

‘I used to cry a lot every night’: Voices of Women with Obstetric Fistula in Bo, Sierra Leone



April 2014

Dedication

*To all the wonderful women who
raised their voices to break the silence
around obstetric fistula*

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Development (FORWARD) and Haikal Foundation

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The Research Partners

FORWARD

Foundation for Women's Health Research and Development (FORWARD) is an African Diaspora women's campaign and support charity that was set up in 1985. FORWARD's work responds to the need to safeguard dignity and advance the sexual and reproductive health and human rights of African women and girls globally. They work with individuals, communities, and organisations to transform harmful practices and improve the quality of life of vulnerable girls and women.

FORWARD's Vision is that women and girls live in dignity, are healthy, and have choices and equal opportunities to fulfil their potential. FORWARD educates policy makers, communities, and the public to facilitate social change and realise the full potential of women and girls. They advocate for sexual and reproductive health to be central to wellbeing. They support programmes that tackle gender-based violence, in particular female genital mutilation (FGM) and child marriages. FORWARD empower and mobilise vulnerable girls and women to articulate their issues and exercise their right to services and choices.

Haikal Foundation

Haikal Foundation is a non-government organisation set up in 2001, working primarily in southern and eastern Sierra Leone. They provide education and health opportunities for young people, and presently run a school, catering for over 800 people. Haikal Foundation also run a training centre for girls and women, to empower young people who drop out of school due to poverty or pregnancy related complications such as fistula.

Haikal Foundation has pioneered an innovative programme which holistically addresses obstetric fistula. Alongside extensive data collection, they carry out fistula prevention programmes and data referrals. Haikal provide women and girls with information on how to access obstetric care and build the capacity of fistula patients to take part in decision making and advocacy skills. Their social reintegration programme works with fistula patients, their communities, and policy makers to reduce the stigma surrounding fistula.

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Please note that the views and opinions expressed in this report represent those of the authors, and not necessarily those of the organisations that supported the work.



Participants of the PEER study on the last day of the research

Acronyms

AWC	Aberdeen Women's Centre
CHO	Community Health Officer
EmOC	Emergency Obstetric Care
FGM	Female Genital Mutilation
FORWARD	Foundation for Women's Health, Research and Development
MCH	Maternal Child Health
MoHS	Ministry of Health and Sanitation
PEER	Participatory Ethnographic Evaluation and Research
PR	Peer Researchers
PS	Peer Supervisors
SRHR	Sexual and Reproductive Health and Rights
TBA	Traditional Birthing Attendant
WAFF	West Africa Fistula Foundation

Glossary

Array girls	Prostitutes or street walkers
Belle ooman	Pregnant woman
Bondu	Women's secret society in Sierra Leone
Matta owdu	Heavy mortar and pestle
Mende nurse	Traditional birth attendant
Pikin	Child under the age of 18
Sowie	Excisors: women who perform FGM and officiate the Bondu

Executive Summary

In Sierra Leone, one of the world's least developed countries, the socio-economic and political context has impacted adversely on the maternal health and wellbeing of women and girls. In the southern region of Bo, where this study took place, the devastating impact of Sierra Leone's decade-long civil war is particularly pronounced. Poverty has intensified and become pervasive. Opportunities for education and employment are limited. Most households rely on farming for their primary source of income, and many are forced to supplement this with wood selling, small-scale petty trading, and vegetable gardening. Women and girls in Sierra Leone face multiple forms of discrimination and disadvantages in many areas of their lives. This is especially true for women living in rural areas, who are at most risk of obstetric fistula.

Obstetric fistula is a devastating pregnancy related disability that affects an estimated 50,000-100,000 women each year, predominantly in Africaⁱ. Fistula happens when, during obstructed labour, the baby's head exerts prolonged pressure on the mother's pelvis. The blood supply to the tissue around her bladder, rectum, and vagina is cut off, causing tissue damage. Consequently, a hole is formed between the vagina, and bladder or rectum. Usually the baby does not survive.

Women with fistula suffer from permanent incontinence and nerve damage to their legs making it difficult for them to walk. They also face premature deaths from infection and kidney failure. What is more, women with fistula experience intense stigma. Many are blamed for their condition and the loss of their baby and are often isolated and rejected by their husbands, families, and communities.

The causes of fistula include child bearing at an early age, malnutrition, poverty, and poor health care. Women suffering with fistula often have limited access to emergency maternal health care due to economic and geographic factors. In some areas it is simply unavailable. Consequently, with improved access to maternal health care, obstetric fistula is entirely preventable.

Obstetric fistula is treatable, even when the fistula is a few years old. When carried out properly, the success rate of fistula repair can be as high as 90%ⁱⁱ. However, the cost of the procedure is out of the

reach of most women affected. Furthermore, repair surgery must be complemented with post-operative care. To make a full recovery and ensure reintegration into society, women need education and counselling to restore their self-esteem. Tragically, many women are unaware that treatment is available, because of the 'taboo' nature of the disability and the subsequent isolation from their communities.

This report is the product of a six month research project, entitled 'A situation Analysis on Obstetric Care and Prevention in Sierra Leone'. It was carried out in partnership between The Foundation for Women's Health Research and Development (FORWARD) and Haikal Foundation with funding from Tides Foundation and The Sigrid Rausing Trust.

This study aims to end the silence around fistula and shed light on the experiences of women suffering from this preventable and treatable disability in Sierra Leone. The conclusions made from this Participatory Ethnographic Evaluation and Research (PEER) are based solely on the experiences of and recommendations made by women affected by obstetric fistula living in Bo, Sierra Leone.

45 women took part in the study ranging from 18 to 50 years old and originating from diverse ethnic backgrounds. In a series of interviews using prompts developed by their peers, they shared their experiences and understanding of sexual and reproductive health, family planning, early marriage, pregnancy, and childbirth. Participants also provided unique insights into living with fistula, the coping mechanisms they have developed, access to information and services, and gave valuable recommendations.

This process has created a strong network of women in Bo, who are confident and speak openly about obstetric fistula. The key findings are outlined below.

Key Findings & Recommendations

Measures must be taken to reduce the incidence and impact of obstetric fistula, an entirely preventable and treatable disability. *“I used to cry a lot every night”*: *Voices of Women with Obstetric Fistula in Bo, Sierra Leone* has highlighted a number of ways to do this. A summary of these findings and recommendations are as follows:

Ending child marriage –

In Bo, the rates of child marriage are among the highest in the world. This significantly increases the likelihood of women developing fistula due to early and repeated pregnancies. The women who took part in this PEER have called for concerted efforts to end this harmful traditional practice.

Facilitate women’s participation in income generating activities –

Nearly all of the women who took part in this PEER were illiterate, and few had the opportunities or relevant skills to undertake viable income generating activities. As a consequence many had been forced to enter early marriages or engage in transaction sex to support themselves and their families. This in turn increases the likelihood of women developing fistula, not to mention other sexually transmitted infections. Girls and young women should have the opportunity to remain in school, acquire key skills, and take part in income generating activities that help to increase their opportunities and choices and allow them to have better options in life.

Improve access to and knowledge of maternal health care –

The participants in this PEER had little or no understanding of how and when to seek specialist health care. Few had access to pre-natal care and many chose to use traditional birth attendants, usually unskilled, during labour. Consequently, many women develop fistula unnecessarily as the early warning signs are not identified as a result of their families delaying seeking medical care. Women must have greater access to information regarding how, what, and when to access maternal health services.

Strengthening of maternal health services –

Improving women’s access to information regarding maternal health must be complemented with an improvement in the quality and accessibility of maternal health services. Many of the participants in this PEER were unable to access health care due to economic barriers as well as their geographic distance to emergency health care. The progress

marked by the introduction of a policy that entitles pregnant women to free maternal health care must be continued. The disparities between rural and urban areas must be addressed, and the policy must be fully implemented. Policy makers must make a commitment to providing rehabilitation and reintegration services for women with fistula. Due to the large number of women living with fistula in Bo, focussing solely on preventing fistula would be misguided. It is essential to work with women living with fistula and their communities, and some examples of how to do so are outlined below.

Break the taboo around obstetric fistula –

Women living with fistula suffer in silence due to the shame and taboo associated with the disability. The women who took part in this PEER spoke of being abandoned by their husbands and families and ostracised by their communities. Women affected and their communities must speak out, and reach out to women who are not receiving help.

Improve quality of and access to health care for fistula patients –

Fistula is entirely treatable, but all too often women in Bo are unable to access fistula repair operations and rehabilitation care. The participants in this study described the economic and physical barriers to accessing fistula care. Those who had tried to access care told stories of overcrowding, being turned away, or doctors making mistakes.

Reintegration and rehabilitation –

Women in Bo who took part in the study, and who had experienced successful repair, rehabilitation and reintegration following fistula expressed great joy. In order to re-enter community life, women with fistula need support to build their skills and confidence. These skills include leadership and teamwork skills, as well as literacy, and opportunities to acquire vocational skills and be reintegrated into their communities.

Support the creation of a network of fistula survivors –

There is urgent need for women affected by fistula to operate as advocates and support the active recruitment of other patients at village level. More importantly, strengthening the voices of fistula survivors will help to reduce the taboos around fistula and help increase access to care as well as transform the lives of women and girls affected.

1. Introduction

This study forms part of FORWARD's programme strategy to provide baseline evidence to shape and inform programmes with vulnerable women and girls. Sierra Leone is one of the five countries where FORWARD works in Africa as part of the programme on "Advancing the health and rights of African girls and young women". This programme aims to improve sexual and reproductive health and related entitlements, and strengthen capacity of partner organisations to deliver interventions that tackle child marriage, female genital mutilation (FGM), and related health issues such as obstetric fistula.

