BMJ Open

Health-seeking experiences of women with obstetric fistula: a qualitative study at two fistula centres in Ghana

Ernestina Asiedua ,[1] Ernest Maya ,[2] John Kuumuori Ganle,[2] Sebastian Eliason,[3] Adelaide Maria Ansah-Ofei,[4] Ephraim Kumi Senkyire,[5] Richard Adanu[2]

To cite: Asiedua E, Maya E, Ganle JK, *et al*. Health-seeking experiences of women with obstetric fistula: a qualitative study at two fistula centres in Ghana. *BMJ Open* 2023;**13**:e064830. doi:10.1136/bmjopen-2022-064830

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2022-064830).

Received 17 May 2022
Accepted 10 July 2023

[1]School of Nursing & Midwifery, Department of Maternal and Child Health, University of Ghana, Legon, Ghana
[2]School of Public Health, Department of Population, Family, and Reproductive Health, University of Ghana, Legon, Ghana
[3]School of Medical Sciences, University of Cape Coast, Cape Coast, Ghana
[4]School of Nursing & Midwifery, Department of Research, Education and Administration, University of Ghana, Legon, Ghana
[5]Ga West Municipal Hospital, Ghana Health Service, Accra, Ghana

Correspondence to
Dr Ernestina Asiedua; easiedua@ug.edu.gh

ABSTRACT

Objectives The study explored the health-seeking experiences of women with obstetric fistula from the onset of the condition until surgical treatment was obtained. It also describes their interactions with health staff and traditional healers.

Design Exploratory, descriptive qualitative study.

Setting Two secondary-level health facilities in the northern and central regions of Ghana; data collection took place in 2018–2019.

Participants A purposive sample of 37 women who had experienced fistula resulting from childbirth and were awaiting fistula repair at the two fistula centres in Ghana was obtained.

Data analysis Thematic analysis was used to analyse the data.

Results Health-seeking experiences and behaviours of women with obstetric fistula were identified. Six major themes were generated: attribution and perceptions of fistula; competing alternatives/multiple sources of care; limited awareness and access to care; financial barriers; psychosocial challenges, and abuse by healers. The results indicate that the health-seeking experiences of women with obstetric fistula were characterised by long delays in care-seeking. The major themes and subthemes are presented with quotes from participants.

Conclusion The women experienced winding pathways of treatment-seeking due to lack of awareness and incorrect attribution. The major barriers to health-seeking included poverty, challenges with transportation and inadequate repair centres. Increased awareness of obstetric fistula and access to repair centres could shorten the suffering women go through while awaiting fistula treatment. Improved awareness of obstetric fistula and establishment of more fistula centres would be beneficial.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Respondents were asked to check that their transcribed data were an accurate representation of their experiences.
⇒ Opportunity was given to each participant to fill in any omission in the interview.
⇒ A back-to-back approach was used to translate the interview guide, which was originally designed in English, into Twi and Dagbanli, by two language experts.
⇒ The sample is limited to women with obstetric fistula recruited at the two selected facilities.

INTRODUCTION

Obstetric fistula is an abnormal opening between the vagina and the bladder (vesicovaginal fistula) or rectum (rectovaginal fistula) or both.[1 2] The major cause of obstetric fistula is prolonged or complicated labour which leads to the head of the fetus pressing on the bladder and the rectum leading to dead tissue and creation of an abnormal hole.[3] Globally, over 2 million girls and women live with obstetric fistula and 50 000–100 000 women develop obstetric fistula every year.[4] In Ghana, 1352 women per 751,205 deliveries develop obstetric fistula each year with an incidence rate of 1.8 per 1000 deliveries.[3] Obstetric fistula affects the quality of life of the affected women and their families.[1 5] The only treatment for obstetric fistula is surgical repair. Early detection and management of obstetric fistula often result in improved treatment outcomes and at a lesser cost than when treatment is delayed.[6 7] However, majority of women do not have access to care either due to the cost involved, stigma or lack of awareness.[4 8] Women's lack of reproductive decision-making has also been cited as a deterrent to seeking treatment for fistula.[9] This leads to delay in accessing treatment. Some women live with obstetric fistula for over a decade before seeking treatment in the health facility.[4 10 11]

