

## **Living with obstetric fistula: Perspectives of obstetric fistula survivors in Zimbabwe**

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### **Abstract**

**Background:** Obstetric fistula is an abnormal connection between the vagina and the bladder or the rectum, a usual result of prolonged obstructed labour. It results in uncontrollable urine and/or faeces leakage. Documentation of life experiences of women affected helps inform programming.

**Methods:** A qualitative research was conducted with participants who were attending a fistula repair camp at Chinhoyi Provincial Hospital, Zimbabwe. Participants were interviewed and the interviews recorded verbatim, transcribed and translated into English. Quality checks on translation were done. Scripts were analyzed using NVIVO 10 for demographic characteristics, circumstances surrounding fistula occurrence, life experiences living with obstetric fistula and participants' opinion regarding the fistula repair program in Zimbabwe.

**Results:** Twenty six women aged between 17 and 76 years were enrolled. Most started having sex and got pregnant while still below the age of 24. Almost all participants got into labor at home and labored for at least two days at home but all ended up at hospital. More than half of the respondents lost the baby. Fourteen women developed fistula in less than 5 years prior to this study. All women reported physical, mental, psycho-social and economic challenges as a result of living with obstetric fistula.

**Conclusions:** Women in this study were affected by fistula while still young. Some of them went on to live long periods of time with the fistula problem. Access to fistula repair should be improved in order to shorten the suffering of the fistula survivors.

**Key Words:** Life experiences, fistula survivors, Zimbabwe

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### **I. INTRODUCTION**

The World Health Organization (WHO) estimates that between 50,000 and 100,000 new cases of obstetric fistula occur worldwide annually<sup>(1)</sup>. Obstetric fistula is an abnormal connection between the vagina and either the bladder or the rectum mainly as a result of prolonged and obstructed labour<sup>(1)</sup>. There is a great disparity in the burden of obstetric fistula between the developed world and developing countries. In the developed countries, obstetric fistula was eradicated decades ago<sup>(2)</sup> with the last fistula hospital in New York closed about a century ago<sup>(2)</sup>. Yet in Africa girls and women continue to endure lives of shame and untold suffering due to this condition<sup>(2)</sup>. The persistence of new cases of obstetric fistula in developing countries signifies inadequate and weak health systems<sup>(1-3)</sup>. In Sub-Saharan Africa and Asia, the incidence of obstetric fistula was estimated to be 1.2 per 1000 women of reproductive age (15-49), from a systematic review of literature conducted by Adel et al<sup>(4)</sup>.

Most literature on obstetric fistula focus on quantitative aspects of the problem like prevalence and incidence<sup>(5)</sup>. Documentation of life experiences of women affected by the problem of fistula helps in understanding obstetric fistula from the view point of affected women<sup>(6)</sup>.

This paper seeks to examine and document experiences of obstetric fistula survivors in Zimbabwe.

Results from this article will assist health managers, policy makers in health and community leaders in designing and strengthening programs for survivors of obstetric fistula basing on verbalized experiences of affected women by the affected women.

This paper is one in a series of papers on documenting experiences of women affected by obstetric fistula in Zimbabwe. The current study explored the day-to-day life experiences of women living with obstetric fistula and to assess their demographic characteristics.

## II. MATERIALS AND METHODS

A qualitative research was conducted at Chinhoyi Provincial Hospital. Chinhoyi Provincial Hospital is the obstetric fistula repair center for Zimbabwe. Surgical repair camps are held on a quarterly basis and target to repair 60 women per quarter. The center was established in August 2015 and more than 700 women have had their obstetric fistula repaired by end of 2019.

**Study Design:** Qualitative retrospective cohort study.

**Study Location:** Chinhoyi Provincial hospital.

**Study Duration:** December 7, 2019 to December 19, 2019.

**Sample size:** 26 participants.

**Subjects & selection method:** All women were first given information about the study verbally then printed content, at least one day before the actual recruitment process. This was done to afford the women enough time to read and critically think about whether to accept participation or not. The women were also given consent forms to read and understand. On the day of recruitment each woman who opted in had a one-on-one semi structured in-depth interview with the principal investigator or research assistant. A research assistant had been intensely trained on the recruitment process and the interview process. The consenting process involved explaining the whole study to the individual participant, attending to her questions and explaining the interview process. Attention was given to the explanation of the need for audio recording and photography so that the participants understood and made an informed decision whether to participate or not.

