

FORWARD

Safeguarding rights & dignity



'Do not hide yourselves, you are not cursed'

A PEER Study on
Obstetric Fistula

-Mpwapwa, Dodoma, Tanzania-



FORWARD and UTU Mwanamke Publication
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PROJECT PARTNERS

FORWARD

The Foundation for Women's Health Research and Development (FORWARD) is a leading African diaspora women's campaign and support charity. FORWARD are committed to advancing and safeguarding the sexual and reproductive health and rights (SRHR), and dignity of African girls and women. The three main issues that FORWARD works on are: female genital mutilation (FGM), child marriage, and obstetric fistula. FORWARD invests in girls and women to enable them to play a key role in changing the practices and policies that affect their rights and wellbeing. FORWARD was founded in 1983, made a fully registered charity in 1985, and works in partnership in the UK, Europe, and Africa.

UTU MWANAMKE

UTU Mwanamke, a Tanzanian organisation, has worked in partnership with FORWARD since it was established in 2012. UTU Mwanamke envisages a world in which all Tanzanian women and girls have maternal health choices, and live in dignity. UTU's emphasis is on preventing obstetric fistula alongside addressing safe motherhood, reproductive health, and girls' empowerment. In order to achieve this vision, UTU Mwanamke's programmes focus on advocacy, accountability, and citizen engagement. They empower young girls and women to assert their rights in 20 villages spread across four districts in the Dodoma Region.



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ACRONYMS

AFNET	Anti Female Genital Mutilation Network
CCBRT	Comprehensive Community Based Rehabilitation in Tanzania
FGM	Female Genital Mutilation
FORWARD	Foundation for Women's Health, Research and Development
NGO	Non-Governmental Organisation
PEER	Participatory Ethnographic Evaluation and Research
PRs	Peer Researchers
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
VHW	Village Health Workers

GLOSSARY

Jando	Traditional teachings given to boys following circumcision
Ngariba	Female circumciser
Khanga	Clothes worn by women made of pure cotton
Tajiri Ngombe	A man who owns many cows
Kitati	Village in Pwaga Ward
Unyago	Traditional teachings given to girls after puberty
Kutumuliwa	A woman pregnant before marriage
Wabibi	Elderly women
Lugubi	Traditional dance
Gogo	Main ethnic group in Dodoma, concentrated in Mpwapwa
Maasai	A pastoral ethnic group in Mpwapwa that originated in North Tanzania
Wanyamuluzi	The name given to boys who are taking part in teachings following circumcision

EXECUTIVE SUMMARY

Obstetric fistula is a devastating pregnancy related disability that affects between 50,000-100,000 women globally every year¹. This neglected childbirth related disability refers to a hole in the birth canal, which is caused by prolonged obstructed labour. This often results in the leaking of urine and or faeces through the woman's vagina or rectum. Obstetric fistula occurs predominantly among poor, marginalized and rural women in developing countries and symbolizes the failure of both communities and governments to address maternal health needs of women.

Women with obstetric fistula suffer with chronic incontinence, and sometimes paralysis of their legs. Women with fistula are commonly stigmatised and isolated by their families and communities. In Tanzania, where this study was carried out, obstetric fistula persists at unacceptably high levels. Recent data indicates that 2,500 to 3,000 women in Tanzania develop obstetric fistula every year².

Obstetric fistula is a preventable disability but socio-cultural factors in affected countries mean many women develop fistula unnecessarily. In Tanzania, women in rural areas are unable to access emergency obstetric services they require during childbirth as rural health facilities are basic, of poor quality, and are physically hard to reach. Often when rural women manage to access health facilities, they could still experience poor quality care. Furthermore, gender inequalities and entrenched social norms means that women have limited decision-making power and access to resources, which can create additional delays in seeking emergency obstetric care and increase their risk of developing a fistula.

Obstetric fistula is treatable in 90% of cases³, even when women have been living with the condition for a few years. However, poor quality of care and inadequate access to health services means that many cases of obstetric fistula go untreated. Additionally because so few people understand the causes, consequences, and treatment of obstetric fistula, it tends to be surrounded by stigma and taboo. Consequently many women try to hide their condition, or are marginalised by the community, which further reduces their chances of finding out about, and receiving the treatment they need.

This report follows a three year maternal health equity project implemented by FORWARD in partnership with Utu Mwanamke in Tanzania and funded by Comic Relief UK. The research component of the project received additional funding from The Body Shop focused on 'Providing Economic Empowerment for Women Affected by Obstetric Fistula in Dodoma, Tanzania'. This Participatory Ethnographic Evaluation Research (PEER), involved supporting obstetric fistula survivors to design and carry out interviews with their peers, in four wards in Mpwapwa District.

Using this unique methodology has produced rich and insightful information, based solely on the words of women living with obstetric fistula. It has shed light on the challenges they face and their support needs. The findings from this PEER alongside recommendations made by the PEER participants and lead researchers from FORWARD and Utu Mwanamke, will inform programme interventions in the project and beyond. This PEER will also be used for advocacy at the local, national, and international level. FORWARD's commitment to PEER stems from its potential to build the confidence, knowledge and potential of the participants. Once isolated and marginalised by their communities, the networks of women formed during the PEER process are now empowered, confident, and inspired to create change.

Obstetric fistula occurs predominantly among poor, marginalized and rural women in developing countries and symbolizes the failure of both communities and governments to address maternal health needs of women.

¹ World Health Organisation (2006), *Obstetric Fistula, Guiding Principles for clinical management and programme development*, Geneva: WHO

² Muhimbili University of Health and Allied Sciences (MUHAS) (2012), *Access and Quality of Birth Care in Tanzania: The problem of obstetric fistula and its implications*, Dar es Salaam: Dar es Salaam University Press

³ The Royal College of Midwives (2010), *Obstetric Fistula, a Silent Tragedy*, London: Royal College of Midwives

KEY FINDINGS

Throughout the PEER, poverty was a recurring theme and overdependence on farming, low educational attainment, and transactional sex were described as both causes and symptoms of girls' and women's poverty. Girls are frequently unable to complete their education because of the pressure to get married as families want to secure bride price payment. Women in Mpwapwa indicated that they experienced poverty more acutely than their male peers and had limited power in decision-making and control over economic resources.

The influence of harmful traditional practices, and beliefs in witchcraft and social taboos on the lives of girls and women was deeply entrenched. The PEER participants spoke in detail about female genital mutilation (FGM), child marriage, and witchcraft. Their stories revealed that great progress has been made in the last few years in reducing FGM, although it is still carried out in secret among certain ethnic groups, and child marriage is still commonplace in most communities.

Early sex and teenage pregnancy are common. Teenage pregnancy outside of marriage tends to be discouraged and is looked down upon, but child marriage, and therefore motherhood, is viewed as a social aspiration. Participants attributed high levels of teenage pregnancy to transactional sex, technology and foreign influence, and young women living and working away from their families and communities. Awareness about and use of family planning varies widely among women, but most men are ill-informed and restrict their wives' use of contraception.

Although some PEER participants had a good knowledge of the causes and consequences of obstetric fistula, many people are unaware the condition even exists. Few people know it can be cured and many women with obstetric fistula rely on traditional healers, or try to conceal their disability. Misunderstandings and prejudice are common, and obstetric fistula is said to be associated with prostitution, witchcraft or the failure or laziness of women. Consequently women with the condition are ostracised by their communities and abandoned by their husbands and families. Even women who have undergone successful repair struggle to overcome prejudice and reintegrate into society.

The PEER participants' experiences regarding access to and quality of obstetric fistula services differed greatly. Despite reports of improved access to information and services, it appears barriers remain. Women have to travel long distances to reach treatment centres, which is expensive and can be distressing for women because of their incontinence. Even when women are able to reach facilities, resources and the number of trained healthcare professionals are limited. Some PEER participants shared stories of the stigma and maltreatment they received in health centres. Many women confirmed that they tend to rely on traditional birth attendants who are commonly unable to identify warning signs that would help them prevent or treat obstetric fistula.

RECOMMENDATIONS

The recommendations in this report are based on the findings from this research, feedback from the PEER participants' final workshop and learning from FORWARD and UTU Mwanamke's ongoing interventions. This report has highlighted the wide range of experiences and challenges faced by women affected by obstetric fistula, as well as decision-makers' failure to respond to the desperate situation. It is therefore critical that a holistic and comprehensive policy approach is adopted to effectively tackle this debilitating and avoidable condition. The following recommendations should form part of this comprehensive policy approach.

Improve access to emergency obstetric care and obstetric fistula services – Transport schemes should be introduced to provide women with timely and inexpensive travel to reach emergency obstetric care and fistula services. This transport should be adapted to meet the needs of women with obstetric fistula, for example providing frequent comfort stops to reduce the shame they experience during travel. 'Delivery kits' and other essential equipment must be available in rural areas. Staff in peripheral health facilities must be trained to carry out basic emergency care, and know when to refer women to other services when necessary.

Improve quality of emergency obstetric care and obstetric fistula services – Health care professionals at the local level, and especially in rural areas, must be equipped with the knowledge to allow them to recognise warning signs of obstetric fistula, as well as how to treat and support patients. They must be sensitised to a level where they can communicate with fistula patients with respect and empathy. Services must be available to prepare women physically for repair operations, and rehabilitation must be mandatory and incorporate social and psychological rehabilitation.

Improve access to family planning services – Access to family planning information and services in rural communities for both women and men should form part of national efforts to tackle unmet needs of couples. Additionally access to comprehensive sexuality education and family planning information should be part of wider prevention action. Girls' clubs and networks both in school and out of school should be targeted to help prevent unwanted pregnancies. Additionally increased use of family planning will enable women to space their children and delay subsequent pregnancies after obstetric fistula repair operations.

Provide skills and livelihood opportunities to facilitate women's reintegration into society after obstetric fistula repairs – Skills training to enable women engage in income generating activities is invaluable in helping women reintegrate into society. Successful initiatives could incorporate an obstetric fistula angle, for example the production of dignity kits containing medicines, sanitary pads, soap and washcloths, for those waiting to undergo repair surgery.

Create support networks to improve the leadership, confidence and agency of young women – Young women's networks can be used to provide information, peer to peer support and advice to young women at risk and those affected by obstetric fistula. Ending their isolation and building their confidence, these networks provide social support for women living with obstetric fistula and a valuable platform from which to voice their needs and speak out against stigma. They can be supported to become local advocates for change.

Engage with communities on maternal health and obstetric fistula – Women rarely make the decision as to when and where they access maternal health care or obstetric fistula services. Consequently, it is necessary to work with multiple actors, including women's families, husbands, and peripheral health workers. This includes informing people about the causes of fistula in order to dispel harmful myths. Community members must be able to recognise signs that women need access to emergency obstetric care. Using relevant communications channels, for example local radio stations, and using positive illustrations of how different actors can and do support women with fistula are invaluable.

End child marriage and other harmful traditional practices – Child marriage, early pregnancy, female genital mutilation are known to contribute significantly to women's risk of developing obstetric fistula, and therefore must be tackled as part of a holistic approach. In order to do so, it is essential to address social norms which reinforce these practices and engage all decision makers to transform behaviour. Engaging with respected community members helps to create new positive aspirational social norms.

Provide an enabling policy environment that addresses gender equality and improve rights of girls and women – Improving maternal health equity and ending obstetric fistula requires political commitment, national coordination and the development and implementation of a national adequately resourced fistula strategy. The Tanzanian government must demonstrate accountable and leadership through this policy commitment. This should include training health professionals as well as local health workers as part of the prevention and treatment of those affected by obstetric fistula. Civil societies should supported to provide outreach and prevention programmes and utilise their unique potential to enable women affected by fistula to access services and socially rehabilitated to live meaningful lives in their communities.