There are reports to indicate that most women with urinary symptoms visited traditional medicine providers before resorting to hospital treatment due to misconceptions.[4 12] The common misconceptions of obstetric fistula are: punishment from God, disloyal and disrespectful behaviour, infidelity or being bewitched by mothers-in-law.[13] Fistula has also been described as an art of

God[14] or 'Allah's will'.[15] Once causation is given spiritual attribution, it is more likely for women to seek for help in churches and shrines rather than hospitals.[16 17] The individual beliefs and interpretations ascribed to the causes and management of a disease condition determine their health-seeking behaviour.[18] This leads to an obvious delay in seeking medical care or resorting to other forms of treatment.[19 20] There is evidence to show that survivors of obstetric fistula delay seeking treatment as a result of varied beliefs.[16 21 22] To most of these women who are poor, the cost of surgery, including postoperative care and rehabilitation, is a major challenge.[4 23 24] These, coupled with the limited surgeons and repair centres, make other forms of therapies an obvious choice. Most women with fistula rely on the mercy of philanthropic agencies which occasionally support obstetric fistula intervention programmes. While the women await treatment, they become devastated, lose hope and confidence, and sometimes resort to other forms of therapy, which are usually ineffective.[24]

At the time of this study (2018–2019), there were limited studies on the health-seeking experiences of women with obstetric fistula in Ghana. Meanwhile, there is evidence to show that the health-seeking behaviour of individuals during an illness reflects their utilisation of available health services.[17] Information on the health-seeking experiences of women with obstetric fistula is therefore essential to improve health interventions.[17 23] This study explored the experiences of women with fistula from the onset of the condition until surgical treatment was obtained. It also describes their interactions with health staff and traditional healers.

METHODS

Research design

This study employed an exploratory, descriptive qualitative approach to explore experiences of women seeking fistula treatment.

Study setting

The study was conducted at the Mercy Women's Hospital (fistula unit) in Mankessim in the central region and the Tamale Fistula Centre in the northern region of Ghana. Data collection took place in 2018–2019.

Sample recruitment

A purposive and convenience-based sampling approach was used to recruit participants who had come for fistula surgeries at the centres. Thirty-seven women with obstetric fistula were engaged in in-depth interviews (IDIs): 22 from the Mercy Women's Hospital (Mankessim) and 15 from the Tamale Fistula Centre.

Data collection

An IDI guide (see online supplemental file 1) was developed based on reviewed literature. The IDI guide was further submitted to the supervisory committee for review before data collection. The interview guide was modified after a pilot survey. The researcher also built on more probing questions. A back-to-back approach was used to translate the IDI guide, which was originally designed in English, into Twi and Dagbanli, by two language experts. The versions were compared for similarities and differences, and the necessary modifications were made. The reason for the study was explained to the participants.

Face-to-face interviews were conducted after both verbal and written informed consent forms were obtained from participants. The information collected from participants included: demographic and maternal information, level of awareness and attribution about fistula, experiences with different healthcare providers and challenges with health care-seeking. For each participant, the non-verbal cues and behaviours during the interview were noted. A field diary was also kept. The researcher also documented her self-reflections and other observations. The interviews lasted 45–60 minutes.

The data collection and analysis were carried out simultaneously. Data collection continued until saturation was reached (the point at which there were no new emerging data) in each of the centres before the data were merged. The researchers examined each audio-recorded interview for completeness before leaving the field. The audio-recorded interviews were transcribed verbatim after each interview session and organised using electronic files and folders. Coding was done by two researchers using NVivo V.12 software.

Data analysis

Thematic analysis was used to identify codes and categories across the data collected. The categories were then brought under the major themes and presented with some verbal quotes from participants.

Trustworthiness of the data was ensured by adopting the four principles of observing rigour proposed by Guba and Lincoln,[25] which consists of credibility, dependability, confirmability and transferability. To ensure credibility of the study, researchers carried out member checking. Six participants had a playback of their recorded interview to confirm whether it was a true reflection of the experiences they shared with the researcher. Pretesting, prolonged engagement and peer debriefing were also carried out. Dependability was also attained through peer and supervisory inquiry audit where the step-by-step process of the study was scrutinised. To achieve confirmability, researchers practised reflexivity; each researcher documented the possible bias that could be introduced to the research due to their background as health professionals. The rigorous steps followed during the data management and analysis also contributed to arriving at objectivity. The researchers made sure the selected participants best represented the research topic. In addition, data collection continued until the point at which there were no new emerging issues. The Consolidated Criteria for Reporting Qualitative Research checklist was adapted to guide the study to enhance rigour.

