husband/in-laws towards you? If not married, would you like to remarry?(probe based on answers)
3. Where do you live? With whom do you live?

**EXPERIENCE DURING REINTEGRATION WITH THE COMMUNITY**

1. Based on previous answers, ask about community participation, prayer, work, celebrations,
2. Is there anything else you would like to share with me?

## **Interview Guide for health professionals working with fistula patients**

### **GENERAL PROFILE OF WOMEN WHO HAVE FISTULA**

1. In your experience, how educated are the women who have had fistula?
2. Where do they come from? Is there a particular village where you see more cases?
3. On average how long do they remain with the condition, before they get treatment?
4. On average how far/how many hours do they have to travel to get treatment?
5. Do these women often know someone else who also had fistula in their village?
6. What age group do you see more of?
7. Did they get it during the delivery of their first child, or do they already have some children?
8. With whom do these women come, to get treated?
9. Do you find any who had visited a health facility for delivery and yet had fistula? If yes, how often do you see such cases?
10. What is their diet like? Do you know?
11. Are these women usually married? Divorced? Single?

### **PERCEPTIONS ABOUT OBSTETRIC FISTULA BY THE WOMEN THEMSELVES**

1. How do the women with fistula perceive themselves?
2. What/whom do they blame for their condition? Themselves? Husbands? Mother-in-laws? Witchcraft? Government?

3. What do they believe caused it?
4. Why do they believe it happened to them?
5. Is there awareness about the prevention/causes of the problem?
6. What cultural beliefs/perceptions do they have about their condition?
7. What traditional or cultural practices do they often have in these communities that are directly related to girls and women? What do you think of them?
8. Do people ridicule women with fistulae?
9. Is social isolation a shared experience?
10. How do women cope with this problem?
11. How does it affect their relationship with the husband? (respect, sexual life, extra marital affairs etc)
12. How does it affect relationship to other family members?

#### **PERCEPTIONS ABOUT FISTULA BY COMMUNITY MEMBERS**

1. What do you feel are the general perceptions around obstetric fistula in the different communities you have worked in?
2. What are the general beliefs about the condition?
3. Is it considered dirty?
4. Do they feel a certain “type” of women get it?
5. Do they feel these women need to be cared for?

#### **THOUGHTS OF HEALTH WORKERS ABOUT THE PROBLEM AND SOLUTIONS**

1. In your experience, who suffers from the condition the most?

2. In your experience, what is the most difficult aspect for the woman who has fistula?
3. From the women with fistula whom you worked with, what was their social experience?
4. How did the women occupy themselves on a day to day basis?
5. To what extent did they socialize?
6. To what extent were they included in activities of their community?
7. Do you feel they're stigmatized? If yes, how? Give examples
8. What do you feel is the core problem that needs to be addressed and given top priority?
9. What suggestions do you give to solve the problem?
10. From these suggestions, how would you prioritize them?

### **CHALLENGES DURING REINTEGRATION**

1. What are the challenges, in your opinion, faced by the women during reintegration?
2. Do you feel she will go back and become pregnant again?
3. What are the challenges, as an NGO, in dealing with reintegration?
4. What are the challenges faced by an NGO generally while working with and for women with obstetric fistula?

### **HEALTHWORKER PROFILE**

1. How long have you been working with women and fistula?
2. What is your education level?
3. Did you get any training before you started working? What kind of training?
4. What do you like about working in this area?
5. What do you dislike about working in this area?

Is there anything else you would like to share with me?

## Ethical approval from Muhimbili University

### DIRECTORATE OF RESEARCH AND PUBLICATIONS

P.O. BOX 65001  
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20/  
Direct line: 2152489

Ref.No.MU/RP/AEC/Vol.XIII/

22<sup>nd</sup> July 2011

Julia Iran  
c/o Dr T. Kohi  
**Elective Student**  
**MUHAS.**

**Re: Approval for Ethical Clearance for a Study Titled "Challenges Related to Re- intergration among women after fistula repair in Tanzania"**

Reference is made to the above heading.

I am pleased to inform you that the Chairman has on behalf of the Senate, approved ethical clearance of the above mentioned study, on recommendation of Expedited Review Sub committee of the Senate Research and Publications Committee meeting held on 11<sup>th</sup> July 2011.

