Consequences of Obstetric Fistula: Lived Experiences of Fistula Patient Women in Jimma University Medical Center, Southwest Ethiopia.

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Research

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Abstract

**Background:** Women in low-income countries, including Ethiopia, experience delays in seeking treatment and suffer from obstetric fistula and its consequences. To assess the consequences of obstetric fistula among women who were patient of the problem in Jimma University Medical Center, Southwest Ethiopia.

**Methods:** An exploratory study was conducted among 24 women receiving obstetric fistula treatment from April 01-30, 2019 at Jimma University Medical Centre. Data were collected by in-depth interviews. Data analysis was done by using thematic framework analysis.

**Results:** Most women with obstetric fistula face various physical challenges such as pain, body weakness, and numbness of legs. They also face various psychosocial problems such as humiliation, stigma, and discrimination, inability to participate in social events, divorce, stress, depression, and suicidal ideation.

**Conclusion:** Obstetric fistula exerts tremendous physical, emotional, financial, and social trauma on those affected. So, strengthening the existing fistula care and integrate psycho-social and economic support is very crucial.

What Is Already Known On This Subject?

Obstetric fistula is one of the most serious and tragic childbirth injuries. A hole between the birth canal and bladder and/or rectum is caused by prolonged, obstructed labor without access to timely, high-quality medical treatment. It leaves women leaking urine, feces, or both, and often leads to chronic medical problems, depression, social isolation, and deepening poverty.

What do the results of this study add?

This qualitative finding shows obstetric fistula exert tremendous physical, emotional, financial, and social trauma on those affected. A majority also experienced socio-economic problems of treatment costs and not engaging in income-generating activities. Most of them keep themselves hide (secrete) and praying as coping strategies rather than seeking treatment.

What are the implications of these findings for clinical practice and/or further research?

The result of this study will help policymakers, program managers, coordinators, service providers, and as well as other stakeholders to minimize the consequences of the obstetric fistula before and even after surgical repair.


**Background**

Obstetric fistula is a significant cause of maternal morbidity sustained by women of all ages due to prolonged obstructed labor and the majority, 78–93%, ended up in stillbirth. The exact prevalence of Obstetric fistula is difficult to estimate due to different factors. Among these are: house survey of all populations are difficult, families may hide the patient during the survey because of the misconception on obstetrics fistula in the population. In Ethiopia, the prevalence varies from 1.5 to 10.6 per 1000 women who ever gave birth and less than one percent of women report that they have experienced obstetric fistula as shown by the Ethiopian Demographic and Health Survey (EDHS) of 2016. (Survey, 2016)

In Ethiopia, women in the rural areas suffer the biggest burden of obstetric fistula (prevalence rate of 21.2%), nearly four times as compared to women in urban areas (prevalence rate of 5.4%). In the country, the prevalence is particularly higher among adolescent pregnancy, where it is as high as 29% among those having first birth below 15 years and 19.4% among those having first birth between 15 and 19 years of age. It is also a common problem in uneducated and unemployed women and is directly linked to poverty, income inequality, gender disparities. (Bellows, no date)

Though obstetric fistula is both preventable and treatable, women in low-income countries experience delays in seeking repair due to several factors, including lack of awareness of their condition as well as the potential for treatment, resources necessary for seeking care, lack of skilled fistula surgeons, and long hospital waiting times. (Bellows, no date)

Women with obstetric fistula are often left with chronic leakage of urine and feces with a foul odor. As a result, they usually are abandoned by their husbands and family as well neglected by the community, which in turn will result in various psychosocial complications. Without treatment, the patient prospects for work and family life usually get disrupted. (Harms, 2012) Obstetric fistula patients suffer from the consequences of the disease before and even after surgical repair. Even though the primary treatment of obstetric fistula is the closure of the fistula, this will not treat the social, economic, and psychological consequences of the disease. (Kimani, Ogutu, and Kibe, 2014) Also, obstetric fistula patients usually have significantly higher symptoms of depression, post-traumatic stress disorders, somatic complaints, and maladaptive coping, significantly lower social support compared to other gynecologic patients. (Symptoms, Obstetric, and Patients, 2016)