Table 1 Themes and subthemes on experiences with seeking fistula care

Main themes	Subthemes
Attribution and perceptions of fistula	1. Evil forces, act of God and bad luck 2. Immoral lifestyle/infidelity 3. Health workers' error
Competing alternatives/multiple sources of care	1. Availability of multiple sources of healers 2. Previous repair failure
Lack of awareness and limited access	1. Limited fistula repair facilities/long periods awaiting surgery 2. Long distance to health facility/multiple travels 3. Ignorance of repair services by patients and health staff
Financial barriers	1. Poverty and unemployment 2. Cost of transport/surgery
Psychosocial challenges	1. Fear of operation 2. Stigma and isolation 3. Support system 4. Travel inconvenience
Abuse by healers	1. Raped by healer/ritual baths, shaming 2. Extortion/exploitation

Patient and public involvement

None.

RESULTS

Most (n=18) of the 37 participants were aged between 28 and 37 years, with 6 participants aged between 18 and 27 years. The age at marriage ranged between 12 and 34 years, with the majority (n=22) of the participants married between the ages 12 and 16 years. At the time of the study, 19 of the participants were divorced. The outcome of the birth or delivery that led to the fistula was mostly characterised by stillbirths (n=19), with nine neonatal deaths. The majority (n=21) of the participants had lived with fistula for 6–10 years. Most (n=22) of the participants had no formal education.

Themes generated from this study were: (1) attribution and perceptions of fistula; (2) competing alternatives/multiple sources of care; (3) lack of awareness and limited access; (4) financial barriers; (5) psychosocial challenges and (6) abuse by healers (table 1).

Attribution and perceptions of fistula

Many of the women attributed obstetric fistula to evil spirit activities such as witchcraft spells, curses and bad luck. Some also attributed it to infidelity during pregnancy and disrespect towards the elderly. A few speculated that though the condition was linked to childbirth, it still had a spiritual connotation. The women further blamed it on delays and incompetence of medical personnel. Whichever attribution they gave to the disease influenced their help-seeking experience.

Witchcraft activities and punishment for misdeeds

The narratives from most of the women with obstetric fistula centred on supernatural attribution to the cause of obstetric fistula and were verbalised by one woman as:

> Madam as for this disease, there is evidence that it is 'sumsum mu yaree' [spiritual disease]. How can one sickness affect you for so many years, and cause you to be barren? The disease affects every part of the body, and if you do not take care, you will end up removing your dress and going mad on the street, or even kill yourself. (P1)

Another woman, ascribing her condition to an act of God, added:

> …He is in control of everything that happens to everybody, if he had allowed this to happen to me…, well he knows why. (P2)

A woman, commenting on how her in-laws attributed her condition to infidelity during pregnancy, said:

> … they blamed me over something I was ignorant about, they said promiscuity during pregnancy was what caused this urine disease, but it is not true, at least not in my case. (P3)

Others who felt they were deceived by the spiritualist consequently developed mistrust, and rather believed in the medical explanation.

> Me, I think the spiritualist does not tell the truth. Initially he said it was my mother-in-law who cursed me, when my in-law confronted him, he now said I was disrespectful, which was also not true. Since then, I accepted what I was told at the hospital initially, that it was the delayed birth that led to the urine disease, so I only prayed at home and waited till Ante [Nurse] brought me this good news. (P4)

Health workers' mistakes

Affirming the perception that health workers' mistakes caused the urine disease, a woman said:

I believe strongly it was the doctors who made a mistake and cut something inside me during the operation when I was going to give birth. I am not the only person in my community who stayed long in the house before visiting the health facility. People in my community even deliver at home and there is no trouble. (P5)

Lack of awareness and limited access to fistula repair services

Perceptions and wrong attribution persisted because of lack of information about the condition and the possibility of repair. Most of the women described how they lived with the condition for a long time before getting information that it was curable. Some even felt they were the only ones experiencing the 'strange' condition. The limited access to repair services was also a major deterrent to seeking medical care.