It is necessary to work with multiple actors including women, their families, their husbands and peripheral health workers. This includes informing people about the causes of fistula in order to dispel harmful myths. Community members must be able to recognise signs that women need access to emergency obstetric care.



1. INTRODUCTION

Obstetric fistula is a widely neglected disability that affects poor, vulnerable, and marginalised girls and women. FORWARD's programme 'Advancing the Health and Rights of African Women and Girls' has responded to and contributed towards a global rise in attention towards obstetric fistula. Implemented in collaboration with local partners in Ethiopia, Ghana, Sierra Leone, Kenya and Tanzania this programme aims to amplify the voices of women and girls, such as those living with obstetric fistula. In doing so, it will also improve partner organisations' ability to successfully address obstetric fistula, and the associated needs of women.

Participatory Evaluation Ethnographic Research (PEER), initially developed by Swansea University and Options Consultancy Services Ltd., has become a key component of many of FORWARD's programmes. Through PEER, members of the target community receive training, which they then use to interview members of their social networks. In providing an opportunity for women marginalised and undervalued in their communities to raise their voices, PEER, unlike traditional research methods, allows researchers to collect rich and intimate data and while simultaneously building the confidence, knowledge, and skills of the participants.

FORWARD has partnered UTU Mwanamke, one of Tanzania's leading obstetric fistula organisations, to implement a three-year project 'Promoting Maternal Health Equity and Accountability in Tanzania'. The project is funded by Comic Relief's Common Ground Initiative (CGI). Together with this broader programme is a second two year project entitled 'Providing Economic Empowerment for women affected by Obstetric fistula in Dodoma, Tanzania'. Also implemented by FORWARD and UTU Mwanamke, this project, funded by The Body Shop Foundation, aims to improve the economic independence and wellbeing of women affected by obstetric fistula in Dodoma region. This PEER study is central to the second project, and the recommendations will inform key programme interventions in the next two project years and beyond. This PEER has served to strengthen the partnership between FORWARD, UTU Mwanamke and other relevant stakeholders.

This report aims to:

- Shed light on the lived realities of women affected by obstetric fistula and their understandings of its causes, its impact on women's lives, and their access to information and support;
- Contribute to a body of research to inform and strengthen programmes focusing on obstetric fistula and related issues;

- Empower those affected by obstetric fistula, strengthening their voice and ensuring that they are at the centre of programmes or research that concern them;
- Build a network of women affected by obstetric fistula who can support each other and reach out to women in their communities affected by, or at risk of developing fistula;
- Raise awareness about the concerns of women affected by obstetric fistula among the community members, policy makers and other relevant stakeholders.

The main body of this report is divided into six sections. This chapter provides the background to the study, including information about obstetric fistula and broader issues of sexual and reproductive health in Tanzania. The report then progresses to section two, which outlines the 'women-led' PEER methodology that makes this research so unique. In section three the PEER findings are shared, relying heavily on quotes from the PEER participants to ensure that the women's voices are at the very centre of the research. Section four describes how their involvement in the PEER research has influenced the PEER Researchers' lives. In section five, the PEER participants' recommendations for programmes to address obstetric fistula are outlined, followed by FORWARD's conclusions and recommendations in section six.

1.1 Obstetric Fistula

What is obstetric fistula? Obstetric fistula is a hole between the birth canal and the bladder and/or the rectum. Obstetric fistulae occur during labour when the baby's head exerts prolonged pressure on the mother's pelvis. This prolonged pressure is a result of obstructed labour which, without medical intervention that would usually comprise a Caesarean section, can continue for a number of days and in some cases can last as long as a week⁴. The blood supply to the tissue around the bladder, rectum, and vagina is cut off, causing tissue damage and a hole between the vagina and the bladder and/or rectum. The woman is left with chronic incontinence and in most cases, a stillborn baby. If left untreated, fistula can lead to medical problems including ulcerations, kidney diseases, nerve damage in the legs known as 'foot drop', and death⁵.

⁴ The Royal College of Midwives (2010), *Obstetric Fistula, a Silent Tragedy*, London: Royal College of Midwives

⁵ The Royal College of Midwives (2010), *Obstetric Fistula, A Silent Tragedy*, London

The psychological impact of developing fistula should not be underestimated, not least because of how it affects a woman's role in society and the family. The smell of leaking urine, faeces or both, is constant and humiliating, often driving the loved ones of the woman away. In addition, the fistula is often linked to a woman's 'failure' to produce a live child, causing them to experience further stigma⁶. Women with fistula are often prevented from helping with routine chores, and may be barred from prayer or other religious activities.

What causes obstetric fistula? Obstetric fistula occurs when labour is obstructed and therefore delayed. Poverty and malnutrition in childhood can lead to a girl's skeleton, and therefore her pelvis, not fully maturing making childbirth difficult or impossible. Late detection of complications, in addition to insufficiencies in transportation, financial means and medical resources and skill, especially emergency care, all lead to a high rate of obstetric fistula⁷. However, it has been argued that a more nuanced understanding should be developed, rather than relying on data merged from a range of countries and cultures. Rather than assuming something is 'wrong' with women who develop obstetric fistula, it is essential to look at the factors specific to the location in which they live⁸.

Many of these location specific factors are socio-cultural. Commonly, cultural restrictions prevent women from taking full advantage of the reproductive health services available. Women's educational attainment, their status in the household, their economic dependence, and social perceptions about labour and child birth all affect women's decision making ability regarding pregnancy and reproductive health. As child marriage invariably leads to early sexual contact, and therefore pregnancy, it increases the likelihood of girls becoming pregnant at a time when they may not be adequately physically developed to permit a problem free labour.

⁶ Ibid

⁷ Muhimbili University of Health and Allied Sciences (MUHAS) (2012), *Access and Quality of Birth Care in Tanzania: The problem of obstetric fistula and its implications*, Dar es Salaam: Dar es Salaam University Press

⁸ Pope, R.J. (2007), *Social Reintegration after Repair of Obstetric Fistula in Tanzania*, Dar es Salaam: Women's Dignity Project

Studies have shown that women who have undergone female genital mutilation (FGM) are also more likely to develop a fistula in childbirth⁹. FGM is the partial or total removal of the external female genitalia or other injury to female genital organs for non-medical reasons¹⁰. The scarring caused by FGM reduces the elasticity of the vagina, which can inhibit the foetal passage during labour.

How common is obstetric fistula? The World Health Organisation estimates that more than two million women, predominantly concentrated in sub-Saharan Africa and Asia, live with untreated obstetric fistula¹¹. In Africa alone it is estimated that between 30,000 and 130,000 new cases develop each year¹². In the global north, widespread access to advanced obstetric care means that obstetric fistula has been eradicated in almost every country¹³.

1.2 Local Context

Tanzania, located in eastern Africa, is home to over 44 million people. 44.2 percent of the population are under the age of 15 and the life expectancy at birth is 51 years. The sex ratio is 96 males per 100 females. In general, Tanzanian women have less access to and control over assets, resources, and information compared to their male peers. Tanzania's constitution has a strong commitment to gender equality, and the government has signed or ratified a number of major international instruments that promote gender equality. These include the Universal Declaration on Human Rights (1948), United Nations Convention on the Elimination of all Forms of Discrimination Against Women (1979), the Millennium Declaration and Development Goals, the African Union Charter and its Protocol on Human and Peoples' Rights and the Charter on the Rights of Women in Africa¹⁴.

⁹ Ibid

¹⁰ WHO (2008), *Eliminating Female Genital Mutilation, an interagency statement*, UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNHCR, UNHCR, UNICEF, UNIFEM, WHO: Geneva

¹¹ World Health Organisation (2006), *Obstetric Fistula, Guiding principles for clinical management and programme development*, Geneva

¹² Wall, I. (2006), *Obstetric vesicovaginal fistula as an international public-health problem*, Lancet, 368 (9542), 1201-1209

¹³ Muhimbili University of Health and Allied Sciences (MUHAS) (2012), *Access and Quality of Birth Care in Tanzania: The problem of obstetric fistula and its implications*, Dar es Salaam: Dar es Salaam University Press

¹⁴ United Republic of Tanzania, Ministry of Finance and Economic Affairs (2010), *Tanzania Gender Indicators Booklet 2010*, Dar es Salaam: Ministry of Finance and Economic Affairs

Girls are frequently unable to complete their education because of the pressure to get married as families want to secure bride price payment.

In the past 15 years, and following the introduction of the Millennium Development Goals, the Government of Tanzania has made significant progress towards reducing the levels of maternal, neonatal and child morbidity and mortality. However, women in Tanzania still have a one in 23 lifetime risk of dying in childbirth. The neonatal mortality rate is highest among mothers under the age of 20, at 45 per 1000 live births compared with 29 per 1000 for mothers aged 20 to 29 years¹⁵. On average, every Tanzanian woman gives birth to five or six children and one in three girls start childbearing before their 18th birthday¹⁶.

Maternal morbidity and mortality rates are closely linked to high fertility rates and the low socio-economic status of women, especially with regards to the lack of influence that women have over their own health care or over the daily household budget¹⁷. About 40 per cent of Tanzanian women do not participate in significant decisions regarding their own health care, and almost 8,000 women die every year during pregnancy and delivery as a result of conditions that could have been prevented or treated. Half of all births in Tanzania take place at home, commonly in unhygienic conditions, and usually with assistance from a relative or traditional birth attendant rather than a healthcare professional. Women are deterred from medical facility delivery as they live long distances from health services, which commonly lack skilled health workers and basic equipment. Women living in rural areas, those from the poorest families, and those with the lowest educational attainment face the most blocks to accessing skilled attendants at delivery. If life threatening complications develop at home, the realisation and decision to attempt to reach health facilities is significantly delayed¹⁸.

These factors dramatically increase the likelihood that women will develop a fistula during child birth. Recent data from Tanzania indicates that there are between 2,500 and 3,000 new cases of obstetric fistula a year¹⁹. However, because of the stigma surrounding obstetric fistula in Tanzania women endeavour to hide their problem from the community by avoiding public activities, wearing lotions to hide the smell, and other strategies. Commonly, awareness of and education regarding obstetric fistula is limited, so many women may live with it without knowing how to access services, or that such services even exist. Consequently the figure above may in fact be a conservative estimate, as it does not include the large numbers of women hiding their disability, and not seeking help.

Fortunately in Tanzania, because of pressure from a number of dedicated non-governmental organisations and the Ministry of Health, funding has been allocated to provide women with obstetric fistula repair operations²⁰. In Mpwapa district in central Tanzania, where this study was carried out, UTU Mwanamke identified 70 different health facilities in a recent survey. However, one third of these are not staffed by skilled health care attendants. There are three facilities in Mpwapa district that provide comprehensive emergency obstetric and new born care (CEmONC).

40 per cent of Tanzanian women do not participate in significant decisions regarding their own health care, and almost 8,000 women die every year during pregnancy and delivery as a result of conditions that could have been prevented or treated.

¹⁵ National Bureau of Statistics Ministry of Finance (2013), Tanzania in Statistics 2012, Dar es Salaam: National Bureau of Statistics Ministry of Finance

¹⁶ UNICEF (2010), Children and Women in Tanzania, Volume 1 Mainland, Dar es Salaam: UNICEF

¹⁷ Ibid

¹⁸ Ibid

¹⁹ Muhimbili University of Health and Allied Sciences (MUHAS) (2012), Access and Quality of Birth Care in Tanzania: The problem of obstetric fistula and its implications, Dar es Salaam: Dar es Salaam University Press

²⁰ Pope, R.J. (2007), Social Reintegration after Repair of Obstetric Fistula in Tanzania, Dar es Salaam: Women's Dignity Project

2. WOMEN-LED RESEARCH: PEER METHODOLOGY

Participatory Ethnographic Evaluation and Research (PEER)

PEER is a qualitative participatory research methodology, particularly effective when working with marginalised groups. It sheds light on insiders' perspectives on behaviour, beliefs and risks. In PEER, members of the target community are trained to carry out in-depth conversational interviews with trusted individuals who they select from their own social networks. PEER has been implemented in over 15 different countries in the past decade and has a strong track record in health and social research.