The validity of this ethical clearance is effective from 11<sup>th</sup> July 2011 to 10<sup>th</sup> July 2012. You will be required to apply for extension of ethical clearance if the study is not completed at the end of this clearance. You are also required to submit a final project report upon completion of your study.

Permission to publish your study findings should be sought from the appropriate authorities at MUHAS and local supervisor at MUHAS be involved in the study implementation and also be a co- author in all publications to acknowledge her contribution in the study.




  
Prof. M. Aboud

#### CHAIRPERSON, SENATE RESEARCH & PUBLICATIONS COMMITTEE

- c.c. Vice Chancellor - Your letter ref. no. MU/01/1022/121/2
- c.c. Deputy Vice Chancellor, Academics, Research & Consultancy (MUHAS)
- c.c. Dean School of Medicine



## Research permit from COSTECH

<b>TANZANIA COMMISSION FOR SCIENCE AND TECHNOLOGY (COSTECH)</b>	
	
Telegrams: COSTECH	Ali Hassan Mwinyi Road
Telephones: (255 - 022) 2775155 - 6, 2700743/6	P.O. Box 4362
Director General: (255 - 022) 2700750/6, 2775315	Dar es Salaam
Fax: (255 - 022) 3775313	Tanzania
Email: <a href="mailto:reference@costech.or.tz">reference@costech.or.tz</a>	
<b>RESEARCH PERMIT</b>	
No. 2011-227-NA- 2011-116	25 <sup>th</sup> July 2011
1. Name : Julia N. Irani	
2. Nationality : Pakistan	
3. Title : Challenges Related to Reintegration among Women after Fistula Repair in Tanzania: A Qualitative Study	
4. Research shall be confined to the following region(s): Dar es Salaam, Morogoro, Mbeya, Singida, Mwanza, Tanga Dodoma and Pwani	
5. Permit validity 25 <sup>th</sup> July 2011 to 24 <sup>th</sup> July 2012	
6. Local Contact/collaborator Dr. Thecla Kohi, MUHAS, Dar es Salaam	
7. Researcher is required to submit progress report on quarterly basis and submit all Publications made after research.	
 M. Mushi for: <u>DIRECTOR GENERAL</u>	

**Residence Permit Tanzania**



JA 23/1691 VOL. II C  
POMISION  
FG



THE UNITED REPUBLIC OF TANZANIA

TIF 4B

The Immigration Act, 1995  
(Section 20)

N<sup>o</sup> 090653

**RESIDENCE PERMIT CLASS C**

Mr./Mrs./Miss JULIA MCHIRI IMANI  
P.O. Box 1112 Dsm  
is hereby authorised to enter Tanzania and to remain therein for a period of three months  
12/04/2012 for specific employment with hauitro

and subject to the provisions of the Immigration Act, 1995 and to the following conditions:-

- (i) (i) Place of work D. SALOMON MBEYA MWANAA MWGA DODOMA
- (ii) Place of residence D. SALOMON MWANAA DODOMA MBEYA MWGA
- \*(b) the holder shall not engage in any employment, trade, business or profession other than STUDENT
- \*(c) wife and children whose names have been endorsed on this permit are not allowed to engage in employment
- \*(d) (other specific conditions) NO CHANGE OF IMM. STATUS

Description of Passport :-

Country of issue POMISION No. A.C. 1908011  
Date of issue 14/ sept 2007 20

Fees: US \$ 50 received vide E.R. No. 42249352 of 20/7/2011  
Issued at D. SALOMON

*Director of Immigration Services*

All persons entitled to enter the United Republic under this permit must on entering the United Republic report to an Immigration Officer without undue delay ( Reg. 18)

(Section 25)

Full Name	Relationship to Holder	Age
/	/	/
/	/	/
/	/	/
/	/	/

Date ..... 20 .....

*Director of Immigration Services*

\*Delete if not applicable

## **Consent form for interview**

### **English**

**Principal Investigators:** Julia Irani

**Institution:** University of Bergen / MUHAS /Women's Dignity

**Sponsor:** NUFU PROJECT/Quota Scheme/ University of Bergen

Information Sheet for the Individuals Participating in the Research Entitled "Challenges related to reintegration among women after fistula repair in Tanzania: A qualitative study"

Hello! My name is Julia Irani, I'm a student at the University of Bergen studying masters in International Health and I am conducting this research study.