This study is a partnership between FORWARD and a local organisation, Haikal Foundation who are based in Bo, Sierra Leone. This report is based on research conducted over a six month period entitled "A Situation Analysis on Obstetric Care and Prevention in Sierra Leone" funded by the Tides Foundation. This report uses the results of Participatory Ethnographic Evaluation and Research (PEER) to amplify the voices and experiences of women affected by obstetric fistula and shed light on this debilitating, and often taboo condition. The study will inform in-country programme development and interventions.

The objectives of the study were to:

1. Shed light on the lived realities of girls and women affected by fistula, including:
 - How the condition affects their day-to-day lives, and the coping mechanisms they may have developed
 - Their understanding of fistula and its causes
 - Their access to and awareness of information and support.
2. Provide substantive data and insights to inform and shape programmes focusing on fistula and related issues.
3. Empower and strengthen the voices of women and girls affected by fistula, increasing their capacity to play a central part in research and programmes that concern them.
4. Raise awareness among community members, policy makers, and other stakeholders on who is at risk of fistula and the needs of affected women and girls.

The report is organised around four main sections. Chapter 2 provides general background information on obstetric fistula, as well as explaining the context of this study. Chapter 3 summarizes the PEER methodology including the recruitment of PEER Supervisors and Researchers. Chapter 4 uses quotes from participants to explore the experiences of women living with fistula. In Chapter 5 the benefits of this research on the PEER researchers are covered, and their recommendations are highlighted. The conclusions and recommendations can be found in Chapter 6.

2. Background

2.1 Obstetric Fistula

Obstetric fistula is a largely neglected disability in the field of reproductive health due in part to its nature and to the position of those affected being largely rural, marginalized, and poor women. The World Health Organisation conservatively estimates that more than two million young women, predominantly concentrated in parts of sub-Saharan Africa and Asia, live with untreated obstetric fistula. A further 50,000 to 100,000 new women are affected each yearⁱⁱⁱ. Unless they have access to a hospital that provides subsidised treatment and care, women may live with obstetric fistula until they die, often at a young age, from associated complications.

The stigma associated with obstetric fistula means that women living with the condition tend to live in silence and isolation. As a consequence many affected women are unknown to the health system. Therefore it is widely understood that the scale of the problem may be underestimated. For example, one report estimates that there may be between 100,000 and one million women living with fistula in Nigeria alone^{iv}. Another report estimates that whilst in Ethiopia 9,000 women annually develop a fistula only 1,200 are treated^v.

The Royal College of Midwives defines obstetric fistula as a “false communication” or hole that is formed between the vagina and bladder (vesicular-vaginal) or vagina and rectum (recto-vaginal)^{vi}. It is primarily a result of prolonged and obstructed labour when the head of the baby cannot pass easily through the birth canal of the mother. Obstetric fistula commonly occurs when women delay seeking care, or have limited access to emergency obstetric care. When trained birth attendants are not present women and their families frequently do not recognize life-threatening complications early enough to access treatment. Access to trained birth attendants is reduced due to poor health care systems, or distance between treatment centres for many pregnant women in rural areas in poor countries. Another cause of this initial delay may be the fear of high costs associated with seeking medical treatment.

Obstetric fistula is also associated with child marriage, as prolonged and obstructed labour

is also particularly prevalent among adolescent mothers with immature pelvises. There is also evidence that type III female genital mutilation - infibulation or stitching up of the vagina - may prolong labour. There is insufficient evidence to determine whether FGM directly influences the occurrence of fistula. However, where women's genitals must be cut open to allow the birth of the baby, there is an increased risk of developing a fistula^{vii}.

Obstetric fistula has significant physical impact. Women with obstetric fistula suffer from incontinence and repeated associated infections. They are often handicapped by ‘foot-drop’; paralysis to one or both of the legs caused by damage to the pelvic nerves during prolonged labour^{viii}.

Obstetric fistula also causes substantial psychological and emotional distress for women. Many women affected by fistula are rejected by their husbands and families and become outcasts from their communities. This is frequently attributed to their ‘failure’ to produce a live child and the constant leaking of urine and or faeces, and the associated odour^{ix}.

Obstetric fistula is entirely preventable and treatable. Obstetric fistula has been completely eradicated in developed countries where women have access to comprehensive emergency obstetric and neonatal care. However for the vast majority of women and girls in poor areas of the least developed countries, prevention, repair and rehabilitation are unattainable due to:

- Limited knowledge of obstetric fistula, its prevention, and treatment
- Large distances between treatment facilities
- Inability to pay fees when health care is available
- Affected women's feelings of shame and isolation

2.2 The Context – Sierra Leone

Sierra Leone is located on the West African coast. Rich in natural resources such as diamonds and other minerals, Sierra Leone is also home to some of the world's most beautiful coastal landscapes, stunning rainforests, and rare wildlife. The population was estimated to be 5.4 million in 2008. Two thirds of the population live in rural areas and most of the urban population resides in the capital

city, Freetown. Sierra Leone gained independence from Britain in April 1961^x.

Sierra Leone is considered to be one of the poorest countries in the world, ranking 177 out of 187 countries in the UNDP Human Development Index^{xi}. After a decade-long civil war ending in 2002, the country lacks infrastructure and human resource capacity. The third national elections held in 2012 marked a move towards peace and democracy, and there has been sustained economic growth between 2010 and 2012^{xii}. However, access to basic social services and vulnerability due to extensive poverty continue to be major challenges^{xiii}.

The life expectancy at birth in Sierra Leone is predicted to be 47 years old, compared to a global average of 70^{xiv}. Sierra Leone has one of the highest maternal and child mortality rates in the world. Under-five mortality is estimated to be 185 per 1000 live births, compared to only 51 worldwide. Likewise, the maternal mortality ratio is 890 per 100,000 live births, compared to 210 globally^{xv}. It is also estimated that there are 30 still births and 49 neonatal deaths per 1000 births^{xvi}. One in eight Sierra Leonean women dies in pregnancy or child birth and this has been declared by Amnesty International to be 'a human rights emergency'^{xvii}.

2.3 The Context of Obstetric Fistula in Sierra Leone

Women and girls suffering from obstetric fistula usually live in rural areas, are illiterate, and have limited access to health services. Furthermore, many tend to be discriminated against, invisible, and marginalised in their communities. As a consequence, the exact number of women living with obstetric fistula in Sierra Leone remains unknown. Poor access to basic preventive and treatment services, especially in rural areas, remains a challenge for the majority of Sierra Leone's women. 42% of births are attended by skilled birth attendants, but the level of skill remains unassessed. It is thought that there is only one midwife for every 1000 live births^{xviii}. For many rural women these averages mask their reality.

There are few organisations and hospitals equipped to perform fistula repairs within Sierra Leone. There are only two centres in Sierra Leone which can perform fistula repair services. Aberdeen

Women's Centre (AWC) is a clinic based in Freetown, and home to the only fully qualified fistula surgeon in the country. The West African Fistula Foundation (WAFF) is a part time clinic based in Bo. These centres offer a range of services including referral, screening, reparative operations, and after-care. They also offer social re-integration programmes.

Haikal Foundation is the only fistula rehabilitation centre in Sierra Leone and works in partnership with these hospitals. They undertake outreach programmes to identify women living with fistula, and take them to hospitals equipped to repair fistula patients. As the hospitals can only accommodate patients for a short space of time, Haikal has a centre where women can complete their rehabilitation. AWC carries out similar work on a larger scale. Table 1 provides more information about these organisations.

There are also very few professionals trained to care for fistula patients. At the time of writing there were five obstetricians in Sierra Leone, one fully trained fistula surgeon, occasional visiting doctors and 111 midwives^{xix}. There is, therefore, just one fully trained fistula surgeon to provide for 3.2 million women in Sierra Leone.

The average cost of fistula treatment including surgery, post-operative care, and rehabilitation support, is \$300. This is equivalent to more than one million Leones, or £135. This is approximately the monthly salary of a professional or civil servant, and therefore well beyond the reach of most women with obstetric fistula. This means that the majority of women living in rural areas with fistula will go untreated and unable to access existing services.

There has been some progress in sexual and maternal health, including treatment of fistula in Sierra Leone. In April 2010 the Sierra Leone government eliminated user fees for pregnant and lactating women at all public sector facilities. This policy means that facility delivery and caesarean deliveries are now free of charge at all government facilities^{xx}.

According to MoHS, there has been a rapid increase in the number of women delivering in health institutions. Between November 2003 and October 2004, 120 fistula repairs were conducted with a 95% success rate. Access to family planning

S/N	Non-Governmental Organisation	Location	No of Beds available/treatable patients per year
Fistula Operation/Referrals			
1	WAFF/Bo government hospital	Bo	34 beds
2	AWC	Freetown	26 patients at full capacity and can treat up to 600 patients per year.
Rehabilitation Services/Referrals			
3	Haikal	Bo	50+ patients per year
Referrals			
4	Gondoma hospital / Medicine San Frontiers – maternity wards, this is not a specialised centre	Outside Bo	200 beds

Table 1: Obstetric Facilities in Bo

has also risen with training of health providers and sensitisation campaigns. It is reported that 15.1% of all sexually active women use a modern method of contraception. The rate was as low as 8.2% in 2008, and 5% in 2005^{xxi}.

Despite the important success of introducing free maternal health care, frequently the planned reforms have not been put into action. In Sierra Leone there is very high institutional mortality, at a rate of around 857 per 100,000 live births.