Using PEER is beneficial as it allows researchers to gain insights into sensitive topics that are typically difficult to research such as sexual behaviour, gender relations, power dynamics within households and communities, as well as barriers and motivators to behaviour change. Similarly, PEER enables access to marginalised communities that can be hard to reach effectively with other research methods. In PEER

the power dynamic between researcher and researched is fundamentally different from extractive focus group discussions or in-depth interviews.

The PEER participants are empowered through their involvement in the study. Over the course of the research they build knowledge on the research subject and gain experience designing research questions, carrying out interviews, and collating the data. Working with other marginalised people like themselves in a well-supported group, means PEER raises the confidence of the participants to speak out about their experiences and needs. PEER received ethical approval from the University of Wales Swansea Research Ethics Board in 2007 and has been trialled and refined extensively by Options, the international consulting arm of Marie Stopes. FORWARD and Utu Mwanamke collaborated in order to design the methodology specific to this research, summarised below.



Sampling and recruitment

Initially three PEER supervisors were recruited in partnership with AFNET, CCBRT's ambassador in Dodoma region. The PEER supervisors were selected from AFNET staff because of their knowledge of the local area and technical understanding of obstetric fistula. Furthermore, they had access to a wide network of women affected by obstetric fistula. The PEER supervisors had to have exceptional listening skills and be literate, compassionate, and non-judgmental as well as available during the course of the study. These qualities were essential as they were required to support the PEER Researchers, both emotionally and in recording the data during the interviewing stage, over the phone and in person.

The three supervisors then recruited 15 PEER Researchers (PRs), between the ages of 25 and 50, from Mpwapwa that had been affected by obstetric fistula. They were chosen randomly from a list of names of women who had been receiving information and training about obstetric fistula through AFNET referrals. The only criteria were that they had been affected by obstetric fistula and were living in the Mpwapwa area. The majority of the women were illiterate; seven of them had never been to school, and a further five were unable or barely able to read and/or write even if they had had some schooling. Ten had been married at some point, but four of these had been abandoned by their husbands or mentioned being unsure about their relationship status. Four mentioned having living children while at least seven had still births or miscarriages.

PEER training

The PEER Researcher training took place over a two day period. It was facilitated by the lead researchers from FORWARD and Utu Mwanamke with support from the PEER Supervisors. The process was participatory with an emphasis on enabling the PEER Researchers to value themselves as 'experts' on the issues being researched. During the training, the facilitators and PEER Researchers worked together to develop prompts to guide in-depth conversational interviews around different key themes. They designed six questions for each interview, as the focus was on the depth rather than the breadth of information collected. These themes were the social and economic life of the community, pregnancy and fistula, and treatment, aftercare and support.

Data collection and analysis

Each of the PRs conducted three interviews with two members of their social networks who were affected by obstetric fistula over a period of three weeks. Consequently each of the 15 researchers carried out six interviews, making a total of 90 interviews. The PEER Supervisors met with the

PRs between interviews to discuss the findings and help the PRs address challenges or concerns that may have arisen. Those PRs able to write were asked to make brief notes of the key issues or stories immediately after interviewing their friends. The PEER Supervisors transcribed the data collected for those unable to write in meetings shortly after the interviews. The PEER supervisors and lead researchers from Utu Mwanamke translated and transcribed the data.

At the end of the interviewing phase the lead researchers from UTU Mwanamke identified gaps in the data. Using this information, they conducted additional debriefing sessions with the PRs, individually and in small groups, to probe further into the responses and stories where necessary. These notes added essential detail for the final analysis.

The data was then fully processed and analysed thematically by the FORWARD team. Emerging themes were assigned codes and the data were divided into text units (paragraphs and stories), and arranged under the coding framework. The data were then re-read, and quotations were selected to capture the essence of each code. They can be found in the results section below.

Concluding workshops

Following the debriefing, the PRs reassembled to discuss the PEER findings. They made recommendations for future initiatives targeting girls affected by and/or at risk of obstetric fistula. 'Thank you' gifts and certificates were distributed.

There was also a stakeholder workshop in Dodoma town where eight of the PEER participants met with government officials, obstetric fistula surgeons from local hospitals, and relevant NGOs. During the workshop, UTU Mwanamke and FORWARD presented the situational analysis of obstetric fistula in Tanzania, explained the PEER methodology and shared the PEER findings. The PRs presented their experiences of life both before and after fistula repair, and gave examples of community perceptions of women with obstetric fistula. They also shared their needs, ideas, and concerns.

The PEER participants were met with a warm reception at the workshop. The stakeholders were particularly interested in hearing the women's accounts of receiving fistula treatment. In the feedback they gave after the workshop, it was clear that they had taken note of the key findings and action points. The PEER participants were equally positive and one said '*I am very confident to talk in front of all stakeholders and I feel very special to be here*'. Another pointed out that in making contact with health professionals, they would be able to reach out to other women with obstetric fistula, and gain more information that they could share with other women.

Limitations of PEER

Like all methods of data collection, PEER has its limitations. The views and stories collected from the women were all subjective and the small sample size means that it is difficult to make generalisations based on the data. The value of the data is dependent on the capacity of the researchers and the quality of the training they receive. The recruitment similarly holds some bias, as the PEER Supervisors and Researchers interviewed women they knew prior to the research. Time and budget restrictions also limited the scope of the research.

The researchers, supervisors and authors, being mindful of these limitations, have made every effort to eliminate bias and represent the voices of the participants as accurately as possible. The questions were designed using a rigorous and participatory method to ensure their relevance and sensitivity. The participants were guaranteed confidentiality and thus shared their thoughts and opinions without inhibition in the safe spaces created by the interviewers and supervisors.

Ethical Considerations

Participatory research like PEER is generally considered to be more ethical than other forms of research. The fact that the researchers and interviewees have a pre-existing relationship reduces the power imbalance, in contrast to research where the participants do not know each other. By continuing their relationship with the PEER participants after the research FORWARD and UTU Mwanamke have successfully maintained the trust built during the PEER. As the data, findings, and publications will be shared in Mpwapwa the participants are also able to own or influence the dissemination of information about their lives.

Measures were taken to eliminate the chance that singling out PEER Researchers and participants could exacerbate existing divisions between social groups based on the stigma and marginalisation that surround obstetric fistula. All participants were ensured confidentiality and anonymity and were required to provide informed consent before participating in interviews. However, some participants did not request confidentiality, and expressed a desire to share their stories and opinions.



3. RESEARCH FINDINGS: VOICES OF WOMEN ON OBSTETRIC FISTULA

3.1 Daily Life

In the first stage of interviews the PEER participants were asked questions about daily life in their communities to help provide the context. A number of key themes emerged, and are outlined below.

3.1.1 Poverty

Many of the PEER participants described their lives as defined by poverty.

We are really affected by poverty; you can see how I'm living with my family. We cannot even afford to have enough food, good clothes and my children cannot have good education.

We cannot even afford proper health care, school fees and we are living in poor houses.

If you poor you cannot get your rights in our community.

They described the direct impact poverty has on their own health and their communities.

Being poor is a big disaster in our community. Many people are losing their health status as they don't have proper treatment because they lack of sufficient funds.

People are dying because of the diseases because they lack money for treatment. There are no free treatments and other people commit suicide because life becomes so difficult and they cannot provide for their families

These poor conditions affect our babies because they lack nourishing food, clothes and other essential items.

Many of the participants provided explanations about poverty in their community.

The source of poverty in our community is due to many people spending a lot of money and not saving anything. For example, people do big ceremonies using a lot of money, making local brews and marrying more women.

You have nothing from income generation. Because of this we engage ourselves in seeking funds from

credit society. The problem becomes worse for those who took loans from bank and failed to pay them back, all their properties have been sold to cover the loan.

Poverty causes people to become thieves in villages as a short cut way to get money for paying fees and meeting other needs.

Others attributed poverty to the community's overreliance on farming and limited resilience to seasonal change.

In our family we are lacking food most of the time because there is seasonal rain and we fail to get enough income from food production. Also in the dry season many animals die due to lack of food and water, resulting in hunger and poverty.

Poverty in our community affects many people especially those who depend on seasonal farming.

We involve ourselves in only farming and livestock keeping to raise income for our family. This causes more poverty in the community because we do not have any other source of income when there is no rain or there are animal diseases.

Poverty is a problem in our society because there is no market for the cash crops we produce and if the market is available the price is not good.

3.1.2 Livelihood

As described in the previous section the majority of families in Mpwapwa depend on agriculture for their livelihoods.

Life in Mpwapwa is just normal. Most people engage in agriculture and livestock keeping, getting food and increasing family income. We keep cows, goats, sheep, ducks, chickens, donkeys and dogs. During summer we cultivate groundnuts, sunflower and beans. There is also farming by irrigation in valleys in which we cultivate onions, sugarcane, beans and vegetable.

A large per cent of our community in Pwaga are farmers compared to animal keepers. Most of farmers use plough which use animals for farming. Although they prefer modern farming they haven't got enough income. We farm maize, beans, groundnuts and millet and we keep pigs and chickens to increase our income.

Farming and livestock keeping are very important to me and my family because it helps us to get money that is used to meet our daily needs. Farming involves maize, millet, sunflower and groundnuts. We also keep cattle and goats in order to sell them when we need school fees for our children. Also, we use the extra income we get to starting small business like kiosk and small retail shops.

Many described the problems they and their families face due to disputes between those focussing primarily on crops (described as 'farmers'), and those raising animals.

A problem we are facing is misunderstanding on land usage between farmers and livestock keepers.

There is a conflict between farmers and animal keepers because they share the same land for farming and pasturing.

There is a chronic conflict between peasants and animal keepers whereby animal keepers feed animals in the peasants farms. This is a source of conflict which causes misunderstanding.

Gender inequality is pervasive in income generating activities.

In our community men dominate agricultural and livestock activities.

Due to gender inequality men dominate land for farming and the money we get from selling crops.

Many women in our community were not allowed by men to run businesses which need large capital so instead we engage ourselves in small income generating activities, like selling fire wood and snacks.

3.1.3 Education

Another key theme that arose in the interviews was education.

Education is very important in our community because it help us to have the knowledge so that when we go to buy animals, clothes and crops in market we can know the price and negotiate.

A few people who get the opportunity to continue with secondary education get work and bring development in our villages.

Some participants described the influence of the government's efforts to improve access to education.

At this time education is good in our community because many parents can afford to pay for the school contribution because the government remove school fees for all primary education. Therefore many children go to school up to standard seven.

At present the government plays important role in education compared to previously because the government dictates that every child aged 7 must start school and if not the parents get punished by paying a fine. Also the government has removed primary school fees in order to enable all children to access primary education.

Parents who fail to send their children to school, and force their children to marry instead are sent to jail. However, some parents have money that they use to pay authority leaders to go against this law without punishment.

However, some participants described a very different picture.

In our community many people do not know how to write and read because they don't go to school and parents think that it is very expensive to take their children to school. Like me I didn't go to school because my parents refused to pay for the school fees.

Here in our community the education status is very low because many people lack knowledge on the importance of education. The majority of people do not allow their children to go to school.

Many people in our Pwaga village have not gone to school because the parents here don't understand the importance of sending their children to school. Parents prefer their children to be herders more than going to school. They believe if they will go to school they must sell their animals to pay school fees and as a result they will became poor.

