International Journal of Women's Health

Dovepress

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ORIGINAL RESEARCH

Understanding Healthcare-Seeking Pathways and Dilemmas Among Women with Obstetric Fistulas in Ethiopia: A Qualitative Inquiry

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Background: Obstetric fistula is a public health problem with a damaging effect on the health of women around the world. The path to medical care is an integral part of women's experience of illness that may have an impact on their health. Studies have addressed the experiences of patients after fistula repair, but fistula victims' care-seeking pathways and dilemmas are still poorly understood in low-income countries, particularly Ethiopia.

Objective: This study aimed to explore the care-seeking pathways and dilemmas among women with fistulas in Ethiopia.

Methods: An exploratory phenomenological study was carried out from April 1 to August 1, 2019, through in-depth interviews and supplementary informant interviews. Data were obtained from 21 purposively selected women with fistulas who survived with morbidity for one and more years and 12 supplementary interviewees at fistula treatment centers in Oromia Region and Addis Ababa. Data were analyzed assisted by ATLAS. ti 8.4 software.

Results: Respondents gave their testimony that most of the women with fistulas first sought care from traditional care places and finally from fistula treatment centers. The reasons for care-seeking path dilemmas were a wrong perception about fistula, its causes, and treatment; families' pressure and lack of decision-making power on where to seek treatment, and a lack of knowledge on where modern treatments are available for fistula. They received psychological, companionship, and transport support from a family and a community; referral and counseling support from health care providers during their care-seeking pathways.

Conclusion: A myriad of reasons inhibits the right care-seeking pathways among women with fistulas. Communities and women with fistula awareness creation on the right places for fistula treatment and psychological support programs are required. Additionally, developing and implementing tactics for community-level screening programs for targeted victims and early admission to treatment centers can minimize the tragic sequela of the fistula.

Keywords: obstetric fistula, care-seeking pathways, women with fistula, dilemma, Ethiopia

Introduction

Obstetric fistula (OF) is a public health problem with a damaging effect on the well-being of women around the world.[1–3] It is a severe and disabling childbirth condition that affects millions of women in impoverished countries.[4–6] Due to a lack of early access to obstetric care, prolonged obstructed labor is the most common cause of obstetric fistula in developing nations.[5,7] Surgical closure of the defect is the treatment for obstetric fistula that works best.[8–10] However, very few hospitals are offering the service, and access to skilled professionals who are capable of repairing fistulas remains limited in developing nations like Ethiopia.[11] Additionally, since the majority of women with fistulas originate from underprivileged and underrepresented populations, healthcare access may be hampered by psychosocial, cultural, economic, and other contextual factors.[12]

Social stigma in various degrees hinders many women with obstetric fistulas from seeking treatment.[7] In addition, a woman may accept these conditions as "normal postpartum healing" rather than seeking treatment due to cultural barriers or a lack of sexual and reproductive health knowledge.[13–15] Women with obstetric fistulas are prevented from

Received: 5 November 2022
Accepted: 18 January 2023
Published: 3 February 2023

seeking and receiving obstetric treatment by cultural norms, gender discrimination, a lack of a rights-based approach, and poor healthcare providers' attention to the needs of women in planning and delivering healthcare services.[16]

Complications during pregnancy and childbirth account for approximately 830 maternal deaths per day worldwide.[17] Over two million women worldwide are thought to have obstetric fistulas, with an additional 50,000–100,000 new patients occurring annually, the majority of which are in Asia and Africa.[18,19] The regional prevalence of obstetric fistula was 1.20 (95% CI: 0.10–3.54) per 1000 women of reproductive age in South Asia and 1.60 (95% CI: 1.16–2.10) in sub-Saharan Africa, respectively.[18] With an estimated 140,500 women of reproductive age who had experienced symptoms of obstetric fistula, Ethiopia had the highest lifetime prevalence of 7.3 per 1000 (95% CI: 5.9–8.7) for women between the ages of 15 and 49. With a total burden of 142,387 (95% CI: 115,080, 169,694) Ethiopian patients with obstetric fistula,[20] it affects about 9000 women annually, but only 1200 are treated.[21–23]

By 2030, the Global Strategy for Women's, Children's, and Adolescents' Health (2016–2030) lays out a course for achieving women's, children's, and adolescents' potential and rights to health and well-being for everyone in all settings.[17] There is also the World Health Organization's (WHO) ending preventable maternal mortality (EPMM) Strategy 7 to address inequities in access to and quality of sexual, reproductive, maternal, and newborn healthcare, in addition to SDG3 on health (SDG Target 3.1 on the reduction of global maternal mortality ratio). Despite these global and regional strategies, obstetric fistula still has a significant impact on the lives of many women because all patients do not receive timely care.[18,24]

More than two million women with fistulas worldwide remain untreated, and many of them live with it for many years before surgery. Previous research indicates that timely treatment seeking among such women is generally low.[12,19] The surgical approach to managing the fistula, the characteristics of fistula patients that contribute to the formation of the fistula, their perception of the causes of the fistula, the experiences of patients following fistula surgery, and the outcomes of treatment have all been the subject of previous studies.[10,25–28] However, the individual and contextual factors that surround and influence the healthcare-seeking trajectories and treatment pathways of women with fistulas have not been fully investigated.