Hospitals have on average less than 50% of the items required to provide the minimum level of comprehensive obstetric care^{xxii}. Health facilities are often short of essential drugs and supplies^{xxiii}, and disparities between rural and urban areas are marked. Women are still charged for medicines. Furthermore, the lack of any effective monitoring or accountability system makes it impossible for reforms to succeed^{xxiv}.

3. Research Methods

3.1 Introduction to PEER (Participatory Ethnographic Evaluation Research)

Participatory Ethnographic Evaluation Research (PEER) stems from anthropological and social research methods that foster and focus on trust and relationships. In PEER, members of the target population are trained to conduct in-depth conversational interviews with individuals they select from their own social networks. PEER ensures access to marginalised groups that may otherwise be neglected or hard to reach using conventional methods.

As the PEER researchers have pre-existing relationship with their interviewees, they are the 'experts' in their community. Through the use of third person interviewing techniques, researchers are able to address sensitive issues. PEER takes a comparatively short time compared to other methods and yields rich, narrative data. This method provides crucial insights into how people understand and negotiate behaviour and (hidden) power relationships.

Over the past five years, FORWARD has used PEER to explore a range of sexual and reproductive

health related issues in the UK, Ghana, Liberia, Sierra Leone, Ethiopia and Tanzania. In this, and all previous studies, participants have reported PEER to be transformational. It has provided them with new skills and helped them build strong relationships with others affected by similar issues. These women and girls have become a source of inspiration due to their commitment to the research and have developed the capacity to reach out and engage with members of their communities.

PEER received ethical approval from the University of Wales Swansea Research Ethics Board in 2007. It has been trialled and refined extensively by Options, the international consulting branch of Marie Stopes. PEER works to a rigorous code of ethical practice that is adapted for each study's unique context.

3.2 Sampling and Recruitment

3.2.1 Supervisor Recruitment

To kick start the process, three supervisors from Bo were identified and recruited to support the PEER study. They were required to be literate, compassionate, non-judgmental and have exceptional listening skills. The three supervisors selected were fluent in English, Krio (the most widely spoken language in Sierra Leone), Mende,

	Age	Education	Marital Status	No of Living Children	Still birth	Age of 1st pregnancy
1	19	Yes	Abandoned	1	0	18
2	25	No	Married	0	1	18
3	20	No	Single	0	0	19
4	20	No	Abandoned	0	1	15
5	25	Yes	Married	0	1	13
6	Unsure	No	Abandoned	0	1	Unsure
7	16	No	Abandoned	0	0	Unsure
8	50	No	Married	2	0	Unsure
9	25	No	Married	0	0	18
10	20	No	Married	0	0	18
11	20	Yes	Single	0	0	18
12	30	No	Single	1	1	Unsure
13	30	No	Married	0	0	19
14	30	No	Married	0	Miscarriage	Unsure
15	18	18	Single	2	0	Unsure

Table 2: Profiles of PEER Researchers

or Temne. This was very important as they were responsible for facilitating the PEER researcher training and supporting the PEER Researchers during the interviewing stage. They also collected and wrote up the data collected in the interviews.

3.2.2 Researcher recruitment

Once they had been selected, the three supervisors recruited 15 PEER Researchers (PRs). Using a 'snowball' sampling methodology, women affected by fistula were identified and invited to join the study through word of mouth, with the help of health staff and field officers. The PRs were women and girls who have been treated for fistula, from Bo region. The age of the PRs ranged from 18 to 50 although the majority were under 30 years old. The majority of the women were non-literate; seven had never been to school, and a further five were unable or barely able to read and write even though they had received some schooling. Eleven of the women had been previously married, but four of them had been abandoned by their husbands or were unsure about their relationship status. Four had living children while at least seven had had a still birth or miscarriage.

The PEER researchers were paid a small fee for their participation in the PEER to cover their expenses. Some women saved some of this money, or gave it to family members who had supported them over the years. The profiles of the PRs can be found in Table 2.

3.3 PEER Training

FORWARD staff facilitated a workshop for the supervisors who had never previously taken part in PEER to train them in their roles and responsibilities. This was followed by a four day participatory workshop for the PRs facilitated by the lead researchers from FORWARD and Haikal, supported by the three supervisors. The emphasis of the workshop was on skilling up the PRs by establishing them as 'experts' on the issues being researched.

During the workshop, the facilitators and PRs worked together to develop prompts to guide in-depth conversational interviews on key themes including daily life in Bo, sex and early marriage, pregnancy and childbirth, experience of fistula, access to information, and services and recommendations from the girls (see Annex 1). PRs had ample opportunities to practice the interview techniques using the prompts they developed. The PRs were equipped to comply with the ethical standards of conduct during the course of the study. They were informed of the importance of confidentiality in data collection and instructed to seek consent from interviewees. All participants could direct interviewees to the appropriate support services when required.



PEER researchers take part in a training session

3.4 Data Collection and Analysis

Each of the PRs conducted interviews with two members of their social network who had also had obstetric fistula. With each friend they held three interviews all on separate occasions. The interviews were conducted in the third person so the interviewees did not have to talk about their personal experiences or share personal information.

In the first interview, the PRs facilitated a broad conversation about daily life. This enabled the PR to build trust with the interviewee so that they felt comfortable and confident when disclosing more sensitive and personal stories. In the second interview the PRs focused on the issue of pregnancy and child birth and in the third, personal experiences of obstetric fistula.

PRs were advised to take brief notes during the interviews, and write up detailed notes as soon as possible afterwards. The PRs met regularly with the supervisors to provide support and discuss the findings. The supervisors also collected the interview notes and typed them up before emailing them to the coordinator.

The lead researcher processed and analysed the data. Emerging themes were assigned codes and the data were divided into text units (paragraphs and stories), and arranged under the coding framework. Data was then re-read and any quotations that captured the essence of each code were selected to feature in this report.

At the end of the interviewing phase, the lead researchers from FORWARD and Haikal conducted additional debriefing sessions with the PRs over the course of two days. When necessary they held further interviews to fill in the gaps and to get more detailed data; essential for the final analysis.

3.5 Final PEER Workshop

During the debriefing session, the PRs discussed the findings of the study and agreed upon recommendations. Role plays were used to discuss obstetric fistula through the eyes of different stakeholders: the president, policy makers, community leaders, and boys and girls. In doing so they made recommendations for future programmes or activities working with women and girls affected by and/or at risk of fistula.

The PRs also gave feedback about the process and made suggestions for future research. Most of the PRs found the process highly beneficial and for many it had been transformative. Their knowledge of obstetric fistula had grown and they had gained important skills and built confidence. 'Thank you' gifts and certificates were distributed.

4. Research Findings

The data collected in the PEER study have been grouped into the following sections. Section 4.1 covers the daily life of women living in Bo. 4.2 explores transactional sex and 'man business' an issue which was widely raised by the study. 4.3. addresses traditional practices and the important role and influence of the 'Bondu Society' on women. 4.4 focuses on child marriage. In section 4.5 pregnancy and maternal health is discussed. Section 4.6 sheds light on family planning and sexual health, and section 4.7. explores obstetric complications and women's perceptions of fistula.

"The fathers usually have died in the war, ill health or old age and there is usually no provision for the family left behind."

The women in the study also described the hard physical labour involved in their day to day routines, and the gendered division of labour. This included collecting water and firewood.

"We normally spend the whole morning in the bush trying to collect good firewood for hours before we can find any and then with the help of the smaller children we carry buckets of water to our village and sometimes we make more than five trips."



Typical homes in Bo, Sierra Leone

4.1 Experience of Daily Life in Bo

The following information is based on the interviewees' personal accounts of their daily lives. This provides a context for the study and illustrates the difficulties, and extent of poverty that is faced by young women living in Bo.

"Life in Bo is not easy. We don't have the chance that people in Freetown have. We don't have things like electricity and running water or health care and education are hard to come by in this village and holds many girls from moving forward."

"In this village women and girls still pound cassava and maize with matta owdu and pencil, as our mother have done for long time. We also walk for miles to carry water in buckets and pots on our heads from the nearest standpipe or stream. We wash all our clothes by hand and cooking is usually done over fire in the compound."

"Most of the girls develop bruises and wounds on their feet from walking bare feet or from wearing worn out shoes or slippers".

"Women and girls' daily jobs are to cook the rice in a pot balanced on three stones. [We have] to be watchful to ensure that visiting chickens and dogs don't help themselves to the food."

The interviewees also explained the economic activities they took part in that helped to understand the limited economic options available to majority of women.

"The girls sometimes follow their mamas to the farm to pick rice so they can sell it in the local market. Our market is not very big and many people don't come to buy so sometimes we don't sell all our things and have to carry them home again which is a long walk."

"In Bo, some girls walk for miles to sites or places where there are rocks and engage in splitting of stones. These stones would then be exchanged for money which will help to feed their family."

"As girls living here in Bo, our day to day lives mainly consist of doing petty trading selling little items such as soap, groundnuts or palm oil during the day to make a living."

"We engage in doing menial jobs for extra income like clearing the bushes for people who want to do work in an area."

"Many girls earn money as petty traders in the village to help with family as the homes they come from are very poor and fathers have illness and cannot go for treatment and the mothers are usually responsible for the home and young children."

Despite the day to day hardships they face, the interviewees also described the more positive sides of their lives. They shared playful memories and their dreams of a better life with their family and friends.

"The younger girls spend time playing rope. Or copying their mother sweeping, cooking and washing and learn to braid hair which is what many girls want to learn so they can make more money. Other girls spend time with their mothers singing songs and dancing."