The number of children who finish secondary education is very low and this makes others get discouraged to start secondary education as the result they remain at street and join street gang.

Many described a generally low standard of education.

The education status in our community is moderate because most of the people in our community have completed primary school and others are illiterate and few others completed secondary school.

The situation in secondary school is not good and many students failed in their final exam due to low standard of education. The major problem is a shortage of teachers... Also, many schools are located far away from where we live.

The education situation is not good due to the fact that there is lack of teachers. Also, there aren't

enough secondary schools for children who want to continue for the study.

Many of students are dropping out from school and running to town.

The level of education in our community is in a very low quality due to many students dropping out from school. Some are getting pregnant [“Kutumuliwa”] and others are getting married.

Others highlighted the particular problems faced by girls in education.

Boys are needed to care for the animals and girls are being married for the family to have some money.

At Mpwapwa education is unsatisfactory due to different customs and traditions that mean girls are forced to get married before they finish primary education and boys forced to keep animals.

Children from the age of 5 to 7 have been enrolled at primary school each year in our community but the ratio of boys is higher than girls due to the belief that girls are for marriage.

My parents told me that there is no need to go to school while there is no job vacant; therefore they forced me to get married when I was 13 years old with 35 year old man who had two wives. As a result now I do not know how to write and read.

Many young people fail to continue with secondary education due to the fact that girls get pregnant and boys go to town to search for good life

3.2 Rites of Passage

Traditional beliefs and practices are highly influential in the lives of young women living in Mpwapwa. Institutionalised religion exists alongside these traditional beliefs and practices. Coming of age ceremonies and rites of passage are common and tend to be highly gendered. Some PEER participants mentioned the importance of chastity and virginity before marriage.

Many ceremonies in our village are done during the period of training youth [“Jando na Unyago”], the transitional period to adulthood. Young people are taught about traditions and customs of our community.



Traditional ceremonies are done like the rite of passage of girls into adulthood after they have attained the age of puberty by performing traditional dances like 'Lugubi'.

The ceremony is accompanied by teaching the girls to avoid early sex practices and respecting themselves as women. Girls are taught on how to clean themselves when they are on menstruation period, how to cover their bodies. They should not be prostitutes, they are taught by elder women ['wabibi'] and it may take a month to be taught this.

A certain girl in my village said that, in "Unyago we are taught not to go in bed with men before marriage, that we should wait until we get married".

'Circumcision' was mentioned as an aspect of coming of age ceremonies.

In our community, we believe that circumcision of both boys and girls is done to honour our cultural beliefs that have been practiced through the ages.

Our community has been practicing culture and traditions like male circumcision, FGM, traditional weddings and praising our ancestors.

3.2.1 Perceived Prevalence of FGM

The women had differing views regarding the prevalence of FGM. Some felt that the practice of FGM had ended in their community. They often attributed this to increased awareness of the harmful effects of FGM following campaigns that had taken place in the community.

FGM is not practiced at all in our community and you don't see any ceremonies for FGM these days.

Ten years ago FGM was common in our community. A certain girl in my village says that back in 1980 FGM was common in this place, even myself I am the victim of it. But nowadays people are educated and understand the effects of FGM. In our Pwaga village people don't practice FGM. This was a result of education which we got from different NGOs and government authorities.

In the past FGM was practiced in order to teach girls good manners to help them avoid prostitution and how to live with their husband. But now days we do not practice FGM because circumcisers [Ngariba] worry that they might be caught by police and go to court.

About ten years ago FGM practice was common in our community. But nowadays people are educated and understand the effects of FGM.

There is no FGM in our community because people have learned it causes severe bleeding and tears during labour.

FGM is not practiced in our community since government announced it's not good for the health of girls. Also, different associations and organizations teach the effects of FGM in our community.

However, other girls painted a very different picture suggesting that FGM persists among some communities, but it is increasingly done in secret.

FGM is still practiced in our community, especially the Maasai tribe here at Mpwapwa, because they still believe that if a girl is not circumcised she will not get married. For example a certain Maasai girl was engaged with a certain Maasai boy because Maasai's used to marry each other. He found that the girl was not circumcised and he decided to abandon the girl. He went to another place and he got the girl who was circumcised and decided to marry her.

FGM has declined in most of the tribes but among Maasai and Gogo they do it to infant girls soon after they are being born. It is being practiced in bushes in secret, and is done by traditional circumcisers.

Most people in my village practice FGM in secret. They take girls to the village at night with female elders [Ngariba].

Currently, FGM is done in our community secretly with a large caution compared to in past when it was common.

The PEER participants explained that the practice had been driven underground because of national laws prohibiting the practice.

FGM is still practiced in our community but it is now done secretly because the government has banned the practice.

Some communities have stopped FGM because of Tanzania's laws but other communities still practice FGM secretly. For example, the Maasai practice FGM secretly.

Maasai and Gogo tribes still practice FGM but to infants because they are afraid of government laws.

3.2.2 Beliefs Behind Female Genital Mutilation (FGM)

One girl described the practice of FGM in her community.

[Parents] send the girls for circumcision in June then they will recover in July. After preparation you have your hair shaved by those grandmothers then you are called for circumcision. You may get them seated around, then you have to sit in between them while you are naked. They will catch you so that you do not run away, then you are circumcised. They apply traditional medicine to prevent blood from coming out. Then you are not supposed to come out until you recover so those who are dealing with circumcision every morning they will come and wash the part until you are recovered.

Others described the beliefs at the root of FGM.

In our community they believe that a woman who didn't attend FGM is a prostitute and when she gets married she cannot be faithful into her marriage.

In our community, a woman who is not circumcised is believed to be a prostitute.

That is why they are circumcised, to make sure when she gets married, she will be faithful. There are girls who are not circumcised and they don't stay with a single man. They want every man to sleep with them. For example, there is a certain girl who was not circumcised and married. She is not stable in her marriage because she is having sex with other men.

3.2.3 Male Circumcision

Interestingly, a number of the PEER participants also mentioned male circumcision in the interviews.

In our community all tribes practice male circumcision from age of 5 years old to 30 years old before men get married.

Male circumcision is mostly done when boys are aged between 10-16. This is the period when boys are taught how to behave as adults.

The circumcised boys in our community are called Wanyamuluzi. They stay for one month in a camp and trained how to behave, for example respecting elderly people, to do work and to be responsible as fathers of taking care of families.

For male circumcision, close related family send boys to and from hospital with traditional dance, and then they keep them in a camp for one month.

During that period they are trained in traditional songs, hunting and cultural and customs of our tribe.

We believe that male circumcision is a tradition practice and has no harm to men.

Some participants explained that male circumcision takes place due to cultural beliefs and social norms.

In my village we believe that, when a man is not circumcised he brings a curse to his family.

My husband was not circumcised and due to that he brings misfortune to our family.

When a woman meets with a man who has not been circumcised, she feels the difference. So, when he observes that every woman avoids him, he must go for circumcision. Other men are advised by their girlfriends or wives.

Male circumcision is always practiced in our custom in order to teach them how to live with their wife.

In some tribes, the practice of male circumcision had begun relatively recently, and was influenced by sexual and reproductive health education.

In our community doing male circumcision is a normal practice. These have been done once per year and we believe that it is preventive measure for them from contracting a disease.

At present all tribes do male circumcision as they believe that it helps to reduce some diseases to men.

In the past men were not circumcised because of their customs but now they are all circumcised due to existence of diseases. They educated themselves when they met together. They observed the differences they faced, hence they were convinced to circumcise boys.

When you are not circumcised you may get sexually transmitted diseases [STDs]. For example, in our village there are some of them who are suffering from STDs like gonorrhoea.

3.3 Child Marriage

The PEER participants explained that child marriage is common in their communities. Young girls often get married to men much older than themselves.

Parents force their girls to get married early as in our traditional belief.

Early marriage happens when the girl gets married before 18 years old and this is being practiced in our community.

At Chilala village where we stay with my family, many girls get married at the age of 12.

There is a certain girl who was forced to get married a man age 70 while the girl was of 10 years. She had to run away so the parents decided to return the dowry. When she came back home, they had found another man to marry her. So she was married and stayed with the man until she undergone menstruation. Then she had him three children and she is 20 years old now.

The PEER participants described a range of factors which explain child marriage. They stated that many families marry their daughters young for financial gain, to help relieve poverty.

Child Marriage is a problem in our community due to families forcing girls to get married so that they can get money to meet family needs.

When the girl reaches the age of 10, she is forced to get married in order to increase wealth in the family. She is told, "My child, just get married in order for me to get some wealth. You can see how your mother is suffering. You just get married in order to help me".

Old rich men who own many animals usually like to marry young girls and give some of their animals to the girl's parents as a dowry.

There are parents who force their daughters to get married even when they are very young in order to get cows. People with cows are forcing their children to get married in order to increase their flock of cattle. There is our neighbour who forced the child to get married at young age in order to get cows. The child was 12 years and the father got 15 cows.

For others the motivation was to secure social support for themselves and their families.

There was a certain child who was married at the age of 10, simply because they had a large family because their parents never used family planning methods. Since she was older than the other children she was supposed to get married in order to take care of her family. Because of hunger her parents decided to take her to the Maasai. The habit of Maasai tribe is, if the child is too young, she stays at home until she grows bigger then is taken to the husband.

You may find a parent with seven children who is not able to take care for them. So her parents force her to get married in order to take care of the others who are at home.

The desire to gain respect from the community motivates some parents to marry their daughters as children.

They believe it is a respect to the community if their daughter gets married.

Many parents feel that it is a prestige for them having many girls in their family because they will solve their problems after getting money as a result of their daughters getting married.

For example my sister got married at age of 14 because she got pregnant.

Some girls chose to get married under the age of 18.

Girls in my community themselves decide to get married without being forced by their parents.

Girls in my village when they finish primary school they don't want to go for secondary education instead they choose to get married so that they can be free from their parents.

Girls in my village see marriage as a blessing from God, so they respect it. Also nowadays girls themselves are the one to decide when to get married and they are free to choose the spouse.

In my village young girls get married with their choice, due to life difficulties in their families they decide to get married so that they can run from life's hardship.

Girls in my community are married at young ages even when their parents try to stop them they fail. For example, there is a certain girl who was in standard [grade] six, and engaged herself in a love affair when she was very young. Her mother tried to stop her but she failed.

However, in many cases girls have no say in the decision for them to get married.

There is a certain father who was forcing his daughter to get married while the girl was too young. She refused but since her father had power, the girl has no voice any more. The girl decided to go to the village leaders in order to get help.

Due to education, girls in my village don't want to get marriage at a young age, they choose to marry when they are on their 20s, and they decide themselves without being forced.

I was married at age of 13 years old when I was in primary school. My father told me to get married so as to save my family. I had no way out and had to accept my parents' decision.

3.4 Early Sex and Teenage Pregnancy

While child marriage is valued and respected, sex and teenage pregnancy before marriage are regarded as shameful. The interviews uncovered an interesting tension between teenage pregnancy and cultural practices and teachings.

Our community do not like teenagers to practice early sex.

Early sex and teenage pregnancy outside of marriage goes against traditional beliefs.

Some practices, like teaching girls how to handle their husbands [during their initiation], inspire girls to practice the knowledge even before the real marriage.

Some women believe it to be aspects of their culture that leads them into early sex.

The interviewees provided a range of explanations for early sex and teenage pregnancy. Links were drawn with child marriage and families' efforts to relieve themselves of poverty.

Poverty is a big contributing factor for early pregnancy as young girls get married as means for them to relieve poverty.

Teenage pregnancy and early sex practice are caused by parents themselves by forcing their young girls into marriage so that the parents get money for food and at least get little relief from a hard life. And a child, realizing the hard life her family has, obeys and sees no other option but marriage in order that her family gets money.