How women living in Ethiopia with obstetric fistulas navigated the treatment options available to them, the types of care they received, and the healthcare-seeking pathways they followed were poorly explored in low-income countries, particularly Ethiopia. The purpose of this study was to understand: in their search for healing in Ethiopia, what patterns of healthcare-seeking do women with obstetric fistulas follow? A significant aspect of women's disease experience is the path to treatment. In addition, the amount of time between the start of care and the end of it may affect women's health and, as a result, their demand for care. Patients with any illness are reflected in the paths they take to seek healthcare, both in terms of how they interact with it and how they ultimately use it.[29] To improve the focus and content of future programs, strategies, policies, and health interventions for women with obstetric fistulas, it is crucial to comprehend these groups of women's healthcare-seeking paths. For that matter, qualitative methods of data collection and analysis were ideal to understand the pathways followed by women with fistulas as they sought treatment for their illnesses.

Methods and Materials

Study Area and Period

A qualitative inquiry was conducted from April 1 to August 1, 2019, at five fistula treatment sites in Ethiopia: namely Jimma University Medical Center, Asella Hospital; Harar, Mettu, and Addis Ababa Hamlin Fistula Hospitals.

Research Design

The research design was an explorative phenomenological facility-based one. This research design has been chosen for its suitability to explore in-depth and comprehend the meaning, lived experiences, and understandings of individual women with fistulas concerning their past care-seeking paths. It deals with describing the experiences of the care-seeking path of participants for the treatment of their obstetric fistula. This includes their experiences related to seeking care while living with obstetric fistulas, how and why they sought particular care, their perspectives towards the care sought, beliefs related to the treatment of obstetric fistulas, and barriers related to their care-seeking paths.

The Population of the Study and Eligibility Criteria

Women with obstetric fistulas who were admitted to the five fistula treatment centers in the Addis Ababa and Oromia region served as the study populations. Women who survived this morbidity for at least one year to get richer information about their care-seeking path experiences before their actual care-seeking for surgical treatment at those facilities were included in this study. However, those who were in the immediate postoperative unit and who were unable to continue with the interview process due to a severe fistula with complications were excluded from the study.

Furthermore, supplementary informants who were family of women with fistulas, who reported knowing about women with fistulas, and who have had any encounter with women with fistulas were included in the study purposively to gather evidence that supplements the idea of women with fistulas.

Size of the Sample and Method of Sampling

One-on-one deep conversations were held with purposively selected twenty-one women living with obstetric fistulas and twelve supplementary interviewees. Purposive selection includes – women who have had an obstetric fistula and have at least lived with this disease for a year or more. The maximum variation was taken into account when using the purposive sampling method (considering and including obstetric fistula patients from each facility with different lived experiences with care-seeking paths based on their duration of survival with this morbidity before reaching the treatment sites and inclusion of different supplementary informants). Age, educational background, residence (rural vs urban), and marital status also varied among respondents. The number of interviewees was amended based on the saturation of ideas and the richness of information reached. Based on recent evidence, we determined that there was data saturation when there was no need to collect any more data based on the data that was already collected; how much data (typically the number of interviews) is required until nothing new emerges (informational redundancy), and whether or not it is compatible with the chosen analytic framework, theoretical position, and research question.[30] In light of our research question, methods, and sampling strategy, as well as the uniformity of the study participants, it was determined that the data were adequate and that data saturation occurred among twenty-one women with obstetric fistulas that is data redundancy started to be seen after twenty participants. The number of participants interviewed continued to twenty-one participants. Then, twelve supplementary study participants, at least two from every five facilities (traditional birth attendant, health extension worker, health care providers, community leader, and family members of women with fistulas) were purposively (who lived around fistula treatment centers, knew about women with fistulas, and had an encounter with them) selected and interviewed to complement the data obtained from women with fistulas.

Approaches and Tools for Gathering Data

For women with fistulas and supplementary interviewees, two in-depth interview guides were used. Both interview tools had two sections, part one was on the respondents' background characteristics, and part two was on the care-seeking pathways experiences of women with fistulas. For the correctness and consistency of the interview questions, the interview guides were initially written in English, translated into Afan Oromo, then back to English, and checked once more by a third party. The instruments were also pretested on two supplementary interviewees and three women with fistulas at the fistula unit of Jimma University Medical Center before the main data collection. The interview guides were reframed in light of the results of the pretest.

At each of the five hospitals, one-on-one in-depth interviews were used to gather information from women with obstetric fistulas and supplementary interviewees. The data were collected by six data collectors—three men and three women, including the first author—and five field assistants—two women and three men—all of whom held master's degrees and had extensive experience in conducting qualitative interviews. For two days, the research instruments and goals were debriefed to the data collectors and field assistants. Women who fulfilled the eligibility criteria were selected and interviewed. All meeting conversations were directed at isolated places where others could not stand by listening to the conversations and in the language that the interviewees talk. The interviews lasted anywhere from sixty to ninety minutes. With the consent of the respondents, audio recordings of the data were made, and handwritten field notes were taken. Before the collection of data, no relationships were established with the respondents, but they were informed of the study's

objectives. When necessary, probes were used to obtain specific responses from participants. The interviews continued until the level of data saturation.