A total of 26 women were recruited and interviewed out of the 29 women who had come for fistula repair. Women living with fistula are identified through their local health facilities, social media groups, radio announcements and snow-balling by women who would have undergone repair. The women are put on the line list for surgery and are invited for the camp by the fistula officer, the officer responsible organizing and coordinate the fistula camps. The repair, transport and all other costs are paid for by partners to the Ministry of Health and Child Care, United Nations Population Fund (UNFPA) and Women and Health Alliance International (WAHA). A full camp caters for 60 women but the camp is divided into two phases to allow decongestion of the admitting wards, each phase taking in 30 women.

**Inclusion criteria:** The inclusion criteria considered consenting women who had come for obstetric fistula repair at Chinhoyi Provincial Hospital for the 4<sup>th</sup> quarter camp of 2019.

**Exclusion criteria:** The exclusion criteria was 'women who fit the inclusion criteria but did not give consent to be enrolled into the study'

**Procedure methodology:** All women were first given information about the study verbally then printed content, at least one day before the actual recruitment process. This was done to afford the women enough time to read and critically think about whether to accept participation or not. The women were also given consent forms to read and understand. On the day of recruitment each woman who opted in had a one-on-one semi structured in-depth interview with the principal investigator or research assistant. A research assistant had been intensely trained on the recruitment process and the interview process. The consenting process involved explaining the whole study to the individual participant, attending to her questions and explaining the interview process. Attention was given to the explanation of the need for audio recording and photography so that the participants understood and made an informed decision whether to participate or not.

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A semi-structured interview guide was used to guide interviews. The first part of the interview guide prompted for sociodemographic information which is useful in assessing circumstances associated with occurrence of obstetric fistula like distance to nearest health facility, place where participant labored and age of participant. This part was captured using a standard data collection tool.

The second part of the interview involved interviews with the participants about the pregnancy which resulted in the fistula formation and the circumstances around labour and delivery including fistula formation. The interview proceeded with discussion around the life of the women in the face of having an obstetric fistula, physical, psychosocial and economic experiences. The interviews ended with asking the women's perspectives of the obstetric fistula repair program and their suggestions for strengthening the program.

### **Ethical considerations**

This paper is part of a larger study which was endorsed by the Ministry of Health and Child Care, Zimbabwe, approved by the Africa University Research Ethics Committee and the Medical Research Council of Zimbabwe (MRCZ number: A/2525). The study site – Chinhoyi Provincial hospital, also approved the study. All study participants gave written informed consent for participation in the study, audio recording and photography for the purposes of the study. The transcripts did not bear the participant names and confidentiality was maintained.

### **Data analysis**

The demographic data were entered, cleaned and analyzed using the statistical package for social sciences (SPSS) version 21 (IBM Corp, Armonk, NY). These data are presented through charts, graphs and narratives.

Qualitative data from the interview recordings were transcribed into written scripts and translated into English. Services of a professional translator were sought. The translator back-translated 5 randomly chosen transcripts into Shona to check whether translation was done properly and to check that meaning and quality of the interviews were not lost during translation.

The scripts were analyzed using NVIVO 10 (QSR International, 2013) software for qualitative data. The process of data analysis was guided by the Ecological frame work. Thematic areas were identified from the theoretical framework and used to guide the in-depth interviews. These are i) personal health consequences i.e. physical, emotional, psychological and economical experiences, ii) interpersonal consequences i.e. relational and emotional transactions with significant others, community transactions and iii) policy level interface. On the wider construct of policy level transactions, only suggestions regarding the obstetric fistula repair program were discussed. Data analysis followed these thematic areas. It must be noted that most of the data obtained were from the intrapersonal and the interpersonal constructs.