"The day can be good as you meet your friends on the road and you can laugh and share your dreams of what life would be like one day."

"Some of us have hopes of having children and some have hopes to be a good businessperson and building a house for my family."

4.1.1 Education

Access to education in Bo is limited. The schools are few and far between, and the quality of education is frequently poor. This limits girls' access to economic opportunities and life choices.

"There is limited access to schools around in our village which makes it impossible to attend school."

"Not many schools are in this village and the ones that are here have many children and no space so the teacher tells them that they should wait till there is space available so the girls return home."

Widespread poverty in Bo means that families cannot pay school fees. Likewise, many parents prevent their children from attending school so that they can take part in economic activities in the home.

"Poverty is a big reason why parents do not send their children to school because they cannot afford to pay the school fees and to buy books for their children."

"Now I cannot send my children to school because I need people to help me pick rice and dig cassava and takes up a lot of work so I need as much help as possible."

"Many parents like me don't have the money to send our children to school because it is very expensive and our children don't even like going there so we don't really worry about sending them there."

This problem is disproportionately experienced by girls because of social norms, which undervalue girl children. Additionally girls are burdened with chores which reduce the amount of time they can spend at school, or doing school work at home.

"In my village, not many girls attend school. This is because their parents cannot afford to pay for their school fees, to buy books and uniforms for them so instead they stay at home to do the household chores."

"Some girls go to school but the number of girls in school is smaller than boys."

"Some girls have never been to school because their parents were not aware about the importance of educating the girl child."

"People around my village don't believe in sending children let alone girls to school because we are very important in our home life and we are always needed to do jobs around the house."

"The girls are not very interested in going to school because they find it hard because they are not given enough time at home to study because of their domestic jobs they have to do."

Often parents prevent their daughters from attending school in the fear that they might get an 'undesirable' boyfriend or become pregnant.

"The parents think that the girls will have boyfriends when they go to school and they do not want their children to get pregnant early."

"Some of them are not able to go to school because they get pregnant very early and most parents do not want to take risks to send them because the chances of that happening are very high."

"Sometimes girls are put into school but they get pregnant very early so their family decides to make them stop going to school and even after they have the baby they still do not continue going to school."

"Many girls do not go to school in our village because of the high rate of unplanned teenage pregnancies and early marriages"

In some cases girls are prevented from going to school because they have entered early marriage. This is discussed in more depth in section 4.3.

"Our parents do not believe in sending girls to school because they might want to give us away into early marriage."

"Sometimes the parents want their children to get married very early so they make the children stop going to school."

However some girls said that the situation had improved, or that they had hopes it would improve.

"There are girls who do go to school and the number is slowly increasing in our village."

"At first there were no girls attending school but now more parents are sending their children to school."

"Many girls go to school in our village because their parents are open to the option of them having educational opportunities as a child."

"Some girls attend formal school some attend non-formal school like vocational tech."

"Most families cannot afford to send their children to school and this can be the most difficult but one day things may change. I hope to go to school and continue my education."



PEER supervisors share a moment

"I work very hard on a daily basis so that I can save money to finish with my schooling. But it is hard and we have to start somewhere."

4.2. Transactional Sex or "Man Business"

"Man business" is the term used to describe sexual relations with boys and men. This phrase is particularly appropriate given that many girls and women take part in transactional sex. "Man business" is one of the ways girls can earn money or provide for themselves or their family. Widespread poverty has made 'man business' part of daily life in Bo.

"There are many ways we try to earn money to survive and this includes selling products that we get from the farm like rice and cassava or we sleep with men that come into the village for money."

"Some of us sleep with men so that we can have money to help feed our families."

"Some [girls] sell vegetables or local goods, and date more than one guy to make ends meet."

"Most mornings, we go the farm to help out our families with planting rice and cassava which is our staple food that we survive on every day. At night we also go with men who pay us to sleep with them for extra money."

"Some girls are influenced by the older girls who have items such as mobile phones and fix their hair well and look nice. They are told that they can have these items if they do what [men] tell them."

For many girls, man business starts at a very young age, and girls are often exploited by men much older than themselves.

"Most of these men are far older than the girls so they take advantage of them by using them to do work in their houses and sleep with them."

"Girls here start relationships with men from as young as 12 years old and the men can be old enough to be their fathers. They do this because they want money from the men or for the men to help them support their family."

"Girls here normally start having relationships with men when they are 13 onwards and most of these men are old enough to be their father."

"For us in Bo, girls start their relationship with men at the age of 15 because that is the time we will find out that we are beautiful; and we know how to maintain men not go far away from us."

"Girls start relationship with men at a very early age from 11 years old because they need the man to help provide for her and the family when they need money and some of the girls want to buy new clothes and shoes to compete with their friends so they need their boyfriends to do this for them."

"In my village girls are recognized as a woman very quickly and that is why they expect them to do certain things with the men for money. They normally start calling them women when they see their period which is normally around 11 or 12 years of age."

Many girls explained the pressure their parents put on them to have sex with men, to earn money to supplement the family income.

"To earn money, parents encourage their daughters to sleep with men for fast income especially when there is no food to eat and the younger ones are hungry."

"Girls here learn to go off with older men early sometimes friends show you, sometimes parents encourage this."

"Girls are expected to earn money as early as possible because most girls serve as bread winner in the homes."

Some girls do see this practice as 'prostitution' and talk about having 'customers'.

"They [girls] engage in prostitution with local men in the villages or people who come to work there and some of them even go to neighbouring villages to find men."

"If we do not have enough money we have our customers who we see at night and they give us a little bit of money when we sleep with them or sometimes they bring their friends and we sleep with them."

"We are also expected to earn money at a very early age by all means possible which as I said earlier on includes prostitution and that is how we tend to earn money and girls as young as 10-18 are involved and partake in this."

"We sleep with men that come into the village for money. We normally spend the night with them or a few hours and they pay us a little amount of money then we go back out on the road and wait for another man to approach us. Sometimes we can get up to as much as five customers in one night."

Some girls expressed sadness that their peers were choosing to get involved with men to earn money.

"These girls now all want money so they can sleep with many men just to get it. It is really sad."

"Our day to day life here in Bo is so unspeakable because girls normally go out for men in this village they see it as a priority to do that. Girls do not go to school in this particular village because they have no plans for that, they will become useless women at the end of their life because they do not have any better future plans for their lives."

4.3. Traditional Practices and the 'Bondu Society'

Many of the participants talked about the role of 'Bondu Society' as a place to learn about the important aspects of being a woman. The Bondu society is a secret society that initiates young girls into womanhood. The members are taught about traditional customs, as well as social grace and good health.

The girls are instructed by an initiated member, and once initiated themselves, they are considered ready for marriage. The initiation ceremony is also associated with the practice of female genital mutilation (FGM) and child marriage.

"We learn how to become women from our friends and other girls in our communities as well as during ceremonies like the Bondu Society."

"You go to society and learn more about being a real woman. My friend who has been to that place tells me that she learnt how to dance

for her husband and how to be a good wife, traditional values with the help for societal head and marital home, personal hygiene. This society is a place for women to learn with the older women who come to teach her these things like how to behave to your husband and to go with him and please him then the how to cook and so many other things. It is impossible for a young girl to get married without having become a woman."

"A woman is recognized and learnt how to become a woman during her menstruation time or during initiation period. It is a ceremony called Bondu Society where they also learn about womanhood and secret business of a woman."

Women and girls living in Bo see the Bondu Society as a critical part of their culture.

"There are many of us who have gone into or want to go into the society because we believe it is part of our culture."

"There is a ceremony which most of us attend which is the Bondu Society and if you do not attend this ceremony it means that you are not a born citizen in our area."

Often, being a member of the Bondu Society is regarded as a necessary precondition for marriage.

"Early marriage is common and when a girl reaches a good age she will enter into society where she is trained in how to be a woman and to make herbs, cook and prepare for marriage. If your family is poor this will be done sooner so that you can go to be in marriage."

"When you enter the secret society they will teach you how to cook even how to take care of your husband to be and just as you will be in the society then you notice that a man will ask for your hand in marriage."

"Without the society you may not get married. Girls who don't go to the society find it very hard to find a husband as men want girls to go through it and become a woman. It is important for a girl to have this as our tradition recognizes you in society if you go to Bondu bush because a girl who does not go to this society is not respected among her equals."

"She is recognized as a woman because her parents have put her into the Bondu society where she has learnt skills to take care of her

husband, how to treat him with herbs when he is sick and also how to cook, speak to your in-laws and how to treat their people when you become a married woman and the special society part. This part is where you cannot talk about it to others but it is something very sacred to a young girl in becoming a woman."

For the most part the girls who took part in the study saw the Bondu Society as contradictory to the 'modern realities' of preparing for marriage, for example with regards to family planning. However, some interviewees highlighted the positive aspects of being a member of the society and the traditional values celebrated there.

"Girls who don't go to the Bush become useless. They start becoming prostitutes and sleeping with men so that they can earn money and that is where they get diseases, and some of them even get pregnant and some of them do not even know who the father of the pregnancy is."

"She had learnt about sexual health and reproductive rights from secret society which is what they teach them during the course of the Bondu bush."

4.4 Child Marriage

4.4.1 Family Pressure

For most girls in Bo, the ultimate aim is to secure an on-going relationship with a 'rich' man who can help support her and her family. Parents often pressure their daughters into child marriage to formalise this arrangement.