Trustworthiness

Credibility was ensured using a semi-structured interview guide with field notes (not to miss information), and peer debriefings were conducted. The triangulation method between the results of women with obstetric fistulas and supplementary interviewees also ensured the study's credibility. There were also triangulations of the investigators' independently generated codes where they compared and agreed on common codes. Using bracketing, subjectivity was ruled out (an interview guide was created without heavily relying on evidence from the literature review). The study's sample size, sampling methods, and thematic table were all clearly and comprehensively described to ensure transferability, and the interview guides used to collect data were made available as Supplementary Files [see Table S1]. Peer debriefing among data collectors and prolonged engagement with participants for building trust and rapport for getting accurate data from interviewees were used to ensure dependability. In this study, conformability was also ensured by bracketing and an audit trail (created by keeping track of the entire research process, beginning with the background section and ending with the conclusion) and a thorough critical examination of the study results by the investigator and the advisors for confirming that the interpretations of the results were data-driven and constructed logically.

Data Analysis

A local language (Afan Oromo) was used to transcribe the collected data, which was then translated into English and consistency was checked by back-translation of the transcribed data. To minimize errors, all transcripts were combined into two Microsoft Word files, one for women with fistulas and the other for supplementary informants, and the transcribed interviews were compared to field notes, proofread, and prepared for analysis. Thematic analysis was used for both analysis and writing based on Braun and Crack's six steps approach.[31] These include: (I) reading the transcripts repeatedly to become familiar with the data; (II) creating initial codes for the entire data set, followed by close coding to compare relevant data with each code; (III) sorting various codes into candidate themes and subthemes to find potential themes and subthemes; (IV) reviewing and fine-tuning the themes and subthemes by reading all collected extracts for each theme and subtheme to ensure that they follow a consistent pattern; (V) defining and naming the themes and subthemes by determining the aspects of the data that each theme captured and the relevance of what each theme was about (along with the themes as a whole); and (VI) putting together the report. Assisted by ATLAS.ti software version 8.4, the coding and overall analysis were carried out. Eventually, themes, subthemes, and quotes were used to interpret the narrative qualitative data that were arranged, integrated, and presented in tables and figures of networks.

Results

Characteristics of Study Participants

Thirty-three respondents: 21 women with obstetric fistulas and 12 supplementary study participants (seven healthcare professionals, one community leader, two household members, one traditional birth attendant, and one health extension worker) took part in the interviews. The majority of women with fistulas were between the ages of 30 and 34. The majority of the women were not educated, were divorced, and were from rural settings. Most of the supplementary informants were more than 35 years of age, at college/university in educational status, married, and urban residents (Tables 1 and 2).

This study contained thirty-three primary documents (twenty-one from women with fistulas and twelve from supplementary informants) which were coded into 98 codes, thirteen subthemes, and four themes. The identified themes include (1) care-seeking paths of women with fistula, (2) care-seeking path dilemmas, (3) support for care-seeking, and (4) suggestions on care-seeking paths (Table 3).

Care–Seeking Paths of Obstetric Fistula Survivors

All participants elaborated on the care-seeking pathways women with fistulas experienced. The subthemes under this theme were where women go first for care, where women go lastly for care, and how women started care-seeking.

Table 1 Socio-Demographic Characteristics of Women with Fistula Participated in an in-Depth Interview at Addis Ababa and Oromia Fistula Centers, April to August 2019 (n=21)

Characteristic	Number of Women (n=21)	Percentage (%)
Age at interview		
<20	1	4.8
20–24	5	23.8
25–29	3	14.3
30–34	8	38.1
≥35	4	19.0
Educational status		
Not educated	14	66.7
Primary school	6	28.5
Secondary school	1	4.8
Marital status		
Married	9	42.9
Divorced	10	47.6
Widowed	2	9.5
Occupation		
Farmer	12	57.2
Daily laborer	4	19.0
Merchant	2	9.5
Student	3	14.3
Residence		
Urban	4	19.0
Rural	17	81.0

Where Women Go First for Care After Developing Obstetric Fistula

When women with obstetric fistulas were asked where they first went for care after developing an obstetric fistula, most of them reported that they first went to religious and traditional places (with a monk in the monastery, Muslim religious leaders, magic, holy water, and traditional birth attendants (TBAs), and some of them stayed at home (Figure 1).

Concerning women's first resort to traditional care places, one woman with a fistula gave her testimony that most of such women went there hiddenly to get care in a hidden way:

> …when they face the problem, first they go to religious and traditional places. (e.g., to magic and holy water). They prefer those places where no one will hear /see about them and they will tell their problem in a hidden way and they will get the solution hiddenly (no one will know anything). (Fistula patient, 30 years)

Some women with fistula first went to Muslim religious leaders (sheiks) and traditional birth attendants for fistula care, but they received care that made their condition more complicated:

Table 2 Socio-Demographic Characteristics of Supplementary Informants Involved in an in-Depth Interview at Addis Ababa and Oromia Fistula Centers, April to August 2019 (n=12)

Characteristic	Number of Participants (n=12)	Percentage (%)
Types of supplementary informants		
Family members (Males)	2	16.7
TBA (Female)	1	8.3
HEW (Female)	1	8.3
HCPs (3 Males & 4 Females)	7	58.4
Community leader (Male)	1	8.3
Age		
30–34	5	41.7
≥35	7	58.3
Educational status		
Primary school	4	33.3
Secondary school	2	16.7
College/University	6	50.0
Marital status		
Married	9	75.0
Divorced	3	25.0
Occupation		
Farmer	3	25.0
Government employee	4	33.3
Non-government employee	5	41.7
Residence		
Urban	10	83.3
Rural	2	16.7

Abbreviations: TBA; - traditional birth attendant; HEW; - health extension worker; HCPs; -health care providers.