Jimma University Medical Center (JUMC), the former Jimma University Specialized Hospital, has been providing obstetric fistula treatment and prevention since 2010. Since then, it has been frequently observed that obstetric fistula patients are presenting late for treatment and some are not happy to go home after treatment. This may indicate that they are having different psycho-social and economic problems. However, the existing studies are limited to counting the number of fistula cases, and qualitative studies addressing the consequences of obstetric fistula are very scarce. Hence, this study aimed to qualitatively explore the physical, social and economic consequences, and coping strategies of obstetric fistula women who were managed in Jimma University Medical Center.
Material And Methods

Study setting

This study was conducted at Jimma University Medical Center (JUMC) from April 01–30, 2019. The JUMC was targeted for this study as it is the only hospital providing fistula treatment (surgical repair) in Southwest Ethiopia. The JUMC also has established Uro-gynecology and Reconstructive Surgery Unit in January 2017, which is equipped with 24 inpatient beds and 10 staff, which we hope, will contribute significantly to the treatment of Uro-gynecology problems, including obstetric fistula.

Study design

An exploratory study was conducted. Data were collected by using an in-depth open-ended interview guide on the physical, psychosocial and socio-economic consequences of obstetric fistula, and their coping strategies.

Study population, inclusion, and exclusion criteria

All women coming to JUMC for obstetric fistula treatment during the data collection period, from April 01–30, 2019 were included in the study. Whereas, women, who came to JUMC for fistula treatment during the data collection period, which were due to congenital cases were excluded from the study. Hence, all the 24 women with obstetric fistula coming for treatment in the one-month data collection period were included.

Data collection process

Experienced BSc holders carried out interviews. After receiving thorough training, the data collectors identified women who met the inclusion criteria, explained the purposes of the study, including data collection methods, principles of confidentiality, and arranged for a suitable time for the interviews.

The interviews were conducted in the JUMC fistula Uro-gynecology ward. Qualitative data collection was conducted in local languages (Amharic or Afan Oromoo) based on patient preference. The in-depth interview guide included topics and probing questions and the audio record was used based on the respondents' consent in order not to miss important points.

Data analysis

Data were first transcribed verbatim, in the local languages by carefully and repeatedly listening to the audio recorded; then, translated into English during analysis. Thematic Analyses were used. codes were identified, and those codes with similar connections were organized together to form themes. Whenever new terms emerge, they were included in the codes. Finally, the codes were categorized and themes were established.

Ethical consideration
The proposal was reviewed and approved by the Jimma University Institute of Health Research and Ethical Review Board before the data collection. Permission to conduct the study was also obtained from the JUMC Uro-Gynecology and Reconstructive Surgery (UGRS) Unit. Written, informed, and signed consent was obtained from all respondents before conducting the actual data collection. All women were briefed about the objectives and procedures of the study. They were also informed about the right to refuse at all or stop at any time if not convenient. No, identifiers were included in the data collections; instead, individual codes were used.

Results

Socio-demographic Characteristics

During the data collection period, 24 women affected by fistula came for treatment at JUMC and all were included in the study. The majority (18/24) were in the age range of 20–39 years. The great majority (21/24) were from rural residents and never had any formal education. Nearly half (11/24) had already divorced because of the fistula. Almost all were unemployed as 19 out of 24 were housewives and 4 out of the 24 were daily laborers. About a third (7/24) were primipara mothers.

Contributors for the obstetric fistula

The findings of this study revealed that the possible contributors for the obstetric fistula were multidimensional and included sociocultural, non-use of services during pregnancy and delivery, and the three delays.

Socio-cultural contributors

Early marriage and early childbirth were the main socio-cultural contributors of obstetric fistula in this study. Majority (19/24) were married below 18 years and 15/24 had their first child before 18 years of age. More than half (14/24) were teenagers (13–19) during the time of delivery when the fistula happened.

Non-use of services during pregnancy and childbirth:

Ten out of 24 never had antenatal care (ANC) visits at all, and 9 out of 24 had inadequate ANC (< 4 ANC visits) during their pregnancy for which the fistula had encountered. The main reason for not attending ANC at least once was the unavailability of a nearby health facility (6/10), followed by a lack of information on the importance of ANC (3/10). Similarly, 10 out of 24 gave their birth at home attended by family members of traditional unskilled attendants and the rest went to the health facility after facing a long duration of labor and facing problems. The major reasons were similar to that of ANC, lack of nearby health facility, lack of transportation, and lack of sufficient information about the complications of delivery and problems of home delivery, including the occurrence of fistula.