"Many of the girls are married or have boyfriends because... once the girl becomes involved with the man, he somewhat becomes responsible for the upkeep of the girl's family to provide the basic things that they need."

"The girls are also given to marriage at an early age for the benefit of the family because they might want money and the dowry paid by the man's family is a means of getting money."

"Girls have to earn money but it can be good when a man wants to marry you as he will bring cows and fowls to your family and maybe a bag of rice every month, so the girl will go to

his house and do the same kind of work there but he will look after her family."

"If they are not going to school their parents will ask for their hand in marriage, they see it as a way of getting money or help from their son in law especially, if the man is physically fit and energetic to work at farm."

"They are also given to marriage to reduce the burden on their parents because that means they will have one less mouth to feed and the parents expect the man's family to provide for them."

"Some families also give their children to men to marry from the day they are born and they start living with them when they reach a ripe age which is fairly young."

"There is a family that gave their 6 year old daughter to a man to marry just so that they could have money to buy a goat for their farm so there are a lot of these things going on here. It is very hard to live in this village as a girl."

In general, the women interviewed in this study portrayed clearly the paradoxical messages from their parents and society more generally. Girls are pressured into finding husbands to support them, and take part in 'man business' to support the family income. Simultaneously, however, many women are encouraged not to mention 'man business' and face extreme stigma when they become pregnant in pre-marital relationships.

"So my friend tells me that I must not tell anyone what she does or she shall harm me. She tells me that there is a man who comes to our village all the time and wants her to do things to him and he usually gives me some money which I use to then give to my ma so she can buy rice and palm oil to make food for the house. My father doesn't work and is sick, so we need the money to help him and the family as we are many in our family. My friend also says that this is the quick way to get out of this situation as she had problem during the rainy season as the roof was leaking and no one to help us fix it."

"We are expected to get a lot of money and our family don't even ask where we get it from. Sometimes we have no other way but to become 'array girls' to survive for money."

"My aunties also accuse me of starting 'man business'. As usual we deny."

"I believe that young girls should get married quickly because they will not get pregnant outside marriage. If you leave them to go to school they might find a boyfriend and get pregnant and that is a very bad thing for us in our village. It is a disgrace. Yes girls should be able to bring back money home for their family because that is the benefit of having a girl child. They should find a good man to help support their family because otherwise who will help us come out of this poverty?"

4.4.2 Child Marriage and Early Pregnancy

Child marriage and early pregnancy are intrinsically linked, and a highly complex issue. In some cases girls find themselves under pressure to get pregnant as soon as possible to please their husband and his family. Child marriage is deeply entrenched in many rural areas in Sierra Leone and is valued as essential for girls.

"If they decide to get married it won't take one year you will see them with big stomach that means they are pregnant. If you do not become pregnant during that period your husband family will decide to bring in another woman."

Frequently young women get pregnant so that they can have children to help them around the home.

"Their families also want them to have children because they need more hands to help them at home and at the farm"

"Many young girls have children early so that the children can help in the household and on the farm. The children grow up to also sell small items to bring money to feed the family."

"Some of them want more children to continue working in the bushes, selling for them and doing household chores."

Because the rates of pregnancy outside marriage are high among young women child marriage is common; either once a girl has become pregnant, or because parents are keen to marry their daughters to avoid the shame of pre-marital pregnancy or alternatively to avoid the possibility of not being supported by the baby's father.

"Many of the girls are married because their parents make them marry quickly so that they do not get pregnant without being married."

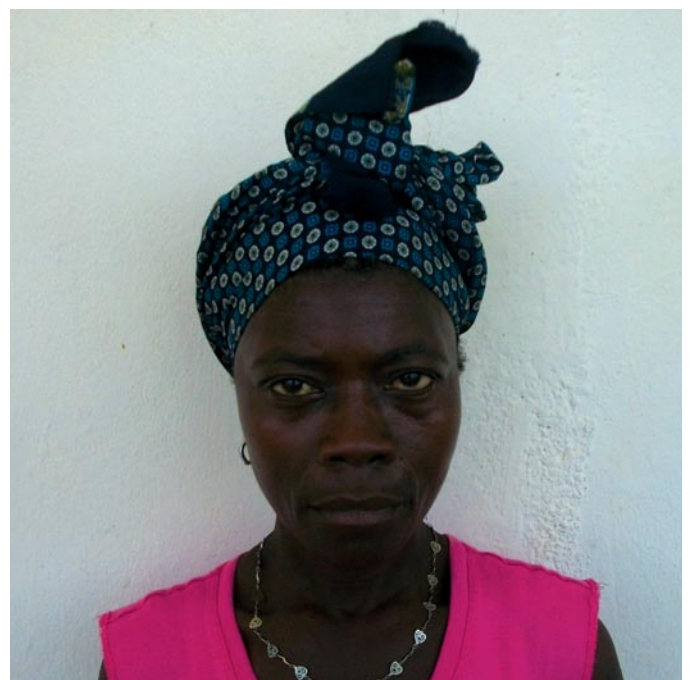
"They start very young because they are exposed to men at a very young age and their parents encourage them to do it in hopes of them finding a husband quick"

"There are many young girls that are having babies in our villages. This is because the parents give their daughters to men to marry them when they are young."

4.5 Pregnancy and Maternal Health

Women's knowledge and experience of pregnancy and childbirth provided insights into their understanding of pregnancy risks and decision making. In general, girls and women in Bo, Sierra Leone have little choice in whether to get pregnant. Many girls are left to raise their babies alone without the help of their children's fathers. This disempowers women, driving them and their children deeper into the cycle of poverty.

"There are many young girls that are having babies in our village like me. There is no protection and the girls want to get pregnant fast because then the man can help to take care of her family."



PEER participant during the data collection phase

"Some babies have no fathers and the women find the daily life challenging as they are faced with many things like no one to care for them so they have to find work and continue on the farm, or sit at home nursing their babies with no-help from the fathers."

"It is difficult but lots of girls make mistakes by going with men and getting pregnant and they cannot always take care of the children as they don't have too much money. The children too will grow up in the village and not go to school."

"Many girls become pregnant and some have to get married early. Girls won't finish school as they have other things to have to worry about now as a wife or a mother and she spends her time selling for a long time. No more going to city to get to school. All things now change. She delayed her life by getting onto trouble and getting pregnant and now will stay here in this village tendering to the farm."

4.5.1 Access to Information on sexual and reproductive health

For the most part, women and girls in Bo gain their knowledge of pregnancy and childbirth from their families and friends.

"Girls learn about being a woman or man business from their friends or families if they have many aunts, grandma living with them."

"Most girls are told by families that if you lie down with a boy you will get pregnant."

"They can find out through friends and from their peer groups."

However, frequently this advice is incorrect and sometimes unhelpful, and can have a detrimental impact on girl's lives.

"Peers also discuss certain issues about pregnancy. I learnt from my friends that a woman gives birth through her stomach but it was during the time my sister gave birth and I was in the room that I noticed the child coming out of her private part and not her stomach."

"Some don't know that you can get pregnant but they go with men anyway."

"There are many young girls that are having babies in our village because of the lack of knowledge of preventive measures they can use

to avoid unplanned pregnancies and sexually transmitted diseases."

Some interviewees mentioned getting their information through health services and through NGOs. There is more information about this later in the report.

"Sometimes girls learn about sexual health issues through medical health centres, private medical institutions or NGOs involving sexual reproductive health."

"Sometimes they even go to a nearby hospital or health centre and talk to one of the nurse secretly."

"Even sometimes girls learn about sexual health issues from medical health centres, Marie Stopes clinic, family life education in school, PPASL, and MSF."

4.5.2 Access to Healthcare

Women in Bo, Sierra Leone use a wide range of pre-natal health care. The nature of the health care depends on what is available locally, what they can afford, and their personal preferences.

"There is a new health centre in Pujehun four years ago; so many women/girls now attend for health check for free every Thursday."

"In my village, women go to health centre. The nurses tell them to exercise and give nutrition advice. Many of them go to hospital to deliver."

"Some will visit their nurse frequently for proper check-up."

"Some girls go to the Marie Stopes clinic and some goes to herbalist."

Many others spoke of giving birth with the help of the 'mende nurse', or traditional birth attendant (TBA) closer to home.

"In my village, when women are in labour, they first go to mende nurse because people in the village believe that before you attend the health centre you need to visit the mende nurse. If there is a problem, the mende nurse takes you to the hospital. The nearest centre is five miles away."

"They visit the mende nurse. She will normally have them visit her often for her to check the pregnancy. She will feel the stomach and give them herbs and she would be the first contact when the first signs of labour happen."

"Many of the women have babies safely with mende nurse."

"My TBA tells me she is an expert and delivered hundreds of babies."

Frequently women in Bo choose to use a TBA and only move to health clinics or hospitals if they perceive there to be complications in child birth.

"Many of the women have babies safely with mende nurse but some girls have difficulties so they take them to the clinic in Viana by hammock which can take one day."

"Most women in my area don't go to the hospital but go to the mende nurse. If the labour is too long, they take them to the hospital."

"There are health centres in my area, they only seek assistance from health centres when they are in labour pain, menstrual pain, or having infections like STIs, or STDs."

For many, choice is impeded by the cost and availability of health care.

"Some will go to the TBAs because she will be local to the village and usually available all the time and she is the cheapest and doesn't require immediate payment."

"The health centres are usually very far from where we live and the mende nurses are less expensive."

"When women in my village are pregnant, most of them go to the traditional birth attendant but some go to the hospital depending on their income."