> To seek healing for my fistula I went to Wollega. Because people told me that there is a sheik who has been curing women with fistulas. Then, I went there. After I got back home, I didn`t see any change in my health, rather my fistula became more complicated and worsened. (Fistula patient, 40 years)

Supplementary informants also gave their testimony that women with fistulas went initially for care to traditional places due to their fear of disclosing their disease condition because of the bad attitudes their society has about fistulas:

> …There is a big problem in disclosing the patient and searching for the proper care since there is a big fear. Generally, a bad attitude in society regarding fistula will make them prefer nonmedical treatment (e.g., praying areas, magic, and herbal medicine)… (Health officer, 38 years)

However, some women with obstetric fistula first stayed at home without seeking care from anywhere:

Table 3 Themes of Healthcare-Seeking Pathways and Dilemmas Among Women with Fistula in Ethiopia, April to August 2019 (n=33)

S. No	Main Themes	Sub-Themes
1	Care-seeking paths of fistula survivors	Where women go first for care Where women go lastly for care How women started care-seeking
2	Care-seeking path dilemmas	Reasons for care-seeking path dilemmas Reasons for late arrival at fistula centers Reasons for going to traditional places first
3	Support for care-seeking	Family support for care-seeking HCPs support for care-seeking Community support for care-seeking
4	Suggestions on care-seeking paths	Suggestions on where to seek care Suggestions on how to prevent fistula Suggestions to families of women Suggestions to fistula treatment centers

I didn't go to other places but instead stayed at home. Simply I was praying myself but didn't go anywhere. (Primipara woman with fistula, 21 years)

Where Women Go Lastly for Care

Women with obstetric fistulas passed through different care-seeking pathways for care-seeking for their fistula problem (going to traditional places, staying at home with traditional birth attendants' care, going to health centers, referral hospitals, and fistula treatment centers) but finally, after a long time trial with traditional cares, they came to fistula treatment centers (Figure 1). Supplementary study participants gave their testimony that most women with fistulas after long-term care seeking from traditional places, were finally compelled to come to a fistula treatment center after their fistula condition aggravated:

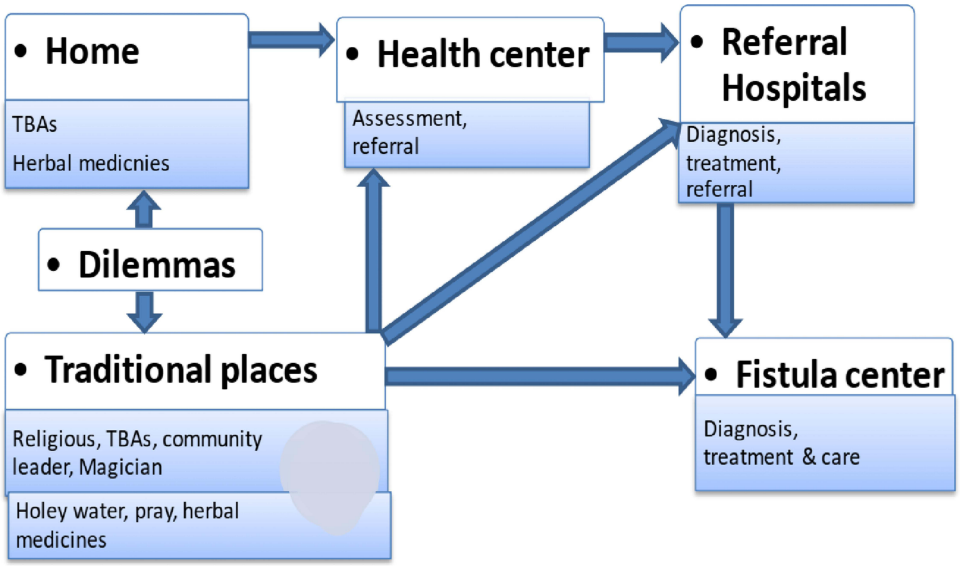

Figure 1 Care-seeking pathways among women with obstetric fistula in Ethiopia.

…Finally, she went to Jimma University Medical Center's fistula unit when her condition became compromised. (Husband of the fistula patient, 37 years)

Some of them unknowingly, initially went to holy water places, Sheik, and then finally come to the fistula center. (Health care provider, male, 42 years)

How Women Started Care-Seeking

In this study, participants reported women with fistulas, started care seeking for their problems, and accessed fistula treatment centers based on the information they got from similar previously treated women with fistulas, church, radio, community leaders, and health extension workers:

After knowing about this disease and starting to meet previous victims of fistula in my kebeles, I got discussed and stayed with them. This made me ready to seek treatment. (Widowed fistula patient, 50 years)

I heard about Hamlin Fistula center from the church and came here two weeks ago. There, the focal person is working with the church to collect women with fistulas. (Married fistula patient, 32 years)

Some of the obstetric fistula survivors also reported that they started seeking care: - after getting advice from care providers through different campaigns, due to the severity of their incontinence, and through family support and motivation:

My fistula problems of urine and fecal incontinence enforced me to go to the health center. My family also motivated and supported me to go there. What motivates me more to go there is that I have friends working at the health facility who called care providers for me to take me to the fistula center. (Divorced fistula patient, 25 years)

Care-Seeking Path Dilemma

Women with obstetric fistulas and supplementary informants noted different obstacles, reasons, and dilemmas (confusion to decide where to seek treatment) that make most women with fistulas not decide and seek care early from the health facility. These include reasons for their care-seeking path dilemmas (confusion to decide where to seek care first), reasons for late arrival at fistula centers, and reasons for going to traditional places first.