Hard life style in my family meant I became pregnant when I was young. There was no food and our house was not in good shape, so during rain, water entered the house. When I was 12 years old I met a 35 year old man who promised to marry me and he helped my family with money and food, so we started a relationship because I thought he was a good person but when I got pregnant and told him he refused and beat me and disappeared to another village and married another woman.

Likewise, many PEER participants explained how poverty causes girls to take part in transactional sex.

Poverty is the main source of teenage pregnancy. Many people in our country depend only on agriculture as a source of income therefore young girls are not satisfied with what they get from their parents and want more income. They decide to enter into sex practice in order to get money.

There are some girls that observe their fellow girls wearing good clothes while in their homes, there is nothing to eat, no soap, etc. So they may meet with boys trying to seduce them but there are also grown up men seducing these young girls by giving them money. Maybe they say, "take this money, go to buy this and that", and they tell those girls that they love them. When they take the money this is the beginning of the child becoming a prostitute due to poverty.

For example there is a certain girl observed that, at her home there was no food. She took money from an old man to buy maize. The man was too much older than the girl. When they were doing sex, she got some pain and she was torn.

Teenage pregnancy is a result of lack of essential needs and girls decide to do sex business at young age in order to get money.

Some blamed a loss of traditional values, due to western influence and technology, for teenage pregnancy.

These days, youth imitate western cultural practices for example modern ways of dancing and dressing. This results in moral decay in which girls tend to copy European life style, take part in early sexual practices and become pregnant as a result.

My friend's father always says that "our children now do not have discipline and because of this they do many bad things and involve themselves in early sexual practices so girls get pregnant at very young ages".

Early pregnancies are a result of youths hatred of their culture, misbehaviour to elders and engagement in sexual practices which are learned in electronic media, for example on the internet.

Many teenagers involve themselves in early sex practice due to advanced technology. For example many go to internet cafe and watch sex movies.

Young girls adopt modern traditions of going out in the evening and watching sex movies and drinking alcohol leading them to early sex practice.

Early sex practice is a result of globalization in which teenagers watch bad [sex] movies.

Others mentioned that young people moving away from their families to attend education also leads to teenage pregnancy.

Here at Kitati village many secondary school teenagers do not stay at home because it is far from school and therefore go to rent house near school. That is where problems start because they start early sex practice which results in early pregnancy.

Poverty and teenage student hostels that are not well administrated, lead teenagers into drug abuse, sexual practices hence early pregnancies.

Due to distance from home to school, my parents decided to rent a room for me near my school, there I was free to do what I wanted and ended up with a pregnancy at young age.

Some PEER participants explained that young people were becoming pregnant because of their curiosity about sex.

Many girls nowadays have nothing else to talk about apart from sex. It is sex which they give higher priority than other things.

Girls in my village see sex as the best thing, every one want to hear stories about it and to practice it.

They are engaging [in sex] at younger ages, for example you may get a girl of 10 or 12 years speaking about love [sex].

In our community, girls start having love affairs at younger ages and you may find a child of 12 years knows everything about love [sex]. There is a certain girl who has started love affair at younger age. She was 12 years, when she got pregnant and her parents helped her to abort.

Some PEER participants blamed teenage pregnancy on parents' inability to 'control' their children, or educate them about the risks of unprotected sex.

Even if the parents tell them about getting pregnant, children these days do not hear them, and you can't protect the girl in each and everything they do. You will just find the girl is pregnant.

The reasons for these issues is a lack of good parental care to their children because most children nowadays dress indecently and go to play disco and come home in the middle of the night and parents behave as if it is normal and not their problem.

In my community people see that girls get early pregnancies and are involved in early sex practice due to poor upbringing of children by their parents.

Some parents are alcoholic and fail to control young boys and girls. They don't provide them with necessary advice and information and therefore teenagers make decisions by themselves and lead to early sex.

In our family, teenage pregnancy and early sex practice, are very common because our parents do not teach us. We don't know anything about the effects of early sex practice.

3.5 Family Planning

Some of the PEER participants had accessed family planning services in Mpwapwa, and many had a positive experience. There appears to have been a positive change in attitude towards family planning services.

Many people in the community have now understood the importance of family planning and many woman have signed up to get family planning services.

Families who use the family planning service like the service because they can plan for the number of children they want. Women get rest from one pregnancy to another and parents are able to provide necessary needs for their families.

One woman in my village was saying that family planning services are good because before family planning, many families failed to provide for their families. Because they had so many children, they failed to send their children to school, to provide needs like food, clothes and shelter.

Even those who used to be against [family planning] are changing their minds now that they have seen the benefits for other families.

Our community members, as opposed to some years back, have taken positively on the issue of family planning because many families now get children depending on their income.

The community's understanding of family planning appears to stem from a range of sources.

Many women in our community use family planning services because it is provided in our health centre.

Health workers help many women to access family planning services because they usually go to the

village after three month to educate and give out family planning services.

People in our community have heard about family planning on the radio and women are taught about family planning every time they attend clinics during pregnancy.

Our community see that family planning services are good after getting education from different NGOs and government health centre.

However, many PEER participants explained that their access to family planning was still limited.

This education is mostly in urban areas, while most people in rural areas haven't clear education on the suitability of family planning methods.

In my village, family planning services are not a reliable source as these health workers are not reaching the interior part of the village.

A problem is that contraceptives in health centre are not enough and when women go there are no services. This makes them disappointed and they do not go back to the facility.

In our village family planning services are not available. There are syringes but when it comes for the case of treatment you are told to buy medicine with your own money in order to be injected. If the person doesn't have money she goes back home.

When you are at the health centre and you want to join family planning services, you will just find the staff roaming around and they will tell that, you have to come at 2pm and others will tell you that you have to come at 3pm. When you go at that time you will find the centre is closed. When you meet her in the morning, she will tell you, "I am busy you have to wait for some time" and because of this the woman never returns.

There are a number of beliefs in Mpwapwa which make people reluctant to use family planning. Some people believe their religion forbids them from using family planning methods.

I believe family planning is good but in my community many people ignore family planning services because they believe that they should bear their children as God wishes them to. As far as they are blessed by God to be fertile, they must deliver to the last egg.

There are people who are against family planning and these are people with very strong religious beliefs. They maintain that God commanded all people to multiply and fill the Earth and that family planning is against this commandment.

Commonly men's negative attitudes restrict their wives' access to family planning.

A certain man in my village said that he cannot use family planning methods as its against his religion, as he believes that God sent him in the world to multiply and fill the earth and that family planning is against his commandment. He said "my wife cannot use family planning methods, and when I realise she is been using it, will leave her for good".

Most men in my village deny [their wives] the use of family planning and say it brings bad impacts to women's health as she is over bleeding.

The problem is that men do not want their women to use contraceptives. Occasionally men beat and even divorce their wives because of this. So only a few women here are using contraceptives and therefore you will not be surprised to see a family to have a child every year.

They [husbands] worry that if contraceptives have side effects they will have to pay cost to send their wives to hospital.

When health workers come in my village to give education on family planning. Men are busy with their chores so their population in the seminar is very minimal compared to women.

People in our community have got education on family planning from social health workers who come to villages and talk to us. Many women attend but only a few men showed up.

In our village there is a certain woman who had her husband and two children, but still the man wanted more children. The woman stopped because of difficulties of life. Her husband asked her, "Why don't you want to bear me more children?" She answered, "We have to settle first our life style when it becomes normal I will give you more children." So the man is forcing his wife to bear children but the woman is now using family planning methods. When she comes with those pills, she has to hide them because when husband sees them he must throw them away.

So, it is better to use injection which will last for three months and you have to ask the nurses for help in order to overcome this disaster.

Family planning is also unpopular as people associate it with prostitution.

Husbands do not want their wives to use contraceptives because they believe their wife will become a prostitute.

Some people find family planning as inevitable while others reject it with a belief that it facilitates prostitution.

Others expressed their concerns about the negative health impacts of contraceptives.

Some of women who have used contraceptives, for example pills, injections and loops have reported health problems against them; some women they had much bleeding and they had to be taken to hospital.

Some people do not use family planning because they believe they won't deliver any more or they will stay for a long time without getting children. But

others are afraid of using it because they become thin while others are becoming too fat and they get blood pressure problems. For sure at my home place, many of them do not use the family planning service due to body disturbances.

A woman in my village said 'ever since I started using pills for family planning my menstrual period has changed for example bleeding, dizziness and loss of appetite. I hate this and I have stopped using the pills'.

Due to these beliefs, people continue to use traditional methods of family planning.

Some men advocate local ways like boiling roots and withdrawal.

Some people use [modern] family planning methods while others use traditional medicine. The traditional medicine is worn on one's waist. The traditional medicine helps them. The medicine is smeared on the beads and worn on the woman's waist hence she doesn't get pregnant. They may stay safe for even five years until they take off the beads they have worn so as to get a pregnancy. I don't know whether it is true or not, because it is just hearsay.



3.6 Barriers to Accessing Health Services

Young women in Mpwapwa face multiple, interrelated barriers to accessing the health services. Many of the barriers are a consequence of problems with the health services themselves.

In village health centres there are few health workers and in other villages they are not there at all.

The small number of nurses in some hospitals, health centres and dispensaries is a big challenge.

Some important tests, like blood tests for pregnant women, are not available in our health centre. This makes it difficult for pregnant women to know their health status.

Not enough beds and insufficient health workers are the main problems that pregnant women face in our society.

Young women are also poorly treated by health professionals when they try to access health services.

There is bad language from these health workers. They look at pregnant women in despair just because they are poor and as many women are poor they will end up not getting good attendance and the services they need.

There was a certain girl who was 18 years old. She went to deliver, she was with her grandmother. They were told that they are dirty and are stinking so they were sent back home for bathing and washing their clothes. They said “we won’t help her until you wash her clothes”.

They asked them [health staff] to diagnose the patient but they started asking the patient, “Why do you like delivering while you are young? Why didn’t you wait? You will suffer now.”

Most times pregnant women get maternity service at Mpwapwa district hospital and most of the women complain that nurses and other workers use abusive language. This is not good for women and we are unhappy because of this situation.

Women trying to access health care also face delays in accessing treatment even once they have reached health facilities.

A problem that pregnant women face when attending maternity service is that health workers tell them to wait even though the time for delivery is ready or a pregnant woman is feeling pain.

Women in our community had many problems when in need of maternity services such as untimely services; the attendants delay giving services to women without sound reasons.

In our village there was a certain woman who went to the hospital and she was about to deliver a child, when she reached to the health centre, she told the nurse to help her. The nurse answered “I don’t have such time I am resting”. The woman took her gear and delivered outside the health centre.

There are also external factors which block women’s access to services. Many of the PEER participants described the problems they faced travelling to obtain health care services.

Transport is a big problem for pregnant women in our community. They have to travel a long distance to get to the health facility. We always have to use bicycles and motorcycles to get there.

Many people in our village travel 20km to reach the health centre and we cross a river but there are others who are travelling too far like 30km to 50km to reach the health centres.

During the rainy season roads are not in good condition and many pregnant women fail to reach health centre and deliver on the road.

Sometimes women are prevented from accessing health care by their husbands.

Men are also a barrier to their wives delivering at health centres.

Husbands prohibit their wives from participating in maternity and family planning services.

In other cases, inability to pay the bribes or payments in kind, demanded by health professionals discourages women from accessing healthcare.

Most health workers at clinic want to be paid when we go to give birth although maternal health is free according to government laws.

In our society there is a perception that women have to pay for delivery services.

Nurses ask for money from women saying that it is for buying necessary equipment.

These workers have bad language and they always want bribes.