The narratives below corroborated limited awareness and access to obstetric fistula repair services:

I never knew of this centre in Tamale here. Although I used to pass by this area often, I did not know until now, it is not popular at all. I also did not know that repair was even possible. All this while, I thought I was the only one afflicted with this 'strange disease'. (P6)

A woman described how she was misinformed and misdirected by health workers whom she thought were the custodians of information pertaining to health:

Even the nurses at Korle-Bu [Tertiary Hospital, Accra] did not know there was any other facility that could repair this condition apart from the Tamale centre. I had come from Half Assini on two previous occasions. I met the doctor this time and he asked me to go to Mankessim to write my name, he also said the operation was free. Abah! I was wondering how both nurses in Half Assini and Korle-Bu could not tell me this long ago? (P7)

The limited number of fistula repair centres in the country makes them inaccessible to the women. This was also compounded by the limited number of fistula surgeons, leading to long waiting times and multiple travels in search of treatment. When there were delays in accessing care, they either resorted to other forms of treatment or resigned to fate as narrated below:

When I became frustrated with the 'go- come go-come', I was told only a few doctors could heal this disease. I finally landed at the Tamale Centre, but they told me they had a tall list. I kept checking on them till one day they had pity on me and added me. (P8)

The women in this study described the long journey to the repair centres as a big burden to them. They also had to travel at least twice to the centres before the surgery was performed. The first travel was usually to make enquiries and subsequent travels either for confirmation or for the surgery. Another participant said:

I went front and back till I landed in Koforidua hospital. They also directed me to Korle-Bu hospital, oh, madam, I have suffered ooh, I was told to bring a referral letter from the hospital where it occurred; when I came back to Suhum, they said the doctor who operated upon me had gone to school. When I went back to Korle-Bu too, they said the fistula doctor has travelled again. I came home and we lost hope, but later, I heard about this unit in Mankessim here. (P9)

The quotes above depict the frustration women with fistula go through, having to travel long distances and multiple times.

Competing alternatives/multiple sources of care

Out of desperation from the long waiting time and lack of access to the repair centres and ignorance, some women resorted to seeking healthcare from multiple or alternative sources which were readily available within their communities. They either visited the hospital first then the herbalist and or witch doctors or vice versa. Others also moved from witch doctors to prayer camps, to 'mallams' then to the hospitals, combining all four. There were only a few who moved from hospital to hospital; even in those situations, they still added prayers.

A woman described how she combined multiple sources out of desperation:

I started with the family herbalist, as things got worse, he introduced me to a powerful fetish in the community, he also tried to heal me, but it did not work. I finally landed in a prayer camp at Elubo, eh! I have suffered a lot. I came home and was only using herbal preparations to keep fit, even when I heard about this clinic, I was already fed up with seeking care. (P10)

Another woman described how she moved from one fistula facility to the other after disappointment with her first unsuccessful surgery hence adding alternative forms of treatment.

I had surgery two years ago. Initially, the urine reduced, but when I got home, it became worse, they rather created a bigger hole for me, I decided not to go there again. I stayed home for 2 years using herbs and prayers and once a while visiting soothsayers who told me all sorts of stories. I go to church but this time I was so desperate. Later, I was advised to go to Mankessim for the second surgery but when I got here, I realised one of the doctors I met in Tamale is part of the team over here too, hmm. (P11)

Financial barriers

Financial barriers came up strongly as a reason why women delayed seeking care for fistula repair. The long-distance, multiple travels to the centre and seeking

care from different sources made seeking treatment for fistula a very expensive venture. The cost in this context included the cost of surgery, transportation and personal items needed for hospitalisation. It also included paying for laboratory investigations and sometimes paying for National Health Insurance Scheme. This brought untold financial burden to the women and their families who were already poor.

The women narrated how poverty and unemployment influenced their care-seeking as follows:

> …I did not have any money, not even for food, even keeping clean was a problem. Ante, you know this condition, sometimes even soap…, so initially I did not make any attempt to visit the hospital, where was the money? I am currently not working. In fact money was the main issue. (P12)

The long distances and nature of roads the women had to travel to the fistula centres accounted for the exorbitant transport fares for these women. Most of the women also travelled with a companion (either a spouse or a family caregiver), and this meant paying double for transportation.

> …We spent a fortune from our place to the hospital. Oh, the roads are bad, so the drivers charge so much. We did not know how often we may have to go there before we meet the doctors, and they said they could not give us the fixed date because the doctors keep changing the time. We had no means to check, and we could not afford going there several times, that was how we gave up because the transport cost was deadly. (P13)

In their narratives, none of the women could tell the actual cost, which according to them, was too expensive. It was also found that the high cost of repair they alluded to was sometimes exaggerated or only imaginary.