The three delays:
Delay in making a decision (first delay), not timely reaching the health facility (second delay), and not receiving care timely after reaching facility (third delay) are the known contributors of obstetric complications, including fistula. Likewise, in this study, about 14 out of the 24 made their decision on place of delivery and for the rest either husband (8/24) or the parents (2/24) made decisions. Even for those, who gave birth at a health facility, it was reported that they went after home delivery failed. The other problem was lack of transport; 8 of the 14 facility deliveries traveled on foot and the rest 2 were by traditional caring (‘Karezza’) by people, and for 9 of them it took more than 2 hours to reach the health facility as there is no nearby facility.

As a result, the majority of them (10 out of 14 facility deliveries) reached the health facility after 24 hours of the start of labor, and the rest 4 reached within 18–24 hours. Overall, 21 out of the 24 mothers had prolonged labor (≥ 24 hours). While 6 of the 14 facility deliveries received care and gave birth within one hour of arrival, 4 of the rest had given birth after 12 hours of arrival.

**Experience of obstetric fistula women**

Most of the women (16/24) have lived for five years or more with the obstetric fistula. During this time, most (14/24) had tried treatment (repair by surgery) at some time, 8 of whom had surgery for 3–4 times. Almost all had the perception that they had delayed seeking treatment; the main reasons of which were lack of information about the availability of fistula treatment (repair) (12/24), lack of money or support for treatment (8/24), and the rest 4 waiting for the follow-up appointments. All of them responded that they have got information very recently about the availability of fistula repair at JUMC. The common source of information was media (12/24), followed by health workers working in other health centers/hospitals (referral) (8/24).

**Consequences of obstetric fistula**

**Physical consequences**

The qualitative in-depth interview findings revealed that women affected by obstetric fistula face various physical challenges. The most commonly mentioned were pain (18/24), body weakness (16/24), and numbness of legs (6/24). As a result of these problems, most of them responded that they were not able to carry out routine daily activities such as farming (14/24), difficulty to sit and defecate properly (12/24), and difficulty of washing and changing closes regularly, including putting on underwear (7/24).

A 35 years old mother, who was para 7 and have lived with the fistula for 4 years expressed her filling as,

.....after having the fistula, because of the high pain at the site of the injury and numbness of my left leg, I can't stand and walk; I can't take and eat my food; I can't even take and drink water. I depend only on my family. Painful! Painful!...

**Psycho-social Consequences**
The majority of the respondents reported that they have been affected by a variety of psycho-social problems that range from not participating in social events to the level of suicidal ideation. Most of them responded that because of the foul-smelling fluid leaking continually, they can’t go for recreation with their peers (19/24), no one won’t be with them or near them (stigma and discrimination) (18/24), and can’t attend social events (14/24) such as coffee ceremonies, ‘Ikub,’ “Idir,’ visiting birthing mothers, visiting sick relatives, attending funeral programs (death of relatives), religious ceremonies and wedding ceremonies.

A 26 years old mother, who faced fistula during her first birth at the age of 18 and lived with fistula for 8 years, expressed her feeling by crying as,

“…because of the bad odor leaking, I can’t go with my peers for recreation as before, I can’t go market, even I can’t join my neighbors for coffee. This is what worries me day and night....” She cried.

She continued saying,

...while I am at home, most of the time I hate myself for making my families suffer from carrying for me; I wish dying. Thanks to this hospital now I have some hope.

The other commonly mentioned psychosocial problem was the husband’s rejection or divorce (11/24). As most of them explained, most community members, including husbands, do not know that fistula can happen to any woman and can be repaired. As a result, the husbands reject their wives and look for another healthy woman.

30 years old and par 5 mothers living with the fistula said,

...people like us when we are healthy and beautiful. Let alone other people, even husbands like us when we wash and look clean and beautiful. No one wants to be near to a woman with fistula; she smells...

Another 35 years old and par 6 mothers, living with the fistula for the last 1 year, expressed her feeling by crying as,

“…my husband ignored me saying, ‘I have to look for a healthy and clean woman;’ a girl, my relative, living with me before also left me. I am alone now; I prefer to die rather than living with this foul-smelling leakage and hated by every people.” She cried.