In our community, pregnant women are supposed to go with different tools when they go for delivery-like basins, two pairs of sheets [khanga], firewood and soap. If pregnant women do not go with them, health workers will not provide friendly service to them.

As a consequence, many women decide not to access modern services, and prefer to deliver their children at home with traditional birth attendants.

Most of the girls in my village don't want to go to hospital and give birth. They decide to give birth at home.

Health workers use abusive language to them and that's why other pregnant women do not go to the antenatal clinic and decide to deliver at home.

Women fear delivering at the hospital because the nurses do not give good care to the pregnant women. You may reach to the hospital and you are about to deliver but the nurses are not even looking at you, that's why they like delivering at home because their neighbours will help them.

In my village most of us depend on these cultural midwives when we want to give birth and these cultural midwives are older women who have experience in giving birth and they have received informal training.

There is much dependence on cultural midwives as an alternative to the poor services provided in the health service stations.

3.7 Obstetric Fistula

The final interviews addressed women's experiences of obstetric fistula. The findings are as follows.

3.7.1 PEER Participant's explanations for Obstetric Fistula

A number of the participants explained that women develop a fistula when they are delayed in reaching the hospital during child birth.

Because of the distance to the health centre and poor transport, many pregnant women fail to reach

the health centre and deliver on road and this can lead to death of a woman or the unborn baby or both and also can cause fistula.

In my village a certain woman reported that when she was giving birth to her first child she was in labour for a long time and she went to dispensary so late and so she developed fistula.

I think when a pregnant woman is late to the hospital during delivery it can lead to obstructed labour and causes fistula.

There is a certain girl who was pregnant but did not go to the hospital for delivering. She was living with her grandmother. The time for delivering came. She took two days then the third day she delivered the child but something remained inside her womb. They stayed at home for three days without going to the hospital. When they went to the hospital the doctors became angry and said, "You are too late". She developed fistula.

Others described how poor quality of healthcare can cause women to develop obstetric fistula.

As result of health workers negligence some women and their babies have lost their lives and other women have been affected by fistula.

I got fistula in 2008. When I went hospital to give birth they told me the child was in the wrong position for delivery process to take place. They left me like that for hours and the child died while unborn. Doctors needed to rescue my life and started to push the kid out from my stomach which caused me to get fistula.

I had prolonged labour which took me almost two days as the child was wrong placed in my womb. The doctors decide to operate on me to save my life as the child was already dead. Due to that prolonged labour, I developed fistula.

Reliance on traditional birth attendants rather than trained health care professionals was also an explanation for fistula.

Delivering at home and seeking help from traditional birth attendants rather than going to a clinic, can cause fistula.

A certain woman in my village developed fistula after she gave birth at home. She was helped by traditional birth attendant but due to prolonged labour she developed fistula.

There are also some others who believe that fistula is caused by traditional birth attendants who hollow out the urinary bladder by inserting fingers into the pregnant women's vagina while claiming to fix the wrongly positioned fetus.

My parents took me to their place, when I was in labour pain. The traditional birth attendant wanted me to push so as I could deliver, she was inserting her fingers into my womb to get the child out; unfortunately my bladder broke because she was hollowing my bladder. That is when I got fistula.

At my village many women give birth at traditional doctors so these women developed fistula since these 'witch' doctors don't have any knowledge on maternal health; they use their hands to get the child out of woman's womb.

The PEER participants explained how becoming pregnant at a young age makes women more likely to develop fistula.

Pregnancies at an early age result in complications during delivery like getting fistula and sometimes it causes death.

There is a certain girl who was married at the age of 14 or 13 years. She got pregnant and went to Mpwapwa for delivering. Because she was too young, she faced delivery problems, developed fistula and died.

In our community teenage pregnancy and early sex practice is big problem because it causes fistula.

Teenage pregnancies have negative effects because some young girls develop fistula, others undergo caesarean section and some even die.

However, misunderstandings surrounding the causes and consequences of fistula are common.

There are some community members who understand that the condition of fistula is due to problems in delivery. Many people don't know the source of the problem.

People in the community do not know fistula is a result of reproductive health problems.

People in our community wonder why a woman with fistula is always wet while she is an adult.

Some members of the community blame women themselves for developing fistula.

Many people in our community don't know the source of fistula and think that pregnant women getting worried during delivery causes fistula.

Many women and men believe that when a woman is suffering from fistula it is due to a fear to push when delivering. For example when I was suffering from the disease my sister in law and my husband told me that I wanted to get the disease, because they told me to push but I didn't do so, hence my husband left me.

Others say fistula is caused due to carelessness of women during the period of delivery and is incurable.

There are some of our community members who do not look at fistula as a health condition but the weakness and failure of women to maintain their body hygiene.

People say women affected with fistula are dirty women, unable to take care of their bodies.

Obstetric fistula has also been linked to prostitution.

There are people in our community who think that women get fistula as a result of being a prostitute.

People believe that women with fistula were prostitutes before they got pregnant.

Some people think that women affected with fistula are prostitutes and on seeing such a woman they will say that she got that condition because of prostitution.

Obstetric fistula is also commonly associated with witchcraft.

Many people do not know what fistula is and take it as a magical disease. This makes people afraid. That's why people wonder why she has to suffer such a disease! It is because since we were young we have not seen such disease now our peers have such a disease. We cannot mention even its name, she must be witched.

People don't believe that fistula is a health problem, they believe that witchcraft is behind fistula. When a woman gets fistula people wonder why it should be that woman to face the problem and not another woman.

People say that fistula disease is foreign disease hence they ignore it and conclude that women with fistula are victims of witchcraft.

Fistula is caused by bad words said upon the pregnant woman and witchcraft.

Even many of fistula patients themselves don't know the source of the problem, that's why many believe in witchcraft and go to traditional doctors [sangoma] because they get this problem during delivery.

Some women are also thought to have developed fistula as repercussion of departing from traditional and cultural norms.

Many people in the community don't know the source of fistula and say that women with fistula have broken customs and traditions of their tribe.

3.7.2 Impact of Obstetric Fistula on Women's Lives

Obstetric fistula has a profound influence on the lives of young women. The PEER participants described the physical implications of developing a fistula.

Women with fistula have health problems as they cannot stop the leaking of urine and therefore they stink all the time. They also sometimes develop wounds around their genitals.

Women with fistula have uncontrolled leaking of urine or stools which results in the stinking of the body.

Fistula patients suffer urinal itching, stress, general physical weakness and instability, hips off-set [displacement], continuous fever, fungal diseases and bruises on the reproductive organs, dehydration, sometimes even death.

Some PEER participants reported people in the community showing sympathy to women with obstetric fistula.

Women with fistula are being separated from other people, they are mostly discriminated but some people do feel sympathy for them. They help them with clothes, food and little money so that they can go for treatment.

There are a very few people with attitude that fistula is a normal condition and these show sympathy to the patients and will help in doing simple domestic jobs like washing clothes and cooking food.

Some sympathize and help fistula patients by giving food, counselling and clothes.

When I was suffering from fistula I was helped by my family. They sold their cattle, both my father and father in law. The money they got has helped me for treatment.

However, women with obstetric fistula also face extreme stigma. The PEER participants described how women are isolated by their community, friends and family.

When I was suffering from fistula my society used to segregate, laugh at and despise me.

When I had fistula every one discriminated against me and segregated me and they despised me just because I smelt bad.

If I try to join them they start to avoid me by disappearing one by one because they stigmatize me.

When I was suffering from fistula everyone in my community including my own children despised me, they looked on me as something which needed to be isolated. I was very ashamed and felt insecure.

Women affected with fistula experience high disregard from the community and people will look at them as person of no value.

They are stigmatizing us. For example, when I was suffering from fistula people were stigmatizing and avoiding me especially my friends. If you try to sell something, they neither buy nor come near to you. They say, "You are dirty and you attract flies. You discharge urine and the flies from you go directly onto the food, how can we buy food from you?" So they are just avoiding us.

Before suffering from fistula, my friends and relatives were visiting me, but after getting fistula they stopped visiting me. Even when it did happen that they came, they neither ate nor drank anything.

Women with fistula are discriminated against because people in our community believe that fistula is not a normal disease.

We look at fistula as a bad and disastrous condition in our community. To many people fistula is not taken as a normal condition like any others that one would face. They think it is because of witchcraft and because of this people do not go to visit and sympathize with the patients as they would with patients suffering from different diseases.

Many women are abandoned by their husbands when they develop fistula.

My husband's relatives convinced him to divorce me when I was suffering from fistula, my mother in-law called my husband and told him, "first she was operated and the child died, now she has urine discharging. Since I was born I have never experienced such a thing. You just take the woman to her home place. If you will remain living with her I'm not your mother."

I know one girl, when she got fistula, she had a child but the child died and her husband abandoned her. He said that he cannot stay with the woman who made the bed wet. Her mother in law told her to go back home because her husband was not there anymore. "Also you have killed our child we have no money to buy you soap every day. You better go back home."

In our community women with fistula are abandoned by their husbands and also in-laws and because of this our marriages break.

Men leave their women when they get fistula.

Fistula causes marriage conflicts and denial of sex.

Some men stigmatize fistula patients and chase them from home and divorce them.

The PEER participants describe how women suffering from obstetric fistula become lonely and depressed.

They have lack of peace of mind and are feeling lonely most of the time.

There is also a problem of stigma from the community because of uncontrolled leakage of urine and also smelling. This leads to other people even family not visiting fistula patients make them experience lonely depression.

When they think of the situation, they get depression. "Losing a child and being in this situation, will I really recover?"

3.7.3 Access to Obstetric Fistula Information and Treatment

Many of the PEER participants felt that their community's awareness of obstetric fistula was improving. They described the ways in which information about obstetric fistula services is being disseminated.

Communication in the past days was a problem and people didn't know where to get treatments. To some extent now we get a little information about fistula.

People say that during the past years there was no information about fistula and treatment, but in these days the information is available through radio.

Previously we didn't have information on fistula and the availability of treatments. But now people have known fistula by listening to radio and others by reading newspapers. There are also village health workers [VHWs] in our villages who give us information about fistula.

These days people have been able to get information on fistula treatments because many pregnant women attend ANC or go to hospital for delivery. Even at village meetings, VHWs talk about fistula.

When pregnant women attend clinic they are told about fistula and the treatment.

Fistula information is usually heard through media and radio and treatment is available at big hospitals like the regional hospital, in Dodoma and CCRBT in Dar es Salaam.

The information on fistula can be accessed from village offices, dispensaries and also from CCBRT ambassadors.

The community helps in giving us information on where to access the treatments and on organizations that may help the patients such as AFNET and Utu Mwanamke through village health workers.

The information on fistula is given at the ward health centre and at village level through VHWs.

Health attendants at the dispensary in our community have been telling women about free fistula treatments. This has helped save lives and marriages of many because after being informed on free fistula treatments, the patients have gone for treatments and now are okay.

Some of the PEER participants explained that obstetric fistula centres are starting to help women with their transport to access treatment.

Sometimes AFNET at Mpwapwa support these patients' bus fare to Dar es Salaam.

The plan for women affected by fistula that I can see in our community is that of assisting them in terms of transportation cost by CCBRT.

Likewise many PEER participants knew that local obstetric fistula organisations provide services for free.

Some people know that there are no costs for fistula treatments and that the service is given free of charge.

At first people had to meet the cost for treatments in Dodoma which was Tshs. 350,000 [around GBP 130]. But now patients are being given treatment free of charge.

Fistula treatments are cost free. A fistula patient does not pay anything at CCBRT hospital but I do not know what the situation is like at other hospitals.

People say that the fistula treatment costs would be unbearable if the patients had to personally pay the charges. People give thanks to the organizations that have taken on the responsibility of helping affected women by paying the treatment charges and now these treatments are free.