> …When I heard the cost involved, I couldn't go back for the repair, that is why I resorted to herbal treatment and prayers till now that this facility has decided to offer us free surgery and transportation, because who will give me transport again? I do not have any property to sell again. (P14)

Probing on the cost of surgery, another woman, replied:

> I did not know exactly how much the surgery cost then; they only mentioned a huge figure and told me it was so expensive that I cannot afford. (P14)

Psychosocial challenges

For most women in this study, the health-seeking experience was characterised by psychosocial hurdles of stigma, travel inconvenience, lack of support system and fear of surgery.

Pertaining to stigma and how it prevented care-seeking, a woman, alluded:

> I felt I did not deserve to go to where human beings are. I was smelling too much no matter what I did, I did not want to come here at all. I thought I was the only one with this disease and did not want to be despised. I had already been despised a lot, even by my own family. I felt the operation was not necessary. (P15)

Travel inconvenience

The inconveniences associated with travelling long distances on a commercial vehicle with leakage of urine, coupled with inability to afford car rental services, made it difficult to access care. The women described how they deferred going for treatment due to the inconvenience of boarding a commercial vehicle.

A woman voiced her experiences:

> After struggling to get my transport fare, I was afraid other passengers may not allow me to join the car due to the stench… look at the distance from Obuasi to this place [Mankessim]? I needed to get down several times… very worrying. I set off at dawn, I had to pick the car 'piece, piece' so I could be changing my rags and clothing, which made the transport cost more expensive…. (P16)

Another woman, who was transported by the district assembly, discussed how difficult it would have been for her to have travelled by a commercial vehicle, considering the long distance:

> I knew I might get treatment in the big hospital, but looking at the place, how do you go there with this stench. Which car will even pick you? … it is quite a long distance… what if the faeces drop together with the urine in the car? Even people in this village are avoiding me and treating me like an animal, what should I expect from those in the city who do not know me? For me, there was no way I could have dared to pick a public transport in this my smelling state. (P2)

One woman moved from one fistula facility to the other after an unsuccessful surgery. A few also resorted to alternative forms of treatment after an initial unsuccessful operation.

Most women described how a lack of support system affected their health-seeking negatively and led to delays. To some, the support system comprised of people who brought the news of the free surgery campaign. In some instances, these persons were not necessarily family members. A woman described how a non-governmental organisation (NGO) assisted her to get repair services.

> Until I met these people [NGO], I had nobody to help me…when I told him [husband] of my plan to travel for treatment, he said it was just an excuse to travel to the city for promiscuity, so he will not allow me. Meanwhile, he had two other wives, so he did not care. I had given up on ever getting treatment. (P14)

A few of the women were prevented by relatives from travelling long distances for treatment. This was verbalised by a woman as follows:

> My in-law said looking for treatment for me is of no use, and that only God knows why this sickness came upon me. They also threatened me not to go anywhere for so-called treatment or I will risk not returning to the compound. He [husband] told me he wanted to focus on the new wife who was about to bear him a son. They [husband and mother in-law] wasted my time for all these years, only to sack me in the end… but every misfortune they say, is a blessing in disguise. (P6)

Another woman described how she was prevented from coming to the treatment centre by rivals who felt going for surgery will affect the family budget.

> My husband complained of poor yields from our farm and said mine could wait…They [rivals] also said that, after all, I have been like this for long, so waiting for one more year will not cause any harm. I became helpless, this was about six months ago, so last month when ante nurse told me the treatment was now free, including cost of transport. I took a loan of 200 Ghc from Ante Nurse and came here with my aunt. (P13)

Fear of surgery

The word surgery to most of the women meant 'cutting a person open'. Some women indicated that they were afraid and thought the surgery may not work or the condition could worsen. This fear of surgery usually delayed seeking medical treatment.

> The doctor told me he will do the surgery, but if I am fortunate, it can stop completely, or it could be 50/50. I was frightened, so I did not honour the first appointment. I missed the second appointment too; they told my sister it was now free so they were calling those of us who could not afford. My sisters forced and brought me here this time,… If not for the fear of operation, I would have been operated upon last two years. (P17)

In addition to the fear of surgery, few of the women were hesitant to show their genital area to the surgeons due to the smell and the sores.