Reasons for Care-Seeking Path Dilemmas

Participants in this study reported different reasons why women with fistulas were confused about where to seek care first for their fistula condition. These include women with fistulas' and communities' wrong perceptions about the fistula, its causes, and treatment; families' pressure on where to seek treatment, lack of decision-making power on where to go first for care, and lack of knowledge and information on whether modern treatments are available for fistula (Figure 2).

Concerning fistula survivors' and communities' wrong perception of obstetric fistula, its cause, and treatment, some women with fistulas gave their testimony as follows:

Neither I nor my family knew the disease was a fistula for at least ten years. We consider it as it happens due to urinating outside the home after delivery and traditionally we call it sunstroke. The community thinks it has no medication/ treatment. Therefore, most women stay at home with this problem. Because they think it has no solution or treatment anywhere. (Fistula patient, 18 years)

As to me, fistula is bad luck and God's punishment rather than a disease. It is a big problem. Because you can`t go anywhere, you can`t be with other people and sit together. For instance, I can`t go to any person. This is the harm of God. (Separated fistula patient, 21 years)

Similar participants gave their testimony that women with fistulas did not know where to seek treatment, had no power to decide on where to seek care, and instead their families decided for them:

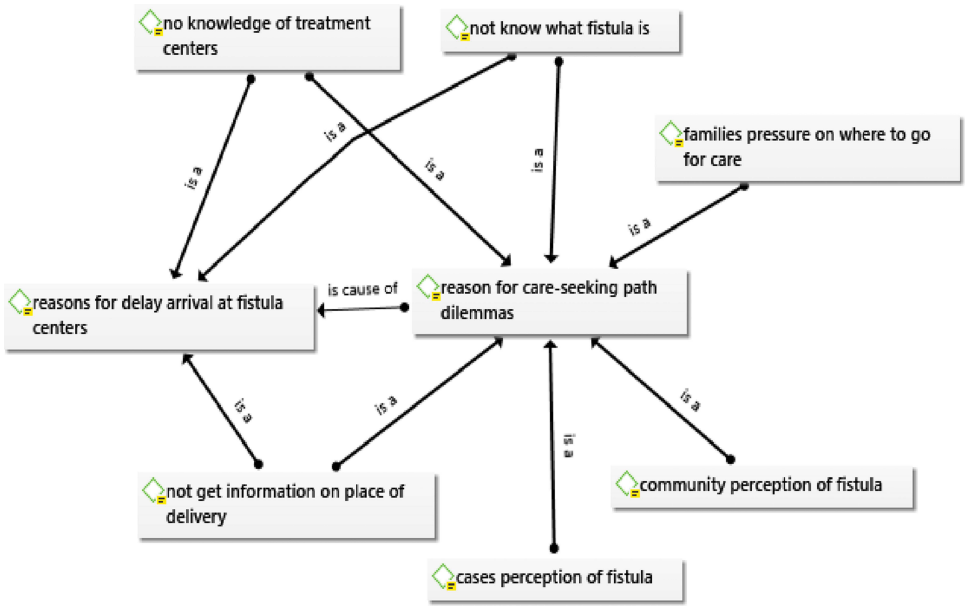

Figure 2 Reasons for care-seeking path dilemmas among women with fistula in Ethiopia.

> I have confused about where to seek care for my fistula condition as my family did not give me a chance to decide on where to seek care. My family decided on each of my visits. I had no decision on where I went. I didn't know and select where to go. (Divorced fistula patient, 30 years)

Participants noted that the community and women with obstetric fistulas hid the problem instead of searching for treatment and no one could talk about it related to their wrong perceptions about the causes and treatment of fistula due to their lack of information:

> The issue was not well known as no one will talk about it including us and health care professionals. Society considers bad luck and evil 'magic' as the probable cause of it. After developing a fistula, both the victims and their families prefer hiding the problem rather than searching for modern medicine. (TBA, Female, 37 years)

Reasons for Late Arrival at Fistula Centers

Participants elaborated on reasons for the late arrival of women with fistulas to treatment centers, including having no accompaniment to the health facility, no availability of health extension workers to provide them with information about the fistula center, the few hospitals around their residence, problems of transportation, and lack of money for transportation costs:

> I stayed one month and was told to go to the fistula center after three months. I came to this hospital after four and a half months because I can't get somebody to bring me here and the lack of money for transportation costs. (Divorced fistula patient, 21 years)

From supplementary study participants, one healthcare provider also added that most of the fistula survivors have no money for transportation costs and therefore stayed with their fistula condition for many years without getting treatment:

> For care-seeking, since they have no potential for transportation costs and it needs enough money, they select staying at their home for twenty or thirty years without seeking treatment. (BSc Nurse, Female, 42 years)

Reasons for Going to Traditional Places First for Care

There are reasons why women with fistulas first go to traditional places, including thinking that the fistula has no solution, believing it is caused by God's punishment, connecting their disease condition with their religion, cultural influences, easier access to traditional places, and more preference for traditional healers to cure their fistula problems:

> The community thinks it has no treatment. However, since they believed that it is caused by the spirit or God's punishment, they went rather to traditional healers. Even for surgery, they ask permission from those places. (Health care provider, Male, 40 years)

> As you know, women with fistulas commonly look for traditional treatment before they go to a health facility. The reason they go to such places other than health facilities is maybe, it is easy for them to go there and other spiritual sites. The culture also influences us, and we are also more familiar with such sites. (Husband of a woman with obstetric fistula, 46 years)

Support for Care-Seeking

Throughout their care-seeking pathways, participants reported numerous supports they got. These themes contained subthemes like family support for care-seeking, Health care providers (HCPs) support for care-seeking, and community support for care-seeking.