### **Purpose of the Study**

The aim of this study is to throw light on the challenges in reintegration of women who have undergone fistula surgery.

### **Procedure**

If you accept to participate in this study, I will ask you some questions as regard to your perception and experiences related to your/women's reintegration after undergoing fistula surgery. I shall also ask you about the coping mechanisms that you/women you have worked with, take in dealing with challenges associated with reintegration.

If you do not wish to answer any of the questions posed during the interview, you may say so and I will move on to the next question. The interview will take place here and a translator will be present with us during the interview.

The expected duration of interview is about one to 1.30 hours

### **Confidentiality**

The researcher is assuring you that high standard of confidentiality will be observed in this study. No name of any participant will be mentioned in the report of this study. Only the information obtained will be used. All interviews, tape recorded, text and other study

documents will be kept in a secure place and only the researcher and his associate in the project will gain access to the documents.

### **Right to Withdraw and Alternative**

Participation in research is voluntary. You are free to decline to be in this study, or to withdraw from it at any point, with no need for providing an explanation as to why you declined. Your decision as to whether or not to participate in this study will have no influence on you in any way. Refusal to participate or withdraw from the study will not involve penalty or loss of any benefits to which you are otherwise entitled.

### **Benefits**

There will be no direct benefit to you from participating in this study. However, the information that you provide may help in informing the policy makers about the magnitude of challenges that women with fistula experience in order to shape policy formulation and interventions that address this critical social problem. You will receive no payment for your participation.

### **Who to Contact**

If you ever have questions about this study, you may ask the researcher on the site or you may call the Principal investigator Julia Irani -telephone ( ) or write to her through ( ), Dar es Salaam.

### **Consent Signing**

If you agree to participate you should sign below.

I \_\_\_\_\_ have read and understand the contents in this form. My questions have been answered. I agree to participate in this study

Signature of Study Participant \_\_\_\_\_

Signature of Person Obtaining Consent \_\_\_\_\_

Date of signing the consent \_\_\_\_\_

**Fomu ya kukubali kushiriki katika majadiliano ya kina/katika kikundi**

**Mtafiti Mkuu:** Julia Irani

**Taasisi:** Chuo kikuu cha Bergen / MUHAS /Women's Dignity

**Mfadhili:** Mradi wa NUFU/Quota Scheme/ Chuo kikuu cha Bergen

Fomu ya maelezo kwa watu wanaoshiriki katika utafiti wenye jina "changamoto za wanawake za kurudi katika maisha yao ya kawaida baada ya kupata matibabu ya fistula nchini Tanzania":

Halo! Jina langu ni Julia Irani, ni mwanafunzi wa shahada ya udhamiri ya afya ya kimataifa katika chuo kikuu cha Bergen na ninafanya utafiti huu.

**Lengo la utafiti**

Lengo la utafiti huu ni kupata mwanga wa changamoto za wanawake waliopata matibabu/upasujaji wa fistula katika kurudi kwenye maisha yao ya kawaida.

**Utaratibu**

Ukikubali kushiriki katika utafiti huu, nitakuuliza maswali kuhusu mtazamo wako na uzoefu kuhusu wanawake waliopata matibabu/upasujaji wa fistula kurudi katika maisha yao ya kawaida. Nitakuuliza pia kuhusu unachofanya wewe au wanawake uliowahi kufanya kazi nao katika kukabiliana na changamoto ya kurudi katika maisha yao ya kawaida.

Kama hutotaka kujibu maswali yoyote yatakayoulizwa wakati wa usaili unaweza kusema hivyo nami ntaendelea na swali linalofuata. Usaili utafanyika hapa na mtafsiri atakuwa pamoja nasi wakati wa usaili.

usaili unategemea kuchukua muda wa kama saa 1.30 hivi.

**Usiri**

Mtafiti anakuhakikishia kwamba usiri wa hali ya juu utakuwepo katika utafiti huu. Hakuna mahali ambapo jina la mshiriki litatajwa katika ripoti ya utafiti huu. Maelezo tu yaliyotolewa ndiyo yatakayotumika. Usaili wote uliorekodiwa kwa kinasa sauti, kwa maandishi na nyaraka zote, vitatunzwa sehemu salama na ni mtafiti tu pamoja na mwenzake katika mradi watakaokuwa wanavitumia.