> …Madam, apart from the fear, the whole place was not good at all [discoloured and disfigured with sores] and sometimes the smell too. It is natural to avoid the operation at the initial stages, but most importantly sometimes I feel like how the place is tight, if they cut and it does not heal well, a bigger hole will be created, and the urine will rather be profuse. (P18)

Abuse by healers

The women suffered dehumanising experiences and extortion from unscrupulous so-called healers. Almost all the women who visited spiritual healers experienced some level of deception and financial exploitation. Their abusers either threatened them with curses after the sex episodes or told them they were challenging the directions from the oracles when they refused to yield to their sexual advances. For those women who escaped the rape attempts, it meant that they could not continue with the treatment regimen. Although this was experienced by only few women, it was of great concern.

The women narrated their experiences with exploitation from healers in the following excerpts:

A woman, recounting her experience with extortion by a healer, reiterated:

> The Mallam demanded so many items from me including old currency in the form of coins, the shells of a tortoise, crocodile bile, fats and oils from a snake and a whole lot of things from the witch market. But I was still not seeing any improvement, then he requested for a cow and huge sums of money as an ultimate sacrifice. We really struggled to pay. Yet… 'no show' [no improvement]. (P16)

Again, P16, describing her rape experience, said:

> …Then he [mallam] said I must come and live with him for 7 days, because the one who gave me the disease also wanted to kill me, but the very night I got there, he gave me some oil to bath, after the bath I felt sleepy, and he raped me. It was as if I was watching a movie. I could not believe it, after that he also threatened me, this was about 10 years ago but I still remember vividly.

Another woman also narrated her near-rape experience at a prayer camp like this:

> … One day he attempted to rape me, and I hit him hard on his groin area and I escaped …early that dawn, I left the prayer camp, this was the second time someone I trusted to be capable of helping me spiritually, nearly raped me. (P1)

Apart from rape, others faced dehumanising ritual baths. A woman recounted her ordeal with a witch doctor:

> I was taken to a small river at noon, then I was stripped naked. They slaughtered a spotless white sheep and poured the blood directly of my head. It dribbled down my face to my whole body, they made me wash myself in the river and brought me a white calico to clean my body. Some people from the shrine followed me with palm branches and hooted at me till we got to an intersection. All this while, I was naked. This, they said was to break the curse of urinating on myself. It was my most humiliating moment with this condition, and yet the urine persisted. (P19)

DISCUSSION

The study explored the experiences of women with fistula in two fistula centres in Ghana, from the onset of the condition until surgical treatment was obtained. It also describes their interactions with health staff and traditional healers. The main themes that emerged were as follows: attribution and perceptions of fistula, competing alternatives/multiple sources of care, lack of awareness and limited access, financial barriers, psychosocial challenges and abuse by healers.

Most women lived with obstetric fistula for over 10 years before accessing surgical care. The narratives from the women depicted frustrations and misery in their health-seeking journey.

Obstetric fistula can only be cured through medical approaches such as surgical repair,[3] yet for the women and family to seek a form of treatment, they needed to have the right attribution to the disease. In this study, obstetric fistula was mostly attributed to evil spirits and punishment for immorality. A study by Wall[26] reports that most women with obstetric fistula do not appreciate the biomedical explanations of the disease. Other studies in Ethiopia,[27] Nigeria,[13] Burkina Faso,[28] Tanzania[14] and Ghana[4 29 30] found similar attribution to obstetric fistula. The few women who believed in biomedical attribution still believed that the disease condition had a spiritual connotation. This probably explains why they sought help from multiple sources. Lack of understanding of the causes of fistula therefore led to increased delays in seeking surgical repair as also reported in other studies.[17 23 31 32] This lends credence to the women seeking other forms of treatment, which were mostly ineffective. This is an indication that even if appropriate care is brought to the doorsteps of women, misconception could still prevent them from seeking surgical care. Once the women in this study gave metaphysical explanations to obstetric fistula, it became obvious that their treatment pathways would include seeking other forms of treatment. Previous authors have indeed suggested that hospital treatment is considered inappropriate and ineffective when a disease is given a spiritual or metaphysical explanation.[9 16 33] In Ghana, faith healing is found in many cultures with each of them having specific healers.[34] Most women in this study were more likely to contact faith healers first, since they were readily available in their communities and were also considered cheaper options. Others used both medical and faith healing concurrently. Indeed, previous studies found that most women with fistula sought traditional medicine first before looking for medical care,[17 29 35] sometimes doing so when other forms of therapies have failed.[12] On the contrary, Maulet *et al*,[14] in their study, found movement from one health facility to another, sequentially, with few seeking help from faith healers only in cases of surgical repair failure. Most women who used competing alternative healers concurrently believed that, when one fails, the other will work, as described in Wall's[26] concept of 'therapeutic pluralism'. It has however been argued that, although women report to the hospital as the first point of contact, the system's failure drives the women away to alternative healers.[17] These system failures in this study included lack of awareness even among health staff, and limited fistula repair centres and surgeons.