Family Support for Care-Seeking

Some participants reported that they got different supports such as support with routine household activities, keeping secret their fistula condition, and emotional support from their husbands, parents, sisters, and other relatives for each of their care-seeking pathways:

> I survived this problem while seeking care with the help of my husband, my family, and my mother-in-law. My mother-in-law performs all household activities for me. My husband and my parents tried to hide my secret. Support from my husband, children, and parents gave me the strength to seek care. (Widowed fistula patient, 50 years)

HCPs Support for Care-Seeking

Some participants reported that they got well-coming and diagnosis support with their initial admission to the health center, referral and linkage services to the fistula center, advice on nutrition and appointments on discharge, and different post-operation counseling on when to resume sexual intercourse, hygiene, and reassurance supports from health care providers:

> …they examined me and said, "she had fistula and anemia". Then, they admitted me to the hospital and gave me different medications and I felt better. They advised me on nutrition, on my fistula, and told me as it is a short time problem; and as I become healthy, give birth again, and have a normal life in the future. (Married fistula patient, 18 years)

> The care providers at the health center organized us there and referred us to Addis. The repair was done for me within twenty days. However, I was not healed, and they discharged me with advice not to start sexual intercourse for at least three months, not to become pregnant for at least two years, and to keep my hygiene. (Multigravida fistula patient, 30 years)

Community Support for Care-Seeking

In this study, participants reported that they got different support from their neighbors for their care-seeking, including accompanying them to the treatment center, contributing money, washing clothes, providing psychological support, and advising on how to reduce incontinence of urine:

> Some neighbors buy soap and wash clothes for me. The rest of the neighbors contributed money and sent it to me to utilize for transportation costs. Some of them came and asked me. (Multigravida fistula patient, 30 years)

> My neighbors brought me to a health facility using a 'traditional ambulance'/ carrying me to a facility with a bed. They worry about my problem; waiting for the time when I will be free from this problem, providing me psychological support by saying, 'you are young, you will be getting cured of this problem soon, be strong and pray'. (Divorced, primipara fistula patient, 30 years)

Suggestions on Care-Seeking Paths

All participants made suggestions concerning the care-seeking paths of fistula patients. The subthemes were: suggestions on where to seek care first, suggestions on how to prevent fistula, suggestions to the families of fistula patients, and suggestions to fistula treatment centers.

Suggestions on Where to Seek Care First

Related to where women with obstetric fistulas should first seek care and how their families should help them with their care-seeking, participants suggested that women with fistulas should come immediately for care seeking to fistula treatment centers, should find similar patients in their area, and bring them to a fistula center, advice them to immediately go to treatment centers, and the families should also support them in all aspects of their life:

> I find for such patients and advise, recommend, and tell them as the service is found at Hamlin fistula treatment center and initially to go there for treatment. Since women with fistulas suffer from both physical and psychological problems, their families should bring them early to the treatment center, give them hope, shouldn't leave them alone in the hospital, and should encourage them. (Married fistula patient, 30 years)

> I recommend them to go to a health facility early rather than going to any other place after suffering from this problem. This problem can be happened to any woman and can be cured; so they should be strong and follow their treatment. (Supportive staff, Female, 28 years)

Suggestions on How to Prevent Fistula

Participants suggested that to prevent fistula, women with fistulas should avoid lifting heavy weights after repair, seek treatment and support from skilled care providers early from a health facility, follow up their treatment appropriately at the fistula treatment center, and not go first for care to traditional care places:

> We have to prevent fistula by avoiding lifting weights. I need to discuss this problem with other women with fistulas. I need if all women get cured of fistula (to come hospital and cure). (Married fistula patient, 27 years)

> Before they develop this problem, I advise them to seek treatment and support early from a health facility. I recommend that unmarried girls should marry when their age reaches marriage and have sexual contact when they are physically mature enough. Those women who seek care late, should come to the fistula center early and follow up on their treatment appropriately. (Divorced fistula patient, 20 years)

Suggestions to Families of Women

All participants suggested that the community, neighbors, and families of women with fistulas should support them with their care-seeking and should take them early to the health facility for assessment and treatment. They should also stop discriminating against and stigmatizing them, treat them with respect and dignity, must have access to information about the right treatment places for the fistula, and should know as the fistula is not due to God's punishment or bad spirit but rather as it is a treatable disease:

> I recommend it to the family as a fistula is a severe and difficult disease. The family of these women must consider and think of this problem as their problem and must give them all the necessary support. They should care for, support, and take them to a health facility for treatment, and tolerate all discrimination in silence. (Divorced fistula patient, 20 years)

> The family, community, and neighbors should: know as fistula is not due to God's punishment or from a bad spirit, help women in labor to give birth at a health facility, need assistance from health professionals/health extension workers/ for getting a right treatment center, report a fistula patient to a health facility, understand, and help her to get the treatment from a fistula center. Therefore, disclosing women with fistulas should be the first measure for them. (Head Nurse, Male, 40 years)

Suggestions to Fistula Treatment Centers

Participants suggested fistula treatment centers should include recreational services and counseling units at their center; strengthen their network of searching for fistula patients; enhance their linkages with government bodies, health professionals, and health development armies; and independently identify, search, and treat such patients:

> Better if they include an advice center or a counseling center (e.g., sometimes you will cry all day for no reason) and we need somebody to breathe in. Treatment centers should increase recreational services (e.g., coffee ceremonies). (Married fistula patient, 30 years).