A 36 years old mother, who faced fistula during her first birth at the age of 16, and lived with the fistula for the last 20 years added,

…my husband used to love me very much; he usually says, ‘I can’t live without you;’ I do the same. But, after I faced this problem, he ignored me saying, ‘you are not healthy and no more important to me;’ and he has married and now living with another healthy woman; but, I remained with my problem and he never asked me at least. I am left alone with nothing; I don’t even have a single hen. Thanks to my father that I am alive till today......
The other psycho-social problems reported by about one-third (8/24) of the respondents were being ashamed of looking at other’s hands, considering themselves as dependents on their families, and making family suffer from their care. As a result of this, they suffer from worrying day and night, lack of sleep, stress, and headache. And about one in four (6/24) had a history of the feeling of hopelessness and suicide ideation.

**Socio-economic Consequences**

Women with fistula face either indirect or direct socio-economic problems. The leading socio-economic consequence mentioned by the majority (18/24) was the inability to carry out routine activities to support their family. This is followed by not able to engage in income-generating activities to earn money (e.g. daily laborer, collecting coffee) (14/24) and difficulty to travel to market for trading, selling, or buying, to fulfill the demand of the family members (12/24).

About a third (8/24) reported that the direct cost of treatment and transportation is beyond what they can afford. The same number (8/24) reported that the foul-smelling fluid linkage needs frequent changing of closes, more than four times a day, and frequent washing by using soap of good odor. This incurs the big cost of buying closes and soap regularly, which most of them can’t able to do.

A 35 years old par 7 mothers, who lived for 4 years with the fistula said,

...individuals can get broken bones; but, this can heal and they can start working to earn money to support the family. But, fistula is non-curing and I can’t work to earn money. Simply looking for support from others ...

**Coping strategies for the challenges of obstetric fistula**

About half (12/24) of the women affected with obstetric fistula used keeping themselves at home to make it secrete and hiding not to be seen by others as a coping stray. This is with the fear that their peers will laugh or tease them. A significant number (10/24) used to sit and simply cry and pray to God/Allah as coping strategies.

35 years old women, who were para 1 and have lived with obstetric fistula for 5 years reflected,

...I have already decided not to be seen by any person. I don’t want to be laughed at. So, I never go out of my home even for coffee. I have told to my children to say, ‘she is sleeping’ and send back whenever someone is coming to visit me...

25 years old women, who were para 4 and have lived with obstetric fistula for 1 year added,

...I can’t go market, I can’t go church, I can’t join my peers for social events; because, I don’t want my peers to laugh at me. Why this happened only to me? This is what God has done to me. So, I always keep myself hide and cry to God. Now, God helped me and I am a good hand of Doctors...
61 years old women, who were para 7 and have lived with obstetric fistula for 16 years supplemented,

...my husband ignored me. He took me and left with my family. But, still, I can’t live with them in the same
room, but in a separate room, because of the bad-smelling. When I try to collect coffee, I do it separately; I
can’t go with other people. I can’t visit sick relatives or when relatives die; if I go, I will remain in the kitchen
in order not to be seen by people or not to smell to them.

About a third (8/24) has left their homes and moved to their families (father and mother). The same
number reported that they use multiple closes (wearing 3–4 closes at once as a diaper) to prevent fluid
linkage and changing very frequently. About a fourth (6/24) reported that they use perfumes or soaps
with good odor.

**Discussions**

This study revealed that most of the women affected by obstetric fistula and visited the JUMC during the
data collection period were non-educated and unemployed rural women. This finding has been reported in
previous studies conducted in Ethiopia and abroad. (Jungari and Govind Chauhan, 2015; Sori, Azale and
Gemeda, 2016; Andargie Asrat, 2017). This may indicate that they have low access to information and
services for the prevention of fistula. This will have a programmatic implication of giving special focus to
those women while designing fistula prevention strategies.

In this study, socio-cultural factors such as early marriage and early childbirth were the leading
contributors to the occurrence of obstetric fistula. These have also been reported in previous studies.
(Jungari and Govind Chauhan, 2015; Andargie Asrat, 2017). This might be due to the non-fully growing
pelvis that might have caused prolonged/obstructed labor leading to the occurrence of obstetric fistula.
This will also have a programmatic implication of reducing early marriage and early childbirth as long
term interventions.