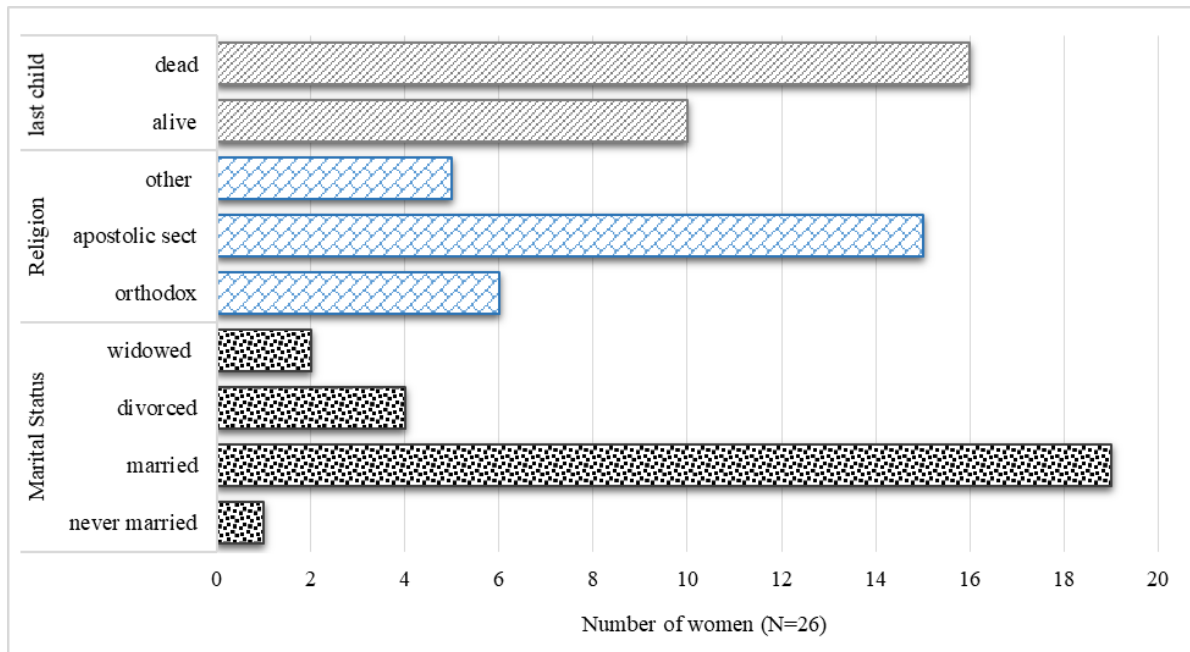
## **III. RESULTS**

### **Demographic characteristic of study participants**

A total of 29 women came for this second phase of the camp. All 29 women were offered the opportunity to participate in the study but three were later discovered not to meet the inclusion criteria, two had third degree vaginal tears and one had stress incontinence. So a total of 26 women were recruited into the study. The median age of study participants was 34 years (Q1: 27, Q3:39). The median age at sexual debut was 18 years (Q1:17, Q3: 20) and by age 23, about seventy-five percent of the study participants had had their first pregnancy.

**Table 1:** Participants' ages at first sexual activity and first delivery

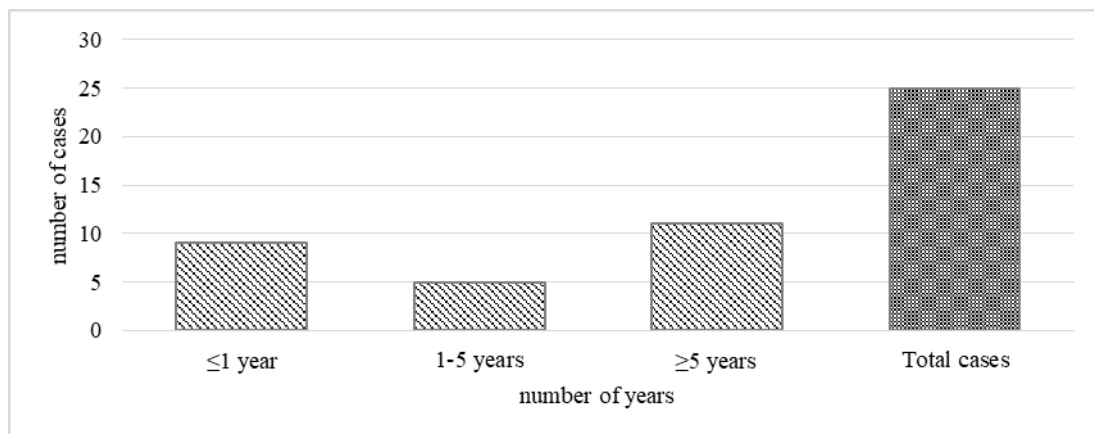
Age	Number of women	
	First sexual contact (n)	First pregnancy (n)
15	4	1
16	0	2
17	6	4
18	3	2
19	3	6
20	2	1
22	1	1
23	0	1
24	1	1
25	1	3
28	2	1
37	1	1
Total	24	24