"Women prefer to go the traditional birth attendants because it's cheaper (you pay 15000 to 30000). At the hospital, you pay between 50000 and 100000LE to cover costs for the doctors and nurses buy soaps and other medical materials."

"When they are in labour, they go to the traditional birth attendant first if there is a

problem, they then go to hospital. If you have 2000LE, the traditional birth attendant finds you herbal but if you go to the hospital, you need more money than that."

"The hospital demand huge amounts of money and upfront payments."

One woman mentioned that maternal child health services are theoretically 'free' – but that in reality this was rarely the case.

"The clinics are free but the women have to take 1,000LE every week to the clinic."

Some women go into the bush when they are ready to give birth to be attended by members of the 'Bondu Society'. The Bondu Society is a women's secret society which is mentioned in more detail in section 4.6.

"Some girls in labour will be taken to the Bondu bush to the Sowie (society head) who will then deliver their baby. They will take things like laundry and bathing soap as payment for this. Small amounts of money will also be given as libation towards the ancestors that have passed away. As a normal deliver they all come together to celebrate... The healthy mother and baby will be taken home and taught how to suckle the baby and teach her how to wash and feed it."

"In my own village the labour is only done by the Sowie."

4.6 Family Planning and Sexual Health

The women and girls involved in the study spoke of very low use of contraceptives. This is a key factor in the high number of unplanned pregnancies and transmission of sexually transmitted infections.

"Many girls have been sucked into this life [having sex with men for money] and that is where they contract many sexually transmitted diseases and have unplanned pregnancies. We do not have preventive measures like condoms or birth control to avoid these things and most of us here do not know about such things."

"There are many young girls having children and this is because they don't know how to prevent themselves from getting pregnant at an early



PEER participants develop questions for interviews during a workshop

age and they sleep with men who don't use condoms as well."

"The men don't even treat us well. Sometimes they leave us with all kinds of sicknesses and we do not have money to pay to cure them."

"Sometimes the men have more than two women at a time and they tend to contract these diseases and pass it to all of them."

"We normally don't use condoms so many of us get pregnant very quickly and it is hard to know who the father is because we have been sleeping with so many men. I have a 2 year old son and I still don't know which one of the men I slept with is responsible for the child."

Many girls and women explained that societal pressures, taboos, and stigma were a primary reason for the limited use of contraception.

"Majority of them have given birth to a baby the reason being is that there are negatives rumours surrounding the preventive measures. Most of them are afraid to prevent themselves as not to be called names or accused of being a prostitute."

"We are afraid to ask for condoms because people will know what we are and we will be driven away from the village."

"There are many girls who are having children now and it is because their parents don't tell them to use condoms but some of them are even afraid to talk to their parents about that."

4.7 Obstetric Complications and Fistula

All of the women involved in the research had suffered or were still suffering with obstetric fistula. They shared stories of long, difficult births, often with tragic consequences.

"She was in labour at home for four days; the health centre was far away (one full day walk.) On the 5th day they took her to the hospital in a hammock. The baby had already died; the nurses put their hand to pull the baby out, she was paralysed for six months. She stayed with fistula for six years."

"She got pregnant when she was in grade 5... about 13 years old. She was not married and stayed with her mum during her pregnancy. She was in labour at home for two days and

then they took her to the mende nurse. The traditional birth attendant transferred her to the health centre. At the health centre she had a still birth, stayed in the hospital for two days and started leaking. The nurses told her that it is beyond their capacity and they can't fix it so they sent her home. She now has fistula."

"She was in labour for many days; she was at the hospital and the nurses tried but she couldn't push so they sent her back home. Later, she passed out so they thought she is dead. Eventually the baby came out, still born. She was left paralysed. The umbilical cord was still in her belly for 40 days, they called a doctor to take it out, and he tried very hard to remove it. When he was trying to take it out, she gained fistula."

"She was in labour for a long time at home helped by traditional birth attendant. There is no hospital in their village and no vehicle. After four days she kept pushing and her legs and hands were paralysed. After that they lay her in a hammock to the nearest health centre (12 miles away) She was unconscious. When she got to the hospital, they pierce the vagina to take the baby out but the cord stayed in her belly for one week. It started to come out piece by piece. That damaged all her womb. The CHO transferred her back to her village and she already have fistula."

"She was taken to the labour room for delivery but couldn't deliver. On the following day they operated on her and the baby was dead. Three days later she continued to leak urine after the surgery. She had no life left in her arms and legs... She returned to the village and during that time she was leaking urine and faeces at the same time and she couldn't control it."

"I want to talk about my friend – she was an orphan. She was living with her aunt and was going to school. When she got pregnant, they chased her out of the house. So she stayed with the boy's mother... She was in labour for two days and the baby died... The ambulance came and took her to the hospital (about 20 miles away). They did caesarean section and after that she started passing urine. They sent her back home as they can't treat fistula."

4.7.1 Reasons for Fistula – According to Women

There are numerous factors mentioned by women that cause fistula, however, the majority of birth stories from the women in the study were linked by common themes. Prolonged labour was cited by many:

"We know many women who suffered from fistula through labour. Most of them developed it during long labour at home."

"I got fistula being in labour for five days with traditional birth attendant."

Many girls understood that obstetric fistula is particularly common among young girls who were malnourished or had underdeveloped bodies.

"Some of them develop birth problems because they are so young and they cannot handle the pain and pressure of giving birth."

"I only knew one 12 years girl who had fistula. Her step mum forced her to marry when she 12 years old. She was pregnant immediately after the marriage. She was in labour at home for four days. They took her to the health centre... she delivered [but] the baby died and she developed fistula after three days."

Poverty was a recurring theme. Many members of the community live hand to mouth, and have no money saved for emergencies. Interviewees spoke of their inability to afford the health care that they urgently required, or even the transport or 'mobile top-up' needed to get there.

"She was pregnant at 14 and she was in labour for four days at home with mende nurse. The hospital is very close to her house. But there was no money to take her to the hospital."

"The nurse told her parents to take her to the hospital. The nurse asked her parents to give her money for mobile top-up so that she could call the Ambulance. But they didn't have money so they took her back home."

Many of the participants explained that they were unable to access emergency care because of the distance they lived from health facilities, their limited access to transport, and other seasonal factors that impeded their travel to hospital when they were in labour.

"During her first birth, she developed fistula. She was in labour for four days at home. Because of big distance, she didn't go to the hospital."

"When she was in labour, they couldn't bring her to the hospital because it was rainy season and the river was too full. She was in labour for two days and the baby died. When the river gets down, they crossed the river and called an ambulance."

"When the labour started, there was no vehicle to take her to the clinic in the next village (three miles away) so she stayed with the TBA for one week during the labour. After one week they took her to the next village by boat, they couldn't help her there so she went to another village where they took the still born baby by a machine. Then she already had the fistula and lived with it for one year."

Even when patients are able to travel to emergency clinics, they remain at high risk of developing obstetric fistula due to the poor quality of health services.

"When she was in labour, she went to hospital but the nurse wasn't there. She waited for three days! Then she gave a still birth. She got fistula."

"She was in labour for four days when she was unconscious and they transferred her to hospital but there was no power."

"Many of these young girls die during childbirth because there is not enough medication and good mid-wives to help deliver the baby safely."

"Not many doctors can do the repairs some of us need the operation one, two, three or even four times. But the doctors can only do one type; we have to wait for a specialist doctor to visit for many months."

"Girls say that the services are good but there are not many doctors who are available to treat the condition - particularly those who have stages 3 and 4 fistula and the more complicated cases."

"She already had three operations that are not successful; tomorrow a specialist doctor from abroad is coming to AWC so she is hoping to have the fourth operation."

"It is not easy for woman and girls with fistula to get help. This is mainly because many

people are not aware of the condition or how to treat it particularly the African nurses and doctors and the other medical staff. Most of us believe that only the white doctors are educated and trained so therefore it is difficult for girls to get treatment. The doctors are so few and more people need to hear and learn about it. The help is limited but there is some help such as Haikal and WAFF in Bo, plus in Freetown there is Aberdeen Women's Centre."

In some cases, women and girls developed obstetric fistula because of medical errors. A number of women narrated experiences where inadequate health care and failure to provide emergency care resulted in the fistula.

"She was in labour in hospital. She couldn't push anymore and her vagina was sore and the doctor used an instrument to clean it and unfortunately he damaged her bladder then she has a C-section to take the baby out."

"They did an operation and the doctor damaged her bladder by mistake and caused fistula."

"After four days they took her to the hospital, she was operated immediately and the baby was alive but the doctor damaged her bladder. For two years, she lived with fistula."

The poor quality of the health care and lack of access to it means that frequently the warning signs of obstetric fistula are not recognised before a woman goes into labour.

"In my village, most pregnant women don't visit health centre for a check-up during pregnancy."

Other women spoke of their peers who had been turned away from health facilities as their condition is seen as too difficult and specialised for them to deal with.

"The nurses told her that it is beyond their capacity and they can't fix it so they sent her home. She now had fistula."

"The nurses sent her back home as they can't treat fistula."

"Women find it difficult to get the treatment because the health centre in our village can't solve their situation."

"Her mum died and then her dad died by car accident so she couldn't afford the transport but a friend helped her to go to Aberdeen. The AWC sent her back to her village to wait for a doctor for another two years due to her situation is very serious."

"They examined her and then told her to return home after three months because the doctor who conducts the surgery has finished his time for the month and will not be returning until three months later. So she should come back then. She returned to the village and during that time she was leaking and faeces at the same time where she couldn't control it."