The issue of lack of awareness of available fistula centres and the possibility of cure influenced the help-seeking pathway and accounted for the prolonged lag time between the onset of fistula and the first hospital visit. The findings of this study concur with that of Wall[26] and Okoye *et al*,[13] where women with obstetric fistula in Nigeria ascribed their long waiting to ignorance about the existence of fistula repair services. Earlier studies in Ghana had similar findings.[29 35] Lack of information on fistula repair services has also been documented in two systematic reviews.[23 31] Regrettably, the few women who visited the clinic at the initial stages of the disease were either misdirected or misinformed by health staff. This implies that the health workers did not have adequate information on where the women with obstetric fistula could access treatment. This was common especially at the rural level. Therefore, the women travelled multiple times to unnecessarily long distances in search of treatment. Khisa *et al*,[17] in a study in Kenya, have referred to the lack of awareness on fistula among health workers as a 'shocking reality'. In view of this, they described the hospital as a 'key disperser' of women seeking medical care for fistula to other competing care providers.[17] This has also been documented in other studies.[14 27 31]

Most women in this study were on long waiting lists before the final call for the surgical repair. This could be ascribed to the lack of resident fistula surgeons. Similarly, previous studies highlighted the lack of skilled surgeons and limited fistula repair centres as major challenges in the management of obstetric fistula.[4 36 37]

For a woman with obstetric fistula to seek help at the hospital, she needed to overcome the psychosocial hurdles of stigma, travel inconvenience, lack of autonomy and fear of surgery. This pushed women further towards non-medical care.

The stigma associated with obstetric fistula led to self-isolation, divorce and abandonment, which made it difficult for the women to access medical healthcare. Stigma, coupled with the inconvenience of travelling in a commercial vehicle, was a common experience in the health-seeking path of the women. This made the women feel uncomfortable travelling in a commercial vehicle. Similarly, other studies mentioned shame and travel difficulties resulting in delay in seeking care for obstetric fistula.[4 9 38] This was often compounded by the fact that the women lived far from the fistula repair centres and could not join public transport because of the stench and constant urination. Stigma remains a major hurdle and a barrier in the women's pathway to seeking health. In some situations, the family also kept the condition as a secret to prevent being stigmatised. Meanwhile, there is a popular saying among Ghanaian cultures that 'it is only when you sell your disease that you receive a cure',

meaning that disclosure rather than isolation promotes help-seeking. Isolation therefore deepened the unawareness level and led to delay in accessing surgical care.

The financial challenges and overdependence on family, which were common among study participants, resulted in a lack of autonomy and waning family support. In the women's narratives, lack of psychosocial support and financial autonomy was mentioned several times as deterrents to care-seeking. There have been similar findings in other studies in Ghana where some women with obstetric fistula needed permission from husbands or mothers-in-law or were prevented from going for treatment.[4 29 35] This also resonates with studies in Kenya,[9] Bangladesh, Guinea[39] and Nepal.[40] The study further revealed that women who lacked social support lived longer with the condition and displayed winding healthcare-seeking experiences. The finding is also consistent with other research works.[23 35 41] The family support might have waned due to economic burden and stigma associated with living with persons with obstetric fistula. A few women who were abandoned by family and community members were fortunate to be supported by other sources. On few occasions, it was the support system who brought the news of the free fistula surgery campaigns to the women, since the affected women were hiding from people. For instance, in this study, some women shared their experiences on how catholic nuns and the district assemblies in the northern region of Ghana transported them to the fistula centres.