**Figure 1:** Summary of selected demographic characteristics of study participants, Chinhoyi Provincial Hospital, 2019

As illustrated by Figure 1, most of the women were married and their last child had died. The majority of the women belonged to the apostolic faith sect (Figure 1). The majority of the women in this study (75%) attained at least secondary level of education and were married. Almost all participants stayed in rural areas and lived more than 5 kilometers from the nearest health facility.

Majority (20/24) of women in this study first had sex by age 24 as well as their first pregnancy or first delivery by that age (Table 1). Most (14/26) of the women in this study lost their child from the pregnancy which resulted in them getting obstetric fistula. The majority (14) had a fistula occurring within the past five years with 9 of these having had their fistula within the past year. Of those who had lived with fistula problem, one (1) woman had had fistula for fifty-seven (57) years (Figure 2).



**Figure 2:** Period participant has been living with obstetric fistula

**Experiences of how the women developed obstetric fistula**

Almost all the women in this study got into labor at home and spent a minimum of two days in labor at home. Some only went to health facilities after noticing a complication like vaginal bleeding, fitting and swelling of the body. In most cases it was not the woman herself who decided whether she should go to the hospital or not, but either her parents/parents-in-law or church leaders. S10 (pseudo participant name) had this to say regarding the circumstances surrounding fistula occurrence:

‘I had my first pregnancy at 17 and registered it with the local clinic. At 7 months I was sent to my maternal home so as to deliver under the care of my maternal relatives as per our tradition. I told them that I

needed to go to the hospital at 9 months but no one cared about me so I stayed home. I started having labour pains at home and labored for a whole week at home. Then my body started swelling. It is only after they noticed the swelling that my aunt talked about taking me to hospital. I was taken to the local clinic which referred me to the district hospital. At the district hospital I was transferred to the provincial hospital immediately. At the provincial hospital I had an operation to take out the babies. Twin boys were delivered but I did not even see them. They came out dead. And I was only told that they were boys. I stayed a full month at Gweru provincial hospital. I was then referred to the central hospital in Bulawayo for a specialist doctor but I did not see the specialist, he was not available. I then came back and went home.'

Another factor which came out is the issue of religion. Women who belonged to the apostolic sects reported that they were not allowed to seek medical care but were only allowed to be attended to by religious birth attendants. Even those women from sects who do not totally object to medical care said their first option was religious care, only using medical care as the last choice. Some women would spend up to 5 days laboring at the religious shrines under the care of religious birth attendants like S12:

'I think the fact that I got married early, and the baby was too big and also the church policy that we should not seek medical care contributed to the occurrence of this problem. I think if I were going to hospital I should not have gotten this problem. I actually blame the church for not allowing us to go to hospital. I did not even register my pregnancy at the hospital. The baby was too big that it was pushing my heart up and my legs were swollen so much. Instead of the baby coming down when I was due, it was pushing up. I was at the waiting shelter at the church birth-attendant with many others.'