Non-follow-up or inadequate follow-up of ANC during pregnancy and giving birth at home attended by
unskilled professionals were among the potential contributors to the obstetric fistula. Low awareness,
lack of nearby health facilities, and the problem of transportation were identified as the root causes for
the non-use of the services. Similarly, the three delays (especially the first and second) have contributed
to the occurrence of the obstetric fistula. These problems have also been reported in previous studies.
(Jungari and Govind Chauhan, 2015; Andargie Asrat, 2017). These all point to the importance of raising
awareness among the community in general and women in particular about the importance of ANC
follow up, facility delivery, and timely decision making and action. Improving access to health services
and transportation (ambulances) may also be considered as a long-term strategy.

This study revealed that most women with fistula face various physical challenges such as pain, body
weakness, and numbness of legs, and as a result of which they usually face problems of carrying out
their routine activities. These problems have also been reported in other studies before. (Tafesse et al.,
2006; Ahmed and Holtz, 2007; Bashah, Worku, and Mengistu, 2018). This will imply the community-based
promotion of early fistula care so that the patient will get relief from the physical challenges and engage in their daily activities.

This study also found that majority of the women affected with fistula face various psychosocial problems. These include stigma and discrimination, inability to participate in social/community events, divorce, stress, headache, depression, and suicidal ideation. Previous studies conducted in Ethiopia and abroad have also witnessed similar psychosocial consequences of obstetric fistula. (Tafesse et al., 2006; Ahmed and Holtz, 2007; Nweke and Igwe, 2017; Bashah, Worku and Mengistu, 2018). These indicated the need for the integration of behavioral interventions, counseling, and psycho-social support with the fistula care both at the community and facility levels. 

This study revealed that women with obstetric fistula face the direct treatment costs as well as the indirect costs, opportunity costs of being unable to engage in income generation activities that have a significant impact on their socio-economy at the individual as well as family levels. This finding is also consistent with previous studies. (Ahmed and Holtz, 2007; Bashah, Worku, and Mengistu, 2018). Hence, it is very relevant to consider for support of the patient’ treatment and other costs by either exemption of treatment fee or financial assistance till they get back to their routine life, particularly the poor rural women. 

This study found that most women affected by the physical, psychosocial, and/or economic consequences of obstetric fistula usually use keeping it secrete (hiding) and leaving their husband, and moving to their parents’ home (mother and father) rather than seeking treatment early and sharing their worries with others. This is also reported in other previous studies. (Bashah, Worku and Mengistu, 2018). This might be due to the wrong perception that fistula can be treated and the women can get curried. This suggests the need for strong community mobilization and awareness creation interventions.

**Conclusions**

The majority of the obstetric fistula patient face various physical challenges such as pain, body weakness, and numbness of legs, and as a result of which they usually face problems of carrying out their routine activities. They also face various psychosocial problems such as humiliation, stigma, and discrimination, inability to participate in social events, divorce, stress, headache, depression, and suicidal ideation. The majority also experienced socio-economic problems of treatment costs and not engaging in income-generating activities. Most of them keep themselves hide (secrete) and praying as coping strategies rather than seeking treatment.

Awareness creation interventions at the community and facility levels on the prevention of fistula and clarifying misconception about fistula that it is treatable and curable need to be in place. Strengthen the existing fistula care at JUMC and integrate psycho-social and economic support as per the need is also crucial. Designing long-term strategies to address the contributors, increase access to and utilization of maternal health care during pregnancy and delivery, access to transportation, and reduce socio-cultural contributors like early marriage and early pregnancies are required.
Abbreviations

ANC: Antenatal care
EDHS: Ethiopian Demographic and Health Survey
JUMC: Jimma University Medical Center
UGRS: Uro-Gynecology and Reconstructive Surgery
UNFPA: United Nations Population Fund

Declarations

Ethics approval and consent to participate

Ethical approval and use of these evaluation data were approved by Institutional Review Board of the Institute of Health, Jimma University. Reference number IRB00090/2020, and date 01/07/2020. Written consent was obtained from each respondent. Data collectors-maintained confidentiality through excluding names or any other personal identifiers from data collection sheets and reports.

Consent for publication

No individual's details, images, or video are included such that consent to publish is not applicable.

Availability of data and material

The Evaluation data will be available upon request. Requests can be sent to zerihu.hordofa@ju.edu.et.

Competing interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Authors' contributions
ZA conceptualized and designed the study and conducted the study. DA, GT, and AB wrote the first draft. ZA, GT, and AB drafted the final manuscript, and all authors reviewed and approved the manuscript.

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