Most women in this study were poor even before the condition occurred and the fistula further worsened their plight. For instance, some lost their jobs and employability due to stigma and weakness associated with the disease. It was therefore more common for them to patronise the competing alternatives especially if they were cheaper and convenient to use. The cost of repair of 3500 Ghanaian cedi was unaffordable to most women, since they sometimes could not even afford the transport cost to the repair centres even where the services were free. This finding corroborates that of other studies which described poverty as a major obstacle to care-seeking.[16 17 41] This could be explained by the outcome of the 'M-PESA' Project in Tanzania, where transportation fares to the repair centres increased the number of women seeking treatment by 65% within the first year.[42] For instance, another donor project in Ghana, instituted by Access Bank Ghana Limited in 2018, where 100 women with obstetric fistula were sponsored for surgical repair and transportation, increased the number of cases repaired within the period. It has therefore been suggested that altering the healthcare services to suit the women's needs encourages early reporting.[43] Providing financial support for surgery and paying for the cost of transportation in cases where the surgery is free are enablers for seeking surgical care.

Women in this study verbalised abuses by traditional healers as being common in their health-seeking experiences, most of the abuses centred on financial exploitation. A few however cited sexual harassment and rape. Yet, the issue of rape in the course of seeking treatment for obstetric fistula is worth discussing, since it borders on human rights abuse of the women. Financial exploitation by traditional healers in a bid to cleanse women with fistula has also been reported in Kenya.[9 17] Other reports have also confirmed sexual abuse of women with fistula by traditional healers.[44] In a related article, women with mental health problems have also been cited as being sexually molested by traditional healers in Zambia.[45] Sexual abuse by healers could be described as an unpardonable offence against women with fistula who could be classified as a vulnerable population. Some women in this study might have not disclosed information on rape due to its sensitive nature. The activities of witch doctors and traditional healers must be strictly monitored, and the unscrupulous healers must be sanctioned. The general lack of information on the disease condition and the lack of sanctions for the culprits could perpetuate the extortion and sexual abuses that are meted out to women in their health-seeking experiences.

As the study was facility based, only women seeking care at the fistula centres were included; this was limiting, since it did not include other women with obstetric fistula outside the healthcare facility. Despite the above limitation, this study was conducted in the two main dedicated fistula centres in Ghana. The women came from varied socioeconomic and ethnic backgrounds across Ghana, giving it some level of representativeness.

Conclusions

Women's attempts to seek fistula treatment were characterised by enormous challenges. These challenges explain why they lived with the condition for a long time before seeking medical care. In most cases, the condition was given supernatural attribution at the initial stages, and this dispersed the women with fistula to other alternative practitioners. The use of alternative healers led to exploitation and abuses, which sometimes led to desperation. Almost all the women in this study engaged in some form of spiritual activities at one point in time during their care-seeking experience. It was common to find the women and their families combine different forms of treatment either sequentially or concurrently. Stigma, travel inconvenience, lack of autonomy and poverty were major barriers that women with fistula needed to navigate to obtain treatment and cure for their condition.

Based on the above findings and discussion, the study authors recommend continuous awareness creation on obstetric fistula prevention and treatment through radio and television broadcast. Improved access to fistula care services by the Ghana Health Service is necessary to encourage early reporting and empower survivors of obstetric fistula. Improvement in referral and ambulance systems to the fistula repair centres and public–private partnership approaches are further recommended to deal with the transport and financial barriers to accessing care. Supervision and punishment of herbalists and

quack healers who abuse women are also recommended. Further research on reintegration of women with fistula after surgical repair is warranted.

Contributors This work was conceptualised by EA. EA designed the study, wrote the protocol, managed the literature searches, collected data and wrote the first draft of the manuscript. This study is part of a PhD study supervised by RA, JG, EM and SE who are all coauthors. AMA-O and EKS supported the literature search, manuscript preparation and proofreading. All authors revised and approved the final manuscript. EA accepts full responsibility for this article.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Ethics approval Ethical clearance was obtained from the Noguchi Memorial Institutional Review Board in Ghana (#031/17/18) and Ghana Health Service (GHS-ERC: 010/10/17). Permissions were also sought from the fistula units. Written and verbal consent was sought from the women who participated in this study. The women were assured of anonymity and confidentiality. Voluntary participation was emphasised. The participants were also assured that they could decline at any point during the study without having any challenges with the care they are receiving from the facility. Consent was sought for the interviews to be audio-taped.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available.

ORCID iDs
Ernestina Asiedua http://orcid.org/0000-0002-2506-9878
Ernest Maya http://orcid.org/0000-0001-6050-6837

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