### **Experiences of living with an obstetric fistula problem**

Women recited their experiences while living with the obstetric fistula problem which they said affected every aspect of their lives. Obstetric fistula negatively impacted their physical, social, relational, emotional and psychological facets of life. The word cloud (Fig 3) illustrates that fistula was the most commonly mentioned word by the women. The high word frequency is attributed to the point that all the participants had obstetric fistula. Living with obstetric fistula presented a wide array of problems for the women and it was clear that most women had visited a hospital at some point in time because of that condition.

#### ***Physical consequences***

The continuous wetness due to leakage of urine led to excoriations of the genitals and in some cases, thighs as S18 narrated:

'I used old cloths in order to cope with the urine flow. I was always wet and very uncomfortable. The wetness caused itchiness and sores on my thighs. At times the lesions became painful deep wounds.'

This resulted in the women limiting walking exercises as it would worsen the sores. Some women reported frequent urinary tract infections. S19 had this to say concerning physical consequences of fistula:

'My vulva was bruised because of the continuous wetness. I stopped going to church or any other gatherings because I could not walk because of the wounds on my vulva and thighs.'

#### ***Psychological and emotional consequences***

All the women in this study narrated psychological and emotional misery while living with fistula. Most women recited long periods stretching up to years of mental torture. These feelings came from the intrapersonal, interpersonal and community interactions in the face of fistula problem. Almost all the women reported thinking death was an easier option at some stage in their lives due to psychological trauma from the problem. One of them (S07) had this to say:

'This life is not easy, I usually contemplate suicide. The only thing which makes me go on with life is the belief that this is my fate from God and I have to accept it. My husband left me in 2014 so now I am a single mother.'

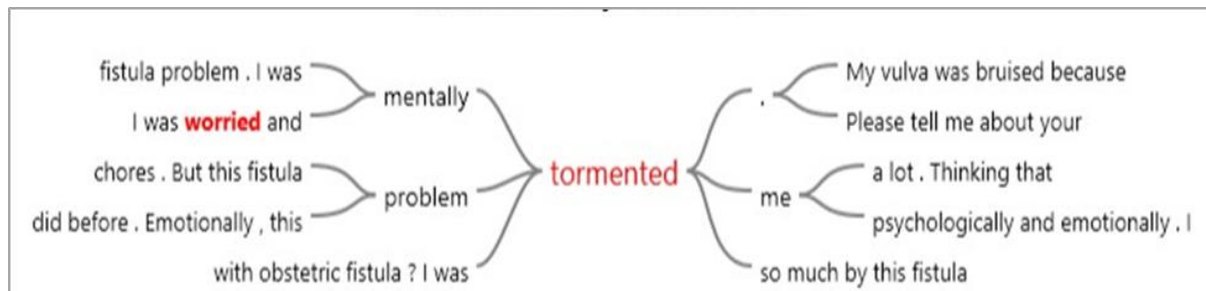


**Figure 3:** Tag-cloud presentation of most frequently spoken words while women narrated their experiences living with obstetric fistula

Some of the women recovered fast from the psychological trauma and looked up to supreme powers (God) to do His will with their lives. The strong belief in God helped them to accept the problem, minimize worry and looked for ways to cope with their problem. However, other women reported being blamed for developing obstetric fistula by the church. S11 said:

‘At church I was being blamed that I had grave sins which led me to develop the fistula. Even the community, because they are mostly from our apostolic sect, they blamed me of having many sins which led me developing this problem.’

The overall psychological consequences of living with a fistula problem on the lives of the study participants are illustrated in figure 4.



**Figure 4:** Psychological consequences of living with obstetric fistula on survivors

### Relational consequences

Half of the women in the study reported that their relationships with their husbands/spouses were negatively affected with half of them being divorced or sent back to their parents as the women would put it across. Some were not officially divorced but were in marriages just for convenience. Here is what S21 said about here staying in her marriage:

‘My husband initially accepted and supported me. He said he valued my presence in his life. But after a year, he told me he could not live with me with this fistula problem. My husband got another wife and had a child with her. He neglected me and lived with his second wife. They had a child but the wife died and their child died also. First I thought of committing suicide but thought of my children. I had to take care of my children. My husband was no longer supporting my children so I had to stay strong for them.’