4.7.2 Impact of Fistula on Women's Lives

The girls and women involved in the study spoke with heart-breaking honesty about how fistula affected their lives. Interviewees shared their feelings of shame, sadness, and isolation. Some women developed mental health issues. Many were abandoned by their husbands, families, and communities.

"I used to cry a lot every night."

"She went back home and stayed with fistula for two years. She was isolated by her friends and family members. Every morning, she goes far away from her house to be alone."

"During the one year of living with fistula, she had a terrible time. All of her friends left her alone, her husband abandoned her."

"Some of them are married but many men have left their wives for having this sickness where they urinate on themselves because they feel ashamed and some of them want new and younger wives. My husband left me for a 13 year old girl his mother found for him and he does not want to come and see his two children. In fact, he denies that the children are his own."

"During the two years that she suffered with fistula, she was abandoned by her grandmother who she was living with, her husband left her too."

"She lived with fistula for six months; she was abandoned by her mother."

"My friend goes from villages to villages because when the villagers find out about her situation, she goes to the next village."

"During my time in the village we were three women who had this condition and two are now dead and I am the only survivor. Whilst I was in my village many people were aware of our condition because we would watch movies with the community but as we showed up people would make whispering noises about us and move away. We were treated so bad that even when we went to wash our clothes our fellow women would usher us away. We only had the three of us as companions as we were going through the same thing. Many people didn't understand our condition."

"My friend got this fistula and became frustrated. She started drink alcohol and behaved as if she was a person who had lost their mind by "showing herself in the streets" this means she walked the streets naked."

4.7.3 Accessing Fistula Care Services

Women spoke with gratitude about the fistula organisations and services which have helped them or their peers turn their life around.

"She was ashamed of what had happened and this was the end her life. Her husband abandoned her... She became the talk around town with all other women gossiping about her and she felt so alone and afraid. During a time she was selling stuff she had the radio on and heard of Aberdeen Women's Centre (AWC) advertising a free number to call. So she went to the health clinic to ask about it. They gave her the number and she called it and then they arranged for her screening. She has had the treatment and is now a champion in the village."

"She thanks God for giving her such a chance to come to Haikal."

"I had continued to urinate uncontrollably and I ask the doctor what was wrong he then advise me not to be worried as that condition would be taken care of by another facility. I was transferred from Gondama hospital to WAFF for further treatment. I was then handed over to the WAFF team where they examine me and explain to me the condition which I now know to be fistula. I was a patient at the

WAFF hospital for three months where I was explained to about fistula, how fistula happens and how I contracted this condition. The nurses were friendly, informative, and knowledgeable about the condition and they made me feel at ease."

"She stayed with fistula for eight years; she went to MSF in Bandajuma. Her first operation was successful. She is happy."

"She was abandoned by her first husband but her second husband took her to Cottage Hospital in Freetown - she had two operations and she is now ok."

Many of the participants, or their peers had undergone successful fistula treatments. These women had been able to remarry and have more children; a stark contrast to years of disability and isolation.

"For two years, she lived with fistula. She finally got treatment at WAFF. She is staying with her auntie. One successful operation and she has since had another baby."

"After operation she is now remarried with another person."

"She lived with fistula for six months; her younger sister took her to WAFF. One successful operation and now she had her second baby called Wasa. She is now 10 months."

The participants had found out about these services through a range of communications channels. These included relatives, friends, and fistula 'champions'. Others had found out about the services through the fistula organisations' outreach, on the radio or via letters.

"Most find out from their relatives and friends."

"Some women hear about the service by radio."

"She had the fistula for ten years, and she heard about Aberdeen hospital on the radio."

"She also heard about Haikal on the radio so she borrowed money and came to Haikal as they said they will refund her. Haikal director came to her village and left a mobile number so the chief gave her the number. She asked the bus driver to call the number. She was the first client in Haikal; the doctor from AWC came to screen her."

"She had fistula for three years. During this time, she lost her first husband. AWC wrote letters to let them know about fistula treatment. She found out through a nurse, she went to Freetown by AWC vehicle."

"She lived with fistula for two years. The nurse told her about AWC, and AWC arranged transportation for her."

"Usually word of mouth at the health centre and hospital will direct us to get treatment. If they have been through the hospital or health centre that would direct them to treatment centres available. I was lucky to get information because my case was dealt with in a hospital."

4.7.4 Key Challenges and Constraints in Accessing Fistula Services

The women interviewed in this study explained that there is still significant unmet need, with many fistula sufferers still not being reached.

"There are many other women in my village who are not aware of these places to get help with fistula."

"The women who are with the TBAs in the villages are not usually informed. It may not be easy to access information because they don't know."

"In Bo city there are adverts on the radio but outside the city it is very difficult to get reception or some people don't have access to a radio for example."

"No it is not easy as most people don't have a radio."

Women living in remote areas often have the most limited access to health care and are in the greatest need of help.

"The distance makes it very difficult for women to get access to help. There are many women in hard to reach areas that don't have the access to come to get help."

"The only way to get the treatment is in AWC in Freetown, which is not easy because it is so far and some of them need more than two operations."

"If it wasn't for the distance it would be easy for the information to reach the other women sufferers from women like me and others such as my friends who are now champions for fistula."

Lack of understanding of fistula by women and their communities contributes to this unmet need, as people do not know what help women need and how they can access it.

"Most women don't know much about fistula so it's difficult to find out about the treatment."

"She got fistula and had the problem for two years 'cos she didn't know about fistula hospitals."

The taboo and stigma surrounding obstetric fistula are a major barrier to women accessing help and treatment. Many interviewees explained how their feelings of shame led them to hide their condition and prevented them from asking for help.

"I know there are many women sick because they are ashamed to disclose they have fistula. This makes it difficult to reach them because they don't know how to get help...they are suffering in silence."

"I know many women who live with fistula in my village but most of them hide it."

"The girls say that because we have this sickness we shall hide."

"For most women getting the treatment is difficult because they isolate themselves."

"There are many people in that village but some are not comfortable to speak openly about it. I met a woman who I was directed to by a friend. I was told she had the condition but when we approached for an interview she denied that she had ever had it. I perceived her odour and then I knew she had been a sufferer but I wasn't going to force her on this occasion if she didn't feel comfortable. I hope to meet her again soon. I also believe there are many other women out there who are not getting the help because they are ashamed."

5. Fistula Champions as PEER Beneficiaries

This section highlights the positive impact of the PEER process on the PRs themselves. By involving the women as researchers, calling them ‘champions’ or ‘specialists’, and ensuring that they were central to the process made the PRs feel empowered. Their participation helped them to network and start building new links. The quotes below are from the discussions with the PRs in the final workshop.

“Before the workshop and research, I thought I was the only one that suffered with fistula but I now know there are many others like me.”

“I felt that the interaction with different people enabled me to talk freely about our fistula condition that I could not do before.”

“I was also able to talk to other women with fistula in a friendly manner as before I didn’t have the confidence to speak freely.”

“I interacted with other women with fistula. I had confidence to talk with them.”

“Other women not affected with fistula said, ‘They were not aware of fistula’ as they never heard of it.”

“What is this fistula you talk of?” Other women asked me “how did you get fistula” and “what is fistula?” I told them that I got fistula during being in labour for five days with TBA, then I was taken to hospital had a caesarean and my baby die.”

“In the first place I was ashamed to explain my problem to others, I only ever thought I was the only one suffering from this sickness called fistula. I thought that when I explained my problem to any one they will gossip or back bite me but this research and workshop has made me realise that I am not alone and that there are others like me and that this process will help other women too.”

Some also spoke about how they spent the money they received for their participation in the PEER.

“Spent her allowance to give to her mum and she received blessings from her.”

“I used money for benefit; I am exposed to new things. My husband had left me but now I can provide for me and my child.”

“I was surprised as I have never had payment of \$50. I used the cash to buy materials for school.”

By the end of the research process the PRs had formed a supportive network amongst themselves. They expressed their desire to maintain the network they had formed and continue working with FORWARD and Haikal or any other Government or non-Government actors. They were confident, eloquent, and true ‘experts’ on fistula in their community.

5.1 Recommendations from Fistula Champions

When asked for their recommendations on how to prevent obstetric fistula and support women and girls affected, the fistula champions came up with the following ideas:

1) Prevention programmes that address ‘man business’, early pregnancy, and child marriage:

“Encourage other girls to delay boyfriends/ pregnancy as long as possible. For the girls who are not pregnant, if you are going to school, continue your reading (studying) as even your boyfriend will run away if you get fistula.”

“Girls should get married after finishing studies not before that.”

“To stop fistula: girls need to use family planning so that girls will not be pregnant at a young age.”

2) Increase access to quality health services:

“It is very hard to access the health centres so the government should build a health centre for every village.”

“Let other girls avoid giving birth with the TBAs and build health centres in every village.”

“My advice for people is ‘when women are pregnant, try to go to the nearest health centre.’”

"I advise girls to go to the clinic when they are pregnant, not to the TBA so that if there is a problem during pregnancy, they will easily identify it at the health centre."

"She suggests that the government need to train more doctors. Because not many doctors can do the repairs some of us need the operation 1/2/3rd or even 4th time. But the doctors can only do one type; we have to wait for a specialist doctor to visit for many months. There should be more operations centres."

"We need to have different doctors to repair women at different levels (level 1/2/3 or 4 level)."

"Provide good foreign doctors to provide cures and relief to several women suffering with fistula."

3) Raise awareness about obstetric fistula:

"It is not easy for a woman to suffer with fistula both in their homes and the community. The government should make aware to the people that fistula does exist and get many agencies involved to help stop women suffering."