### Haki ya kuacha na uhuru wa kuchagua

Kushiriki katika utafiti huu ni uchaguzi wako. Una uhuru wa kukubali au kukataa kushiriki katika utafiti huu au kuacha kushiriki muda wowote bila haja ya kutoa maelezo ya sababu za kuacha. Kukataa kushiriki au kuacha kushiriki katika utafiti huu hakutakuathiri kwa namna yoyote. Hautapata adhabu au kukosa kufaidika na yale unayostahili kupata ukikataa au kuacha kushiriki katika utafiti huu.

### Benefits

Hakutakuwa na faida ya moja kwa moja kwa kushiriki katika utafiti huu. Lakini maelezo utakayotoa yatasaidia kuwajulisha watunga sera kuhusu ukubwa wa changamoto ambazo wanawake wenye fistula wanapitia ili waweze kutengeneza sera na mikakati itakayosaidia kutatua hili tatizo la kijamii. Hautalipwa kwa kushiriki kwako.

### Mawasiliano

Ukiwa na swali lolote kuhusu utafiti huu, unaweza kumuuliza mtafiti atakayekuwepo au unaweza kuwasiliana na mtafiti mkuu Julia Irani – simu  or au kuandika kwa S.L.P  Dar es Salaam. ;

### Sahihi

Ukikubali kushiriki unaweza kusaini hapa chini

Mimi,  nimesoma maelezo ya fomu hii. Maswali yangu yamejibiwa. Nimekubali kushiriki katika utafiti huu.

Sahihi ya mshiriki

Sahihi ya anayeomba ukubali Julia Irani

Tarehe ya ukubali wa kushiriki 13/11/11

# **Consent form for picture and video capture**

## **English**

**Principal Investigators:** Julia Irani

**Institution:** University of Bergen / MUHAS /Women's Dignity

**Sponsor:** NUFU PROJECT/Quota Scheme/ University of Bergen

Information Sheet for the Individuals Participating in the Research Entitled "Challenges related to reintegration among women after fistula repair in Tanzania: A qualitative study"

Hello! My name is Julia Irani, I'm a student at the University of Bergen studying masters in International Health and I am conducting this research study.

## **Purpose of the Study**

The aim of this study is to throw light on the challenges in reintegration of women who have undergone fistula surgery. This consent form deals with a sub-portion of the study involving digital media.

## **Procedure**

If you accept to participate in the digital media part of the study, I will ask you to use a video camera or someone will take a video of you, while you share your story regarding your experience after getting treatment for fistula, with us. We want to know your experience, and you have complete freedom to choose how and what you would like to share your story. If you prefer, your face does not have to be visible in the video and you can show other things while simple narrating your experience.

## **Confidentiality**

The researcher is assuring you that high standard of confidentiality will be observed in this study. No name of any participant will be mentioned in the video, only the information obtained about your experience will be used.

### **Right to Withdraw and Alternative**

Participation in research is voluntary. If there is any part of the video you would like removed, you can ask us to do so at any point in time. All media content (audio/video/photographs) will be kept in a secure place and only the final movie created will be shared with policy makers and others to increase the understanding of the experiences women face after surgery so that better interventions can be developed for comprehensive care. You are free to decline to be in this study, or to withdraw from it at any point, with no need for providing an explanation as to why you declined. Your decision as to whether or not to participate in this study will have no influence on you in any way. Refusal to participate or withdraw from the study will not involve penalty or loss of any benefits to which you are otherwise entitled.

### **Benefits**

There will be no direct benefit to you from participating in this study. However, the information that you provide may help in informing the policy makers about the magnitude of challenges that women with fistula experience in order to shape policy formulation and interventions that address this critical social problem. You will receive no payment for your participation.

### **Who to Contact**

If you ever have questions about this study, you may ask the researcher on the site or you may call the Principal investigator Julia Irani, telephone ( ) or write to her through ( ) Dar es Salaam.

### **Consent Signing**

If you agree to participate you should sign below.