Others were getting support from their spouses but in-laws did not support their marriages. This is what S11 said about what she experienced with people close to her due to having obstetric fistula:

‘Because of this fistula problem, I spent most of the time indoors because the smell of urine was too much to be around people. I could not do much work. My in-laws did not support me or like me because of the fistula problem. Also my husband started having relationships with other women and eventually left me. But there is only one sister-in-law who supported me so much. This problem is like a curse, everyone leaves you and

no one wants to be associated with you. Loneliness and boredom is your daily bread. I even contemplated suicide.'

Almost half (12 of the 26 women) told of loving support from their husbands. But all the women said their in-laws lacked support and at times openly expressed disinterest and hatred towards the women because of the obstetric fistula they were living with. The word cloud on relationships shows that relatives were mentioned most by the women [Figure 4]. Further follow-up on participants who mentioned "relatives" associated relatives with negative experiences like;- relatives wanted the husband to divorce the participant, relatives supported the husband to take another wife and relatives said it was black magic from the study participant's parental home which caused the fistula problem.



**Figure 5:** Most frequently spoken words while women narrated how living with obstetric fistula affected their inter-personal relationships

A closer look at how exactly the relationship between women living with obstetric fistula and relatives were affected, S07 said:

'My husband supported me very much but my in-laws were not happy at all with my problem. They would tell me openly that they did not like the smell of urine following me always. It was painful but I had to accept it because it was not my will to have such a problem. I had to tolerate it since I was staying at their home. But it was tormenting.'

#### ***Economic consequences***

On the economic front, women who were previously engaged in public activities (outside their homes) reported much disruption in productivity due to the occurrence of the fistula problem. Said S15:

'I am a hairdresser but after developing the fistula problem I could not go to work. My urine was flowing uncontrollably so I could not go to work. Only a few clients came to me at home.'

But those whose economic activities were home-based and those working in wet environments reported being able to continue their activities with minimal disruptions. S18 said:

'I am a gold-panner. I continued with gold panning and I did not face much problems as the urine would flow in the water and no one would see that I was wetting myself. That was an advantage I had.'

Asked about how the women got to know about the fistula repair program and their recommendations regarding the program, participants said they heard about it mainly through friends who would had had the similar problem but had been repaired. They also reported getting messages on social media platforms and a few had heard from health workers and radio broadcasts.

## **IV. DISCUSSION**

From the 29 women who had come for fistula repair at Chinhoyi Provincial Hospital during the December 2019 camp, a total of 26 women were recruited for the study. The ages of the women were varied, the median age was 34 while the youngest was 17 and the oldest was 76 years. In tandem with the general findings from the Zimbabwe Demographic and Health Survey (ZDHS) of 2015, the median age at first sexual encounter was 18 years<sup>(7)</sup>. Although this is a relatively mature age to start sexual activity as compared to findings from other studies<sup>(8,9)</sup>, the majority of these women became pregnant within a year after their first sex. A quarter of the women got pregnant by age 19 while three quarters had their first pregnancy by age twenty-four. This

finding may also be a pointer to why these women developed fistula. It has been identified from literature that early age at first pregnancy increased the risk of developing fistula<sup>(1,2,10)</sup>. It may also be questioned that access to contraception for these young women is limited.

Half (13/26) of the women attended secondary level of education. This proportion is lower than the proportion in the general population where about 73% of women attend secondary level of education in Zimbabwe<sup>(7)</sup>. In this study it was noted that most of the women had low educational levels. This finding is similar to findings from a study done in Malawi<sup>(11)</sup>. Majority (20 out of 26) of the women were married, this finding is unlike in many other studies on experiences of obstetric fistula where most of the women were divorced<sup>(5,12)</sup>. But a closer look at the quality of relationships reveals desperation and low self-esteem on the part of the women affected. Another demographic characteristic of note is that of religion, fourteen (14) of the 26 women were from the apostolic sect. There are some religious sects in Zimbabwe known for objecting and resisting modern medical care and opt for their members to be attended to by their religious healers and even religious birth attendants<sup>(13)</sup>.