"It is a plea to government and other humanitarian organisations to raise awareness about treatment and prevention."

4) Provide treatment, support, and rehabilitation for those affected:

"Centres like Haikal are very important."

"Those who are living with fistula, they need support to get treatment and support to make a living after that."

"She wants the government to help them to continue their school or another vocation."

"I would like someone to help me start business."

"It is also important to provide women affected by fistula a petty trading as their situation does not allow hard work like farming."

"Education may be good for younger ones."

5) Work with women who have lived with fistula to strengthen outreach efforts in order to find those suffering in silence:

"They need to do more sensitization so that more women find out about the treatment."

"I would like to take a boat trip to visit other women suffering from fistula."

"I know three women who suffered from fistula including my sister in law. After this workshop, I am planning to go and visit my sister in law to find out more and advise her to come to Haikal."

"One lady tells me that she advocates and tells her friends in the same compound that she has this sickness and that if they know of others please tell me so we can be friends."

"She will talk to women with fistula to encourage them that there is a way to cure. I used to cry a lot every night but I am now feeling better because I now realized that there is a way."

"She told me, she want to continue to fight for women with fistula to be healed."

6. Conclusions and Recommendations

The research methodology had a huge impact on the PEER researchers who were recruited to support the research. Their participation in the research directly impacted on their own lives and enabled them to acquire skills and confidence in communicating their situation to others but also in being able to listen to the situation of other women in similar situations. Many of the women found the supportive network to be very valuable and many expressed the desire to continue this process. The recommendations here are informed by views expressed by the researchers during the data analysis and debriefing sessions as well as issues raised during the interviews with peers.

End child marriage –

This report has shown how fistula is closely associated with child marriage. In Bo, rates of child marriage are particularly high. Women are forced to enter marriage as young as 12. Their bodies are underdeveloped, and so when they become pregnant they are at high risk of developing fistula. Furthermore, as child marriage is associated with poverty, child brides are less likely to be able to pay for health care to prevent or treat fistula. As

highlighted by the fistula champions, without ending this harmful practice, it will be impossible to tackle obstetric fistula.

Relieve women from poverty and economic dependence –

Obstetric fistula can be linked to poverty and a woman's limited capacity to generate an income. The fistula champions in Bo explained that poverty forced them into early marriage, and 'man business' from a young age. Their limited control over resources also reduced their access health care, increasing their risk of developing fistula. Women living with fistula described how their poverty and economic dependence limited their access to repair and support services.

Scholarship schemes would enable young women to stay in school. This would reduce their dependence on men to support them, either through child marriage or 'man business', and indirectly make them less likely to develop fistula. Micro-loans could help women with fistula to kick-start businesses, and help them cover living costs if they want to return to school. This would be a critical enabler for women to reintegrate into their communities.



Haikal Staff, PEER researchers and supervisors

Improve quality of and access to health care –

Despite the Sierra Leone Ministry of Health and Sanitation's introduction of free health care, fistula champions in Bo shared stories of expensive, low quality or non-existent health care.

It is essential to work with local-, national-, and international-level policy makers to ensure that the free health care policy is implemented. This will require an integrated approach. Infrastructure must be upgraded to ensure that women are not barred from reaching medical care because of the state of the roads or limited access to transport. There must also be a substantial investment in the training of health care professionals to increase their diagnostic ability.

Improve quality of and access to care for fistula patients –

There must also be efforts to focus on the care of fistula patients. Obstetric fistula is preventable, and it is unacceptable that women are being turned away from health care facilities and forced to live with the condition for years.

At the national level, investments must be made to ensure that health care professionals can recognise the warning signs of fistula, and treat the condition when it develops. 'Dignity kits', which include sanitary pads, toiletries, incontinence bed mats, towels and clothes, would substantially improve the lives of women living with and suffering from fistula. Rehabilitation and reintegration must be strengthened and become a priority.

Rehabilitate and reintegrate fistula survivors –

Because of the nature of obstetric fistula, and the stigma that surrounds it, treating fistula must be complemented through efforts to rehabilitate and reintegrate women into their communities. The fistula champions described the emotional upset experienced by women with fistula. Many were abandoned by their husbands and families, ostracised by their communities, and blamed for their condition and loss of their children.

Advocacy and awareness-raising will secure more commitment and funding from decision makers to develop resources for rehabilitation and reintegration. Haikal intend to expand capacity of their reintegration programme to accommodate more women. They will also extend the length of their programme. They also have projects helping

women develop livelihoods and extend their education.

End the stigma of obstetric fistula –

The stigma surrounding fistula means that women hide their disability and are reluctant to access help when it is available. Consequently, the true scale of the problem is not recognised by decision makers, so resources remain strained. Ending the stigma surrounding obstetric fistula is a crucial precondition to ending the disability, and caring for survivors.

Stake-holders at all levels must be educated about fistula, its causes, and how it can be prevented. This includes members of rural communities and policy makers at a national level. Creating teaching and learning materials would facilitate this.

Create networks of fistula survivors –

Previously isolated from their peers and communities, the PRs in this study expressed their joy at sharing their experiences with women like themselves. Alongside providing each other with emotional support, they shared information about how to access care. In some cases, they grouped together to overcome challenges. Alongside the personal benefits to members of the networks, this collective voice has the potential to engage the attention of policy makers and to strengthen fistula prevention and treatment.

Civil society organisations can strengthen such networks, enabling women to attend meetings by providing child care or assisting with transport. In the case of this study providing daily sustenance and reimbursing their costs helped remove some of the economic barriers to women attending meetings.

Annex 1 – Sample Interview Questions

Below is a sample of the questions used in the PEER. These questions are about pregnancy and childbirth, and women's experiences of fistula.

Where do you come from?

The other women you interviewed, where are they based? How did you find them?

What do pregnant women and girls do for their pregnancy health check?

Where do pregnant women/girls go when they are in labour? Why?

Were there many other women with fistula in your area or where you interviewed the women?

Tell me a story about a girl/woman you know who suffered (or is suffering) from fistula? How did she get it? What happened to her?

How do women/girls find help to get a treatment? Do they find it easy or difficult? Why?

Are there many girls with fistula who have not received help? Can you give an example or tell a story.

What do girls say about the quality of fistula service available? Tell a story/give an example.

What do you think should be done by people (government or others) to support women affected by fistula?

Annex 2 – Samples of Women's Stories

The complications had begun while she was at the TBA. The baby died in her stomach and she started leaking urine from her vagina. The umbilical cord was hanging from her vagina and the TBA urged her to keep pushing so the baby would come out.

Her relatives then put her in a hammock and walked for seven miles to the nearest health centre where she was told that they could do nothing as the complications required surgery. They had to go to Pujehun hospital further four miles away with the baby's head and cord hanging. They went to Pujehun by a vehicle two hours away. On arrival at the hospital the nurses called a doctor immediately to conduct surgery. The doctor arrived within ten minutes of her arriving at the hospital.

She felt no pain and couldn't feel her legs. She was moved to a hospital bed and this time she was unconscious. When she woke from unconsciousness she saw her son in a big bowl that where her mother had placed the baby. She said: 'When I saw my dead son and my heart just bled. My mother was shedding tears for the loss but I couldn't just cry as I had no emotion of what had just happened to me.'

Her story has a sad beginning but then she met a man and entered into a relationship with him. She told him 'I suffered from this condition called fistula which I got during long child birth of four days where I lost my baby and I have constant leakage. If you could have me in this condition then we can engaged in relationship.'

He promised her he would work with her to find a solution. In 2003 they heard about AWC on the radio. Her partner came home one day with some news of some doctors who can help women who are ashamed because of the condition that leaves them unable to control their urine or faeces. She said 'to God be the glory for sending a man who loves me unconditionally'.

They went to the clinic and she received successful treatment. She adopted her partner's children and they have been together for more than 12 years. She told me, she wants to continue to fight for women with fistula to be healed.

My step sister got pregnant by her boyfriend. She was in labour for two days at the hospital. Then they transferred her to Gondama hospital (far away) by public transport. They operated on her as soon as she arrived, and she had a still birth. She developed fistula immediately after the operation.

The health care professionals returned her to her village, without telling her how to access help. She lived with fistula for two years. She was isolated by her friends and family members. Every morning, she went far away from her house to be alone. Then she decided to kill herself, but fortunately her friend persuaded her not to. AWC staff come to their village every three months, but because she was hiding herself, most people didn't know about her situation.

One day her friend found out about AWC and she told them about her friend's situation. So they took her to Freetown and she underwent a successful operation. She is fine now. She is doing petty trading and married with one child.

I would like to tell my story. I was in labour for six days at home as it was hard to get to the hospital because it was war time. But my husband decided to take me to Pujehun hospital. On the way, there was an ambush and my husband was killed. A soldier took me to the hospital.

When I got to the hospital, they called the doctor, the baby was dead inside but its arms came out first. So I had an operation, but during the operation, the doctor made a mistake and I developed fistula. There was no treatment available because of the war. I lived with it for six years.

After that, I heard on the radio about fistula so I went to Gondama hospital and was sent to AWC. I got treatment and have felt much better in the last four years. I live with my sister and farm rice, cassava, and so on. I gave most of the money I received in the PEER workshop to my sister to thank her for looking after me all these years.

After taking part in the PEER, I was able to talk to other women with fistula in a friendly manner as before I didn't have the confidence before to speak freely. Before the workshop and research I thought I was the only one that suffered with fistula but I now know there are many others like me. I interacted with other women with fistula. I had confidence to talk with them.

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PEER study participants celebrate the first International Day to End Obstetric Fistula