I \_\_\_\_\_ have read and understand the contents in this form. My questions have been answered. I agree to participate in this study

Signature of Study Participant \_\_\_\_\_

Signature of Person Obtaining Consent \_\_\_\_\_

Date of signing the consent \_\_\_\_\_



1051

**Fomu ya kukubali kurekodiwa sauti au picha**

**Mtafiti Mkuu:** Julia Irani

**Taasisi:** Chuo kikuu cha Bergen / MUHAS /Women’s Dignity

**Mfadhili:** Mradi wa NUFU/Quota Scheme/ Chuo kikuu cha Bergen

Fomu ya maelezo kwa watu wanaoshiriki katika utafiti wenye jina “changamoto za wanawake za kurudi katika maisha yao ya kawaida baada ya kupata matibabu ya fistula nchini Tanzania”:

Halol Jina langu ni Julia Irani, ni mwanafunzi wa shahada ya udhamiri ya afya ya kimataifa katika chuo kikuu cha Bergen na ninafanya utafiti huu.

**Lengo la utafiti**

Lengo la utafiti huu ni kupata mwanga wa changamoto za wanawake waliopata matibabu/upasujaji wa fistula katika kurudi katika maisha yao ya kawaida. Fomu hii ya ukubali ni sehemu ya utafiti kwa kutumia vifaa vya kupatia habari (digital media)

**Utaratibu**

Ukikubali kushiriki katika utafiti wa kutumia vifaa vya kupatia habari (digital media), nitakuomba utumie kamera ya video au mtu mwingine atachukua picha yako ya video wakati unatoa maelezo kwetu kuhusu uzoefu wako baada ya kupata matibabu ya fistula. Tunataka kujua uzoefu wako, na una uhuru kabisa wa kuchagua namna utakavyotoa maelezo yako. Ukipenda, sura yako sio lazima ionekane kwenye video na unaweza ku ukaonyesha sehemu zingine wakati unatoa maelezo ya uzoefu wako.

**Usiri**

Mtafiti anakuhakikishia kwamba usiri wa hali ya juu utakuwepo katika utafiti huu. Hakuna mahali ambapo jina la mshiriki litatajwa katika video, ila maelezo tu yaliyotolewa kuhusu uzoefu wako ndiyo yatakayotumika

**Haki ya kuacha na uhuru wa kuchagua**

Kushiriki katika utafiti huu ni uchaguzi wako. Kama kuna sehemu ya video ungetaka iondolewe unaweza kutuambia wakati wowote. Habari zote (sauti/video/picha) zitatunzwa sehemu salama na ni

video/picha tu itakayotengezwa mwishoni ndiyo itakayoonyeshwa kwa watengeneza sera na kwa wengine ili kuleta uelewa zaidi kuhusu mambo ambayo wanawake wanakutana nayo baada ya matibabu/upasujaji wa fistula ili mipango bora iweze kuandaliwa kwa ajili ya kushughulikia matatizo yote. Una uhuru wa kukubali au kukataa kushiriki katika utafiti huu au kuacha kushiriki muda wowote bila haja ya kutoa maelezo ya sababu za kuacha. Kukataa kushiriki au kuacha kushiriki katika utafiti huu hakutakuathiri kwa namna yoyote. Hautapata adhabu au kukosa kufaidika na yale unayostahili kupata ukikataa au kuacha kushiriki katika utafiti huu.

#### **Faida**

Hakutakuwa na faida ya moja kwa moja kwa kushiriki katika utafiti huu. Lakini maelezo utakayotoa yatasaidia kuwajulisha watunga sera kuhusu ukubwa wa changamoto ambazo wanawake wenye fistula wanapitia ili waweze kutengeneza sera na mikakati itakayosaidia kutatua hili tatizo la kijamii. Hautalipwa kwa kushiriki kwako.

#### **Mawasiliano**

Ukiwa na swali lolote kuhusu utafiti huu, unaweza kumuuliza mtafiti atakayekuwepo au unaweza kuwasiliana na mtafiti mkuu Julia Irani – simu  or au kuandika kwa S.L.P , Dar es Salaam.

#### **Sahihi**

Ukikubali kushiriki unaweza kusaini hapa chini

Mimi,  nimesoma maelezo ya fomu hii. Maswali yangu yamejibiwa. Nimekubali kushiriki katika utafiti huu.

Sahihi ya mshiriki

Sahihi ya anayeomba ukubali Julia Irani

Tarehe ya ukubali wa kushiriki 24/9/11