Of note is that even those sects which do not totally object to medical care, the first choice for place of treatment is religious care. Participants got blamed for developing fistula, this is a common finding in other studies where relatives and the church thought and told the survivors that they were being punished for their sins<sup>(14)</sup>. This thinking may result in low self-esteem and self-worthiness to the fistula survivor and add to tendencies of suicide. On top of stigmatization by the community and relatives, some of the women would self-stigmatize and self-isolate. This occurs when the women lacks confidence in socializing due to an internalized belief that people do not like to be associated with them so they stay away from people.

Obstetric fistula is usually an outcome of prolonged obstructed labour. Some of the women in this study narrated long delays in accessing health facilities for appropriate obstetric care due to living far away from health facilities and lack of transport to the health facilities. This finding was also noted in Eretria<sup>(15)</sup>. All, except one, women got in labour either at home or at religious shrines and more than half developed obstetric fistula during tender ages of adolescence below 24 years. Early pregnancy is known to be a contributing factor leading to development of obstetric fistula<sup>(16,17)</sup>. All these factors have been pointed out in literature to increase the risk of developing obstetric fistula<sup>(18-20)</sup>.

To most of the women, obstetric fistula occurrence presented a double tragedy of uncontrolled leakage of urine/stool and loss of a baby. Sixteen (16 out of 26) women lost their babies from the pregnancies which ended up in them developing fistula. Obstetric fistula affected all spheres of life for the survivors, this finding is tandem with results from other studies<sup>(21)</sup>.

Unlike developed countries where fistula has been eradicated<sup>(3,22)</sup>, this study noted that more than half of the women (15 out of 26) developed obstetric fistula less than 5 years ago, with more than a third (9 women) having developed obstetric fistula in the last 12 months. This finding points to the continuing need for health education for the prevention of fistula, and clinical services for its repair. Eleven (11/26) women had been staying with fistula for more than 5 years prior to this study with one woman having developed the problem 57 years ago.

Only eight (8) women from the study participants sought medical treatment for their obstetric fistula prior to their attending the repair camp they had come for. All except three women, tried looking for remedy of the problem from religious and traditional healers. But all ended up at hospital. This may be used as an opportunity window. Even though the women had strong beliefs in church doctrine of not subscribing to modern medicine, they at one point sought medical attention anyway. So there is possibility of them accessing health care before the development of the fistula problem.

## V. CONCLUSION

Participants of this study developed obstetric fistula below the age of 24 years. The majority of the participants resided in rural areas far from health facilities and had transport challenges. The fistula problem affected almost all aspects of their lives resulting in physical, emotional, psychosocial and economical challenges. These experiences coupled with lack of support from spouses, relatives and the community led to perceptions of self-worthlessness, low esteem and suicidal tendencies in others. Some women believed that their fistula was actually caused by evil spirits, witchcraft and black magic. Most of the women in this study are of the apostolic sect. They lacked knowledge of obstetric fistula as a medical condition. The communities from where the study participants may also be lacking information on obstetric fistula resulting in them not supporting the affected women.

### Recommendations

It is recommended to strengthen and expand sexual and reproductive health and rights information and education to needy (rural, remote and hard to reach) communities. This will empower adolescents and young women to get pregnant when they want to and prevent incidental pregnancies in young girls and women. It is



also recommended for the government to engage religious leaders and women in those church groups regarding allowing their members to access medical care.

It is also recommended that the Ministry of Health and Child Care continues to strengthen its reproductive health services especially the basic emergency obstetric and neonatal care (BEmONC) program. BEmONC has been noted and recommended as one of the low-cost-high-impact interventions in preventing maternal mortality and morbidity, obstetric fistula included by the World Health Organization.

This study also recommends that the MoHCC publicizes and disseminates information on the fistula repair program to help affected women understand that help is available and informs them where and when they can access the help. Information about the fistula problem needs to be disseminated to community leaders, religious leaders and all stakeholders so that they know and appreciate the problem so as to demystify myths and misconceptions surrounding the condition and to advocate for social and moral support for affected women in the communities considering that some women lacked support from their husbands/spouses, family members and the community at large.

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