> Still, there is a big gap in identifying and searching for victims. This is not practiced in the health post or health centers/hospitals by themselves except in the schedule of Hamlin fistula centers. Therefore, each fistula treatment center should be able to independently identify, search for, and treat such patients. (Health officer, Male, 38 years)

> …Lastly, what I want to say is, there should be a strong linkage between fistula centers, government /administrative bodies, health professionals, and health development armies /HDAs…. (TBA, Female, 37 years)

Other participants suggested to healthcare providers working at fistula treatment centers that they should support and treat women with fistulas critically with tolerance and should work more on the prevention of fistulas:

> I recommend for health care providers to critically assess women with fistulas who come for consecutive repairs. I need it if they work on the prevention of fistulas. I don't want other women to be affected like me. (Divorced fistula patient, 20 years)

> Decreasing both the physical and mental trauma of women with fistulas is essential for care providers since it supports the treatment processes. They should have patience in the treatment process as it may take long-duration stays and repeated appointments. (Health care provider, Male, 42 years)

Discussions

This was a one-on-one in-depth interview-based qualitative inquiry that investigated care-seeking pathways and encountered dilemmas among obstetric fistula survivors in Ethiopia. We found that obstetric fistula patients passed through different routes for seeking treatment for their fistula condition starting from the time when they encountered the disease until they arrived at fistula treatment centers. All participants reported that most women with fistulas who gave birth at home were first going to traditional care places for treatment of their fistula. We found that numerous obstacles and dilemmas made obstetric fistula patients not seek treatment first from fistula centers and rather seek traditional care that must be addressed to make all such patients first come immediately to fistula treatment centers. Women with obstetric fistulas and a community had wrong perceptions of the meaning, what caused the fistula, and how to treat it. We found also that all study participants had suggested that women with obstetric fistula and other pregnant women should seek care first from a health facility to prevent fistula. There were also suggestions to the families of women with fistulas and to the fistula treatment centers to support and help women with obstetric fistulas to seek care early from health facilities and prevent fistula.

In this inquiry, fistula patients first sought care from traditional care places related to their unawareness of what a fistula is, whether or not it is treatable, where its treatment centers are found, lack of support to decide where to go first for care, and lack of transportation. This confirms previous findings in Burkina Faso that a woman who does not know enough about sexual and reproductive health or does not want to talk about it because of cultural norms may accept these symptoms as part of the normal healing process after childbirth rather than seeking treatment.[14] Similarly related to their need for care, obstetric fistula patients encountered dilemmas on where to seek care first related to the wrong perception they have about a fistula and its cause, families' pressure on where to seek treatment, and their lack of control over where to get healthcare first. This collaborates with previous studies' reports that obstetric fistula patients who do not seek obstetric surgical care do so for a variety of reasons, including a lack of knowledge about the illness's signs and symptoms, a lack of access to services, and a lack of transportation options.[32] It's possible that many women and/or their families, particularly those who do not receive skilled care during pregnancy, are unaware of the existence of fistula

treatment or the appropriate time to seek it.[33] In some places, considering surgery over in-home vaginal birth is also regarded as less feminine and unnatural.[34]

We found that obstetric fistula patients got support throughout their care-seeking pathways from families, neighbors, communities, healthcare providers, TBAs, health extension workers, community leaders, and religious leaders. The support they received includes emotional support, accompaniment to a health facility, financial and transport support, counseling and information support, food, health care, and treatment support. Nonetheless, a study's findings in Ghana showed that fistula patients got help from mates/partners, relatives, and different family members, and a lot of such support was restricted to tangible help that focused on access to information and money.[35] However, a study conducted in Tanzania demonstrates that partners and family members provide women with a fistula with varying degrees of emotional, monetary, and social support.[36]

In our recent study, women with fistula and a community perceived and defined fistula wrongly as it is not a disease but rather a punishment from God or something that occurred due to sunstroke, and something that caused by a bad/evil spirit and as should be treated by traditional remedies by visiting Sheiks/Muslim religious leaders, magician, and different religious places. This collaborates with the study in Uganda, Malawi, and Nigeria that the majority of the community and women who have obstetric fistula have misconceptions about its cause, clinical presentation, and prevention. Some wrongly believed that a fistula was caused by improper use of family planning, having sex during menstruation, family curses, sexually transmitted infections, witchcraft, rape, gender-based violence, punishment from the gods for infidelity, unanticipated natural forces during childbirth, poison from the skull bone of the dead macerated fetus, or manipulation by Traditional Birth Attendants (TBAs). Others believed it was a curse from God. Concerning its possible treatment, they believe obstetric fistula had no cure while a few of them perceive that it could be treated with herbal products by experienced TBAs.[37–41]

Concerning the appropriate care-seeking path that women with fistula should follow and how to prevent obstetric fistula, participants suggested that women with fistula should first seek care from fistula treatment centers, their families should also support them to decide early to seek care from a health facility, and take them to a medical facility. To halt obstetric fistula, healthcare providers should advise and counsel pregnant women and fistula patients on the risk factors of fistula, what a fistula is, where they should get the correct treatment, and where they must seek care first for a fistula. They also suggested fistula treatment centers should have a refreshment area, promote their independent search for fistula patients through outreach activities, and provide them with full and correct information about a fistula, its risk factors, prevention mechanisms, and about its treatment before and upon their discharge and at each of their visits per appointment to centers.