Some of the PEER participants gave detailed accounts of the positive experiences they had of obstetric fistula services.

I heard from this organisation that fistula is treatable at CCBRT hospital. I came to my [fistula] ambassador and communicated with them that there was a patient coming for treatment. I travelled by bus and I wore a lot of clothes in order for urine not to come out. When I arrived I was welcomed well and I was treated well.

Without CCBRT service many people would never recover because CCBRT has its own agents. When we were suffering, they came to search for us and take us to Mpwapwa then to Dar es Salaam. When we reach to CCBRT hospital they welcome us very well. After treatment we were given washing soap and they told us to drink more water and not to have sexual intercourse for six months.

There is a certain woman when she was suffering from fistula she was stigmatized by the community and family at large. She was living alone. She was afraid to stay near other people, later she got some information that there is a place which treats fistula. She got the information from the CCBRT agents. She told her relatives but they said they had no money.

She was told that there at CCBRT, she will be given bus fare so not to worry. She went to the hospital. She was treated and recovered.

After delivering, she started seeing urine discharging but did not understand what was happening. Even the nurses did not explain what had happened and why the child she delivered died. She went back home without being told the kind of a disease she had. Later on a fistula ambassador visited her home and told her that the disease is treatable. She went for treatment and was given some procedures to follow in order to live normal life.

There were reports of the joy and gratitude expressed by women who had received successful treatment for obstetric fistula.

After having survived fistula I am now feeling happy and free. I can even dance our local music and integrate with other people. My community is happy to see me well and we are collaborating in many activities.

Women who have accessed fistula treatments now have happy faces and the people in the community are happy to see that they are treated.

When I had fistula I received free treatment and I was given food and clothes. I was very happy because AFNET and CCBRT took very good care of me.

We are thankful for organizations like AFNET and CCBRT Dar es Salaam, as after I recovered from fistula CCBRT gave me clothes, a pair of khanga and money to use for my transport back home.

However, other PEER participants described their community as generally having a poor understanding of obstetric fistula. As a consequence, many do not know or believe that it can be cured.

Our community doesn't have enough information on the availability of fistula treatments. The information is completely unavailable.

People believe that women with fistula will never be cured, therefore they will be crippled forever.

People in the community do not know the cause of fistula and so don't believe that it can be cured, especially in our health centres.

In our village, there was a girl who was suffering from fistula. She does not believe the disease is treatable. Even her parents believe the same. Hence, she has remained with the disease until today.

Access to information about services varies according to where people live, and tends to be worse in rural areas.

Information about fistula and its treatment may be available in town, but in the villages it is not possible.

The information about fistula and the treatment is not easy to get at the villages, as there is no magazine or education system available.

The information on fistula has not reached many patients, especially those who live in villages where transport is also a problem.

People get fistula information only in those wards where AFNET is working.

Many people are unaware that obstetric fistula services are free and, afraid they will not be able to afford it, they do not try to access treatment.

The community do not know the exact cost for fistula treatment.

People say that the cost for treatment of fistula is so high. That's why people go to witch doctors.

Many people find it difficult to believe there are free fistula treatments. Because of this, many women affected with fistula remain behind closed doors fearing that they can't meet the cost of treatment.

The cost of treatment for fistula patients is high and there is no help at the village level to show how much people need to pay for patients to get treatment.

Some of them think that they are using their own money for treatment and find themselves with no money. So they decide to hide themselves at home. Others, even if they hear that treatment is free, still don't believe the disease is treatable until a person who has recovered tells them.

Deep rooted beliefs and misunderstandings about obstetric fistula mean that, even when women receive successful treatment, they continue to face prejudice from community members.

I got fistula and as a result, I was isolated by all the family members; including my husband, brothers, and sisters. My husband's relatives convinced him to divorce me. After I got information that AFNET helps people of my kind, I consulted them and I was sent for cure in Dar es Salaam. I came back healed but still the society couldn't believe that I was healed

until they ordered my sisters-in-law to prove I could urinate normally.

It is difficult for people in our community to believe that a woman who has accessed fistula treatments has completely recovered. Some want her to urinate without losing control to prove it.

When I arrived at my village from hospital they never believed that I have recovered, so they gave me an exercise to stand for an hour to see if I will get wet with the urine.

It is hard for other people in our community to believe that fistula patients have completely recovered, and because of this women still face discrimination when they are selling small consumable items and people do not buy from them.

Yes, when a fistula patient recovers, everyone in the community is surprised and asks the person how they recovered. I told them that I went to a certain hospital in Dar es Salaam, I got treatment and have recovered. I can now urinate like you and I have worn skin tight pants as usual. But they do not believe it until I take off my pants and urinate. Others will watch me urinating when we go to fetch water (as is usual in the village). Even the person who helped me to reach the hospital did not believe until she saw me urinating.

The PEER participants described the discomfort and high cost of travelling long distances to reach relevant services.

When person is suffering from fistula in the village, they face difficulties to transfer her to the district hospital because they have no money.

The treatment cost is free but the problem is transport cost from here [Rudi village] at Mpwapwa to CCBRT Dar es Salaam. We do not get any assistance and as you know fistula patients always leaking so it is very difficult to travel through public transport.

To get treatments, you will have to go to the Regional Hospital or travel to Dar es Salaam. This discourages the fistula patients as it can cause a great trauma because when in buses travelling for treatments, people find us disgusting and they mistreat us.

Fistula treatments are not easily accessed. You have to travel a long distance from Mpwapwa to Dar es Salaam while leaking. This makes us fistula patients embarrassed and sometimes we are abandoned by bus conductors when travelling.

Due to these barriers many women continue to rely on traditional medicine or treatment, which is rarely successful.

As many people in our community think that fistula is a result of witchcraft or failure to observe community taboos, families help the patients by taking them to witchdoctors where sacrifices are offered.

Many victims, especially in the village used to go to witch doctors. The witch doctor dances, covers up with witch's clothes [a black piece of cloth], the evil spirits speak with him, and he keeps on touching you. The first time, you have to go with money, either 3000 Tsh or 5000 Tsh depending on what the evil spirits wills. He then tells you your problems. For example, my friend was suffering from fistula. She

went to the witch doctor and she was told to bring a goat to be cooked. After the goat was cooked, she was given the medicine.

Fistula patients can spend a lot of money seeking for traditional medicine treatments and all of them prove unsuccessful.

Some say that fistula is a disorder that must be treated by witch doctors. For example in the village, when you are suffering from fistula, you will be taken to a witch doctor, who will say that the problem is minor. Even me, I was taken to the witch doctor by my mum. He told us to bring a goat. We brought it and he cooked it. In addition, he gave me medicine to use which did not help me with anything.



4. BENEFITS OF PEER FOR THE PEER RESEARCHERS

FORWARD is committed to using PEER methodology, because as well as producing rich and informative data, PEER has a unique and highly positive influence on the participants. Through the training of young women to interview their peers and collect data, PEER develops the participants' communication skills and knowledge of research. It challenges the participants to find ways to talk about taboo subjects and the prejudice and stigma they face. As the PEER participants go through the process together, networks and support systems inevitably form, helping to end individuals' loneliness and isolation.

Throughout the PEER process, the PRs are referred to as obstetric fistula 'champions' and 'experts' because they have personally experienced the condition. This is an all-important step in building the confidence of obstetric fistula survivors to reverse the influence of the stigma and discrimination they face. The PRs are also made aware of existing information and resources, which they can then use to sign post women with obstetric fistula and other members of the community towards relevant services. Consistent with FORWARD's previous experience, this PEER has created a network of confident and outspoken young women, vocal about the limitations of the health system and associated support structures.

Below are quotes from the PEER participants, collected in the concluding workshop.

I learned to be a good teacher and gained trust.

Being a PEER Researcher helped me to become more confident and be able to stand up and talk.

Consistent with FORWARD's previous experience, this PEER has created a network of confident and outspoken young women, vocal about the limitations of the health system and associated support structures.

Being a PEER Researcher has helped me to have close relations with my fellow women at my village. We came together and talked a lot about social life and the health life of a woman.

Being a PEER Researcher has helped me gain self-confidence, and I feel free to talk to my fellow villagers and about fistula and other health problems.

I have learnt to be a good ambassador and act as a link between people in my village and UTU Mwanamke.

Also being a PEER Researcher has taken away the sense of fear. Today I'm free to talk to any woman in my village as they trust me.

The PRs have decided to maintain and build upon the network they formed during the PEER. They expressed their desire to keep working with FORWARD and UTU Mwanamke, or indeed any other stakeholders that would value their contribution as 'experts' in obstetric fistula.

The PEER researchers shared the research findings in role plays and panel discussions during a stakeholder meeting at the conclusion of the PEER. This event gave them a platform to share their experiences and voice their concerns and needs in the presence of key stakeholders from the government health department at regional and district levels.



5. WOMEN'S RECOMMENDATIONS ON OBSTETRIC FISTULA CARE AND SUPPORT

In the final stage of the PEER, the participants were given the opportunity to make recommendations for obstetric fistula prevention initiatives, and how to support women living with the condition. Their recommendations are grouped below under three headings:

- Recommendations for the government, NGOs, and communities;
- Recommendations for other girls/women;
- Recommendations for other girls/women suffering with obstetric fistula

Recommendations for government, NGOs, and communities

Improve sex education and family planning at all levels:

There is a need for family planning education to continuously be transmitted to the society.

We are lacking education on teenage pregnancy therefore, government and NGOs should educate the whole community starting from primary school, on the causes and effects of teenage pregnancy.

Parents need to educate their children about SRH and the effect of early sex practice.

My recommendation is that parents should talk with their young girls on the effect of early pregnancy.

Improve people's understanding of obstetric fistula and how to access treatment services:

With clear education about fistula, more people will know that it is a delivery disease, not witchcraft.

People wish to see that all women with fistula get treatment but there isn't enough information on where to get the treatments.

Fistula patients need to know that they can get money for the fare to go and get treatment.

Education about fistula treatment should be disseminated in our villages.

We need help at the village level to work out how much money exactly is needed for patients to get treatment. Otherwise people stay away as they are too scared of the costs.

Disseminate information about obstetric fistula using the following methods:

There should be facilitators at village level so as to reach as many fistula patients as possible.

NGOs and other institutions should put more effort into making the community understand fistula in the villages. There should be seminars by health workers at the village level.

After receiving treatments, fistula patients should tell other people that fistula treatments are available and that patients should go for treatments.

Subsidise transport to obstetric fistula treatment centres:

Fistula patients want money to support them during travel for treatment.

Fistula patients should be given a special card so that the cost for transport charges is reduced.

Patients would like to see that there is a special means of transport to reach and collect all fistula patients in the district, because we have difficulty on the public buses.

Decentralise obstetric fistula treatment centres, bringing them closer to the women in need:

There should be treatment of fistula disease that can be accessed at the village and doctors should be available there.

Villages should have special doctor who can repair women living with fistula as it is difficult for a fistula patient to travel from Mpwapwa to Dar es Salaam for treatment.

Women with fistula should be able to access fistula treatment nearer their village in district hospitals rather than travelling to Dodoma or Dar es Salaam.

We suggest that it will be better if all government hospitals will offer these treatments and that they are freely accessed just like health facilities for pregnant mothers and children.

Improve the provision of health care:

The government should increase the number of

medical and maternity services to overcome the problems of deaths, fistula and disability.

I suggest that every government health facility should supply sufficient equipment like beds and medicine and also doctors to help us during delivery.

Fistula is a disease caused by insufficient numbers of health care officers and it should be solved by increasing of the number of health care professionals.

The government should stop corruption in the maternity wards.

Tackle the stigma obstetric fistula patients face at all levels, even after successful fistula repairs:

This issue of health workers' bad attitude needs urgent attention.