Strengths

This was an original facility-based phenomenological qualitative study in Ethiopia that deeply and comprehensively explored care-seeking pathways and dilemmas among women with fistulas from the perspectives of fistula victims and supplementary informants. The study included a comparatively larger number of interviewees and used the purposive sampling technique. The involvement of both obstetric fistula patients and supplementary study participants helped to understand clearly where women with fistula initially and finally seek care, the reasons behind that, and the dilemmas they faced. The study guaranteed the reliability of the gathered information. Furthermore, to fully and thoroughly gather the data, the participants were interviewed in a private room with additional probes, field notes, and audio recordings.

Limitations

The lack of member checking and repeated interviews with study participants is one of the study's limitations. Moreover, there is an inability to use a maximum variation sampling strategy with supplementary study participants because some of them were not available or accessible during the data collection period. Even though we utilized strategies such as introducing the study's purpose, anonymity, and confidentiality of their responses to the respondents; prolonged engagement to build trust with them, peer debriefing, and further probes to overcome bias, due to the sensitivity of the topic, there might be some social desirability bias.

Practice and Research Implications

This study looked at the care-seeking pathways and dilemmas among women with fistulas from the perspectives of fistula victims and supplementary informants and helped to understand those more clearly. Accordingly, this study adds significant knowledge to the current literature on care-seeking pathways followed by fistula patients and the underlying care-seeking path dilemmas. Their care-seeking paths, dilemmas, reasons for such care-seeking dilemmas, perceptions of women with fistula, and a community about fistula, its causes, and treatment modalities signify the current existing obstacles for women with fistulas not to go early to fistula treatment centers for care. Hence, women with fistula families, communities, health care providers, and fistula treatment centers should work in integration to halt such obstacles and enable fistula patients to get obstetric surgical care early from fistula treatment centers. This study explored the care-seeking pathways of women with fistula and other related emerging themes such as care-seeking path dilemmas, reasons for care-seeking path dilemmas, and supports received. But the lived experiences of fistula patients after social rehabilitation and evidence for their easier and earlier community outreach screening and linkage to fistula treatment centers should be a focus of future studies.

Conclusion

Most women with fistulas used inappropriate pathways for seeking care for their fistula treatment. Due to their and communities' wrong perceptions of fistula's causes and treatment, families' pressure, lack of knowledge and power to decide where to seek care first, and cultural influences, they first sought care in traditional care places. Healthcare practitioners, healthcare professionals, and educators should create awareness among women with fistulas, their families, and the community on the causes, risk factors, treatment, and prevention of fistulas. There is also a need to create awareness among women about hospital delivery, and to take well-directive efforts to counsel and teach them what the fistula is and where to seek care first. Healthcare providers should teach women and their families to strongly interdict early marriage and pregnancy; educate and counsel pregnant women to timely access to skilled care only from a health facility; create awareness among traditional care centers and religious leaders to encourage women with fistulas and refer them immediately to fistula treatment centers. Regional health bureaus, healthcare practitioners, and all initiatives and campaigns working on fistula treatment and prevention should emphasize designing strategies to battle social stigma, discrimination, and cultural biases; should identify, support, and link women with fistulas to treatment centers for their earlier access to repair and prevention of fistulas. To help millions of women with fistulas with early access to surgical care, the development of evidence-based practices for easier and earlier community outreach screening of fistula patients and linkage to fistula repair sites must be the primary focus of future studies.

Statement on Data Availability

The corresponding author can provide the datasets used and/or analyzed in the current study upon reasonable request.

Ethics Approval

The Jimma University Institutional Review Board (IRB) reviewed and approved the study's protocol (Ref. No: IRB 000281/2019). Participants were adequately informed and understood the purpose of the study, confidentiality of the information, and publication of anonymized responses. Then, each interviewee signed an informed consent form. Teenagers under the age of 18 gave their assent, and parents or guardians gave their consent. The verbal exchange was recorded with written permission. The Helsinki Declaration's pertinent guidelines and regulations were followed throughout the study process. All important steps were taken to guarantee: the participants' rights, dignity, autonomy, interest, and well-being throughout the study.

Acknowledgments

The data collectors are acknowledged. We are also indebted to the managers of each fistula treatment center, who permitted us to carry out the processes of data collection at each facility. We thank our study participants for their time

and acknowledge Jimma University for its ethical clearance of this study. Additionally, we are indebted to the Center for International Reproductive Health Training (CIRHT) for providing us with technical assistance for this study.

Author Contributions

All authors made substantial contributions to the conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; agreed to submit to the current journal; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

Funding

Jimma University provided a student research fund for data collection for this study. The study's design, data collection, and writing of this manuscript did not involve the funder.

Disclosure

The authors report no conflicts of interest in this work.

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