To be honest, here in our community there aren't any programmes to help fistula patients before and after treatments; the patients are in isolation. The community only looks at us in embarrassment. We need more help for these women.

We need more help from the community. I was really feeling lonely and hopeless and there is no help for patients from the community.

Provide training and economic support for fistula patients, both before and after fistula repair treatment:

Fistula patients want to be supported to have essential things like food, accommodation, oil and soap to help take away the stink and also medicine to treat bruises caused by urine.

They need money as capital to start a small business due to the fact that some fistula patients are left by their husband when they developed fistula.

Fistula patients want support to be organized as a group who can do business and support each other's daily needs.

Fistula patients would like to receive capital after treatments that they can use to start engaging in income generating activities like keeping of pigs, goats and others.

Fistula patients would like to see the government setting apart special funds to help them engage in small business activities so as to improve their lives. This is especially important during the period when they have fistula and treatments, when they are unable to earn an income. We also ask organizations to help us on this.

Recommendations for girls and women without fistula

When you want to get married you should be at the age which is good for you to get married and not any younger.

For women who have not yet suffered from fistula, they have to be educated about fistula to make sure they don't get it. I advise them if you know that you are pregnant, go to the clinic for check-ups.

When women are pregnant and they are about to deliver, they should rush to the health centres, and not to deliver at home because if they deliver at home they may be late and get fistula.

My suggestion to women is that when they want to deliver, they have to go to the hospital because in the hospital they can get help from nurses. If you feel pain of delivering they will help you, even when you are sick and not delivering they will help you by operating you and save your life.

Recommendations for other girls and women with fistula

They should go to the health centres and explain their problem because all centres are aware of the disease even in every village the village leaders are also aware. For example, at my place you can just go to the village chairman and express yourself then he will tell you where to go or the ambassadors to advise you and they will tell you where to get treatment.

I ask my fellow women with fistula, they have to show up without fear, because the disease is treatable.

We should educate other women by telling them to go for treatment. There is a certain hospital which treats the disease and you will be recovered which is CCBRT hospital or Dodoma regional hospital.

When you conceive; seek for delivery services from a health centre or hospital. Also, do exercises, drink a lot of water every day after treatments and avoid tough activities like digging and collecting firewood.

They should never lose hope as now they survived fistula they need to engage in economic activities like farming so that they can sustain their lives and avoid dependency to their husbands.

They [fistula patients who have received treatment] should visit others with fistula so as to educate them about the services they can receive in the hospital and other health centres.

6. CONCLUDING RECOMMENDATIONS

This PEER has provided a unique insight into how obstetric fistula impacts the lives of women living in Mpwapwa, Tanzania. The recommendations outlined below are a combination of suggestions from the PEER researchers and supervisors, and learning from FORWARD and Utu Mwanamke's interventions. As the women who took part in this PEER described a wide range of experiences and challenges regarding fistula, it is essential that holistic approaches are used to tackle this debilitating condition.

Improve access to emergency obstetric care and obstetric fistula services – Instituting transport schemes enabling women to access emergency obstetric care promptly will reduce the incidence of child birth related injuries and maternal mortality. Providing free transport specifically for women with fistula to specialist facilities two or three times a year is also essential. Those providing public transport, including drivers, should be educated about the needs of women affected by fistula. Adaptions should be made, for example providing seat protectors, and frequent comfort stops, to minimise the shame women with obstetric fistula experience during travel.

'Delivery kits' and other essential supplies must be made available at rural and remote health care facilities for expectant mothers. Health care workers should be taught how to perform emergency operations when complications arise. Paying for health care is a major obstacle for many women, so these services should be subsidised using district health budgets, donor funding, and financial support from NGOs.

Improve quality of emergency obstetric care and obstetric fistula services – Training should be provided to health care professionals to improve their ability to recognise the warning signs of obstetric fistula, and to treat and rehabilitate patients. Health care workers must be trained to communicate appropriately, effectively, and respectfully with fistula patients, and other poor, disabled or marginalised women and girls.

Where necessary, women should be admitted to these specialist centres with adequate time for them to gain the strength they need for the operations to be successful. Women must also remain in fistula centres long enough for them to recover physically, but also to ensure that they start their social and psychological rehabilitation into society. The difference in the needs of women who have lived with fistula for a long time compared to those who were repaired relatively quickly must be recognised.

Critical supplies and equipment must be made available to health care workers in clinics at all levels. Traditional birth attendants and health care workers at peripheral facilities must have the knowledge to make quick, informed decisions about when women need to be transferred to facilities with the equipment and expertise to manage complications when they arise.

Improve access to family planning services – Improved obstetric fistula services must be complemented with better access to and knowledge of family planning among both men and women. This is important to prevent fistula, but also in ensuring women are able to fully recover from repair surgery before they get pregnant again. Information can be provided through girls' clubs and networks.

Build skills and livelihood opportunities to facilitate women's reintegration into society after fistula repairs – In the past, FORWARD has carried out training in skills like needlecraft and cattle rearing to improve women's ability to take part in income generating activities. General business skills training including book keeping, financial management, sales marketing, and customer care is also invaluable. Market research is essential, to ensure products are profitable.

Particularly successful initiatives could incorporate an obstetric fistula angle, for example helping groups of women to develop and produce dignity kits, which contain medicines, sanitary pads, soap and washcloths, for those waiting to undergo repair surgery.



Create networks and girls' clubs to improve the confidence and leadership potential of young women

– Creating girls' clubs and networks is essential to end the isolation women with obstetric fistula face. In well supported discussions, members of the group share their experiences, concerns and ideas with women like themselves. They can provide each other with the mutual support they need to overcome challenges.

Groups and networks are also invaluable in providing an avenue through which to distribute information. This is true for information about services for women affected by fistula, as well as information to help prevent other women from developing the condition. At the conclusion of the research, many of the PEER participants described the advice they would give to women with, or at risk of developing fistula.

With increased confidence and knowledge of issues surrounding fistula, members of women's and girl's networks have been empowered to raise their voices and speak out against the stigma they face. There are practical ways in which civil society organisations can strengthen these networks, for example reimbursing travel to meetings, or providing daily sustenance for those attending.

Engage with communities on maternal health and obstetric fistula

– Pregnant women are very rarely the single decision makers regarding when and where they seek emergency care during delivery. Community members, particularly those in decision making role such as husbands, in-laws and peripheral health workers, must receive education about obstetric fistula. This includes teaching people to recognise danger signs during delivery, and make plans in case they need to access to emergency health services.

Initiatives to tackle obstetric fistula must invest time and resources into building trust and relationships with communities, to facilitate reflection and behaviour change. It is important to explain the causes of fistula, and highlight that any woman can develop it, including those who have already had 'normal' deliveries. This will help dispel myths which link obstetric fistula with witchcraft or prostitution.

Communications channels must reach a range of actors at the local level, and engage people living in rural areas. This might include radio broadcasts, or outreach through influential and respected community members including faith-based leaders. Using positive illustrations of how family, husbands, friends and communities can and do support women with fistula, can help end stigma and discrimination.

End child marriage and other harmful traditional practices

– Child marriage must end as it invariably leads to adolescent pregnancy, thereby increasing girls' likelihood of developing fistula. As child marriage is a key aspect of local identity in Mpwawa, it must be tackled appropriately and sensitively. Heavy handed approaches can serve to estrange the target community, create resistance or backlash and cause people to carry out harmful practices in secret making them difficult to regulate.

It is essential to acknowledge the views and roles of multiple actors, including parents, husbands, or potential husbands as well as girls themselves. FORWARD has used positive examples from other initiatives and has engaged with respected members of the community to create positive aspirational norms.

Provide an enabling policy environment that addresses gender equality and the rights of girls and women

– Ending obstetric fistula requires political commitment, national coordination, the development of a national fistula strategy and the resources to ensure it can be implemented effectively. The Tanzanian government must be held accountable to its policy commitments that influence the prevalence of obstetric fistula. All women are entitled to free birth care at all public and private health care facilities. The legal minimum age of marriage for girls is 15, according to the 1971 Law of Marriage Act, and the 1998 Sexual Offences Special Provisions Act (SOSPA) prohibits FGM of girls under the age of 18.

Girls' clubs and networks should be supported, to give girls the confidence to raise their voices to express their needs. Civil society organisations must use their position to facilitate this. Women and girls from clubs and networks should be brought into spaces where they can share their experiences and ideas with key decision makers, at both the local and national level.

Global commitment and leadership should prioritise advancing the maternal health and rights of marginalised women and girls. Action on obstetric fistula from UN agencies and international community needs to be strengthened through increased resources, research and monitoring at the national level. The aim should be to ensure that governments integrate fistula action within maternal health programmes. International actors must advocate for these interventions to address the political, social and cultural discrimination, which reinforce women's vulnerability.'

7. CASE STUDIES

My friend SM was living with her parents at Kitati village in Lumuma Ward. The father of SM died when she was in standard three. Her mother decided to get married to another man and they were living in the same house with SM. SM was not happy at home since the man who was not her father hated her always. SM was forced to leave the house and was told to go and live with her grandmother at a nearby village. The life of SM and grandmother was so tough and when she was in class six she forced herself to become involved with boyfriends, to meet her daily needs such as soap, sugar, cooking oil, pens and exercise books. DS was the boyfriend of SM; they stayed together for two months and SM got pregnant. Because she was pregnant SM failed to continue with school hence the school life of SM came to an end. She continued to live with her grandmother with no hope in life because she was uneducated and DS denied the pregnancy.

MM, a resident of Pwaga, got her first pregnancy in 2006 when she was 14 years old and a primary school pupil at Kimagai Primary school. When it was time for her to deliver, she went to seek delivery services from a traditional birth attendant. Because of her young age, she faced difficulty in delivery. She had a still born baby and got a fistula as well. Life became very difficult for her and she decided to live with her grandmother. Due to lack of information about fistula she stayed with fistula for six years until 2012 when she went to Arusha for treatment.

A lives at Mwenzele village. She got pregnant at the age of 16 and she was at standard six at Kidenge primary school. When it was time for her to deliver, she went to Mpwapwa District hospital where she stayed for four hours waiting for service. When they came to attend her, they said that it was not possible for her to deliver normally because her of her age and because she was very weak as a result of being delayed in getting to hospital. She had lost a lot of blood, and while they were looking for an alternative way to help her, she and her baby passed away. This happened in 2009.

G who is 32 years old was a friend of mine. She got pregnant at the age of 14 and was sent to Rudi health centre for delivery... She got a fistula because she was young and was circumcised before she got pregnant. When G got fistula she was sent to witch doctor for treatment but she was never cured. Her mother didn't know that her daughter could be cured, so she stayed with her for 15 years. One day in 2012 she heard from a fistula ambassador who explained how her daughter could be cured. G and her mother did not go to CCBRT hospital for treatment because they tried a different medicine. However, it didn't work and also her mother never believed that fistula can be totally be cured, so they had no hope. Her mother till today is hiding G and she does not want to send G for treatment. Myself, I also had fistula and went to CCBRT for treatment. I am recovered now and after coming back from treatment I went to talk with G's mother and told her that I am completely cured but still she did not believe me. Her mother loves G so much that she cannot accept her daughter to go for treatment. She thinks that she will die if she is sent to CCBRT for treatment and she is the only daughter to her.

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Delivery ward, Pwaga Dispensary



FORWARD is an African Diaspora women's campaign and support charity. As well as working with local partners in Africa, FORWARD works in the UK delivering training to professionals to raise awareness of FGM and working in schools to support girls at risk and affected by FGM. FORWARD works closely with communities and youth groups as well as advising other organisations and policy makers on the issues of FGM and Child Marriage. You can find out more about the work FORWARD does by visiting our website: www.forwarduk.org.uk