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North-central Nigerian women's experiences of obstetric fistula risk factors and their perceived treatment services: An Interpretive Description

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ABSTRACT

Background: An obstetric fistula also known as vesico vaginal fistula (VVF), or recto-vaginal fistula (RVF) is an abnormal opening between the urogenital tract and intestinal tract caused by prolonged obstructed labour; when the head of the baby presses on the soft tissues in the pelvis leading to loss of blood flow to the women's bladder, vagina, and rectum. This can cause necrosis of the soft tissues resulting in debilitating fistula formations.
Aim: This study aimed to uncover North-central Nigerian women's experiences of obstetric fistula and their perceived treatment services.
Design: Qualitative, interpretive descriptive methodology underpinned by symbolic interactionism involving face-to-face semi-structured interviews was used to explore North-central Nigerian women's experiences of obstetric fistula and their perceived treatment services.
Sample: A purposive sample of 15 women who had experienced obstetric fistula at a repair Centre in North-central Nigeria were eligible.
Results: Four themes emerged from North-central Nigerian women's experiences of obstetric fistula and their perceived treatment services i) I was left alone in the room ii) Waiting for the one vehicle in the village iii) I never knew about labour until that very day iv) and We kept following the native doctors and sorcerers.
Conclusion: The findings from this study highlighted the depth of women's experiences from the devastating complication of childbirth injury in North-central Nigeria. Analysis of insights from women's voices directly affected by obstetric fistula demonstrated that in their views and experiences the themes identified were majorly responsible for their fistula status. Thus women need to raise their collective voices to resist oppressive harmful traditions and demand empowerment opportunities that will improve their social status. Government should improve primary healthcare facilities, train more midwives and subsidise maternal care for antenatal education and birth services spending for childbirth women may result in improved childbirth experiences for women in rural and urban communities.
Tweetable Abstract: Reproductive women call for increased accessibility to healthcare services and the provision of more midwives to mitigate obstetric fistula in North-central Nigerian communities.

What is already known about the topic?

Previous studies on the topic of obstetric fistula have postulated its causes, however, none have reported the insights of fistula sufferers.

What is this paper adding?

This study adds women's experiences of obstetric fistula and views about its cause to the literature on the topic and provides previously unreported insights into this devastating complication of childbirth.

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1. Background

Obstetric fistula is a devastating complication of childbirth that affects over 2 million birthing women in the developing world [2,31]. An obstetric fistula is an abnormal opening between the urogenital tract and intestinal tract that occurs because of prolonged and obstructed labour, which causes the head of the baby to press on the soft tissues in the pelvis; this in turn leads to loss of localised blood flow to the soft tissues of the women's bladder, vagina, and rectum, resulting in necrosis of the soft tissue [15,30,33]. In Nigeria, the prevalence of obstetric fistula is estimated at 3.2 per 100 births; approximately 13,000 new cases are recorded annually [11]; [25]. Obstetric fistula occurs mostly from injury to the bladder during gynaecological procedures or radiation treatment, however, it remains a major problem in sub-Saharan Africa and Asia [26,41]. The condition is uncommon in the industrialized world, however, and it has been put forward that this may be due to a comparatively higher standard of midwifery care in higher-income countries [21,44].

The most common cause of obstetric fistula in developing countries is obstructed labour from a lack of skilled birth supervision and poor access to prompt quality interventions that could have saved the mother and the child [2,18]. Nigeria experiences an insufficiency of healthcare providers and emergency services for birthing women, with poor access to healthcare facilities, emergency transportation, and skilled birth attendants (SBAs) [1,15]. Traditional birth attendants (TBAs) are more accessible and available than qualified midwives in rural communities in Nigeria, and at a lower cost for birthing services [11]. This means that many women in rural areas are attended by such TBAs if they choose to give birth at home. Unskilled birth supervision also results in high numbers of birth injuries such as obstetric fistula, and stillbirths [34]. Obstetric fistula can be repaired if women affected by it seek appropriate care or treatment [30]. Many women affected by fistula have historically believed that it was caused by a curse from witches or inflicted by God, and that they must bear it: this means that historically there has been a strong reluctance to seek medical care [32].

There is increasing recognition, however, both that this is not the case and that women affected by fistula have lost their key social roles such as wife or daughter and motherhood are unlikely to have a living child and are often abandoned by their husbands and wider family network [9,12]. Financial hardship and decreased employment are also characteristics of women with obstetric fistula, as well as a diminished capacity to socialise because of incontinence and its associated odour [9,10], resulting in erosion of self-worth and psychological trauma [22,43,45]. The Nigerian Federal Ministry of Health published a national strategic framework for the elimination of obstetric fistula (NSFEOF) that is between 2011 and 2015, however the goal was not met and no subsequent strategy has been produced [4,20]. It is now timely to address the complex causes of obstetric fistula, but the voices of women who have experienced this devastating complication of childbirth are largely absent in the scientific literature on the topic. The study reported in this paper aimed to address that gap in knowledge by examining North-central Nigerian women's experiences of obstetric fistula and their perceived treatment services.

2. Methods

2.1. Research design

An Interpretive Descriptive approach that honours subjective individual accounts, but also aims to bring to light what is common across individuals, was employed for this study [37,38]. In respecting these subjective individual accounts, space is created for the multiple realities represented by different individuals' perceptions of a phenomenon [38]. Researchers place their focus beyond individual participant accounts and narratives to better comprehend how all participants make meaning from and understand phenomena. In this way, interpretations emanate from actions and interactions with the inquirer through language, symbols, and texts [16]. The approach was deemed suitable for this study in which it was necessary to listen to women affected by obstetric fistula to learn from their experiences about what interventions may alter the risk factors for the condition in their communities. The research team comprised an experienced midwife who has practiced in northern Nigeria, two experienced Australian midwives who have worked with African migrant women who have sustained an obstetric fistula, and an experienced neonatal nurse who has worked in Africa with the neonates of women born unwell after extremely prolonged labour. Ethical approval to conduct the study was obtained from Edith Cowan University Human Research Ethics Committee; approval number 2020–00971. Ethical approval was also granted by Bingham University Teaching Hospital Jos, Nigeria approval number NHRec/21/05/2005/00705.

2.2. Study participants

Women who were affected by obstetric fistula formed the sample for this study. Purposive sampling, by which individuals who have experienced the phenomenon under study [23], was used to recruit participants. Criterion sampling was used in conjunction with purposive sampling to select suitable participants based on specific selection criteria [28]. The setting for the study was the Evangel Vesico Vaginal Centre of Bingham University Teaching Hospital (BUTH) in Jos, Northern Nigeria. Women aged 12 years and over with an obstetric fistula as a result of childbirth and able to give informed consent (>18 years) or for whom a responsible adult was willing to give consent (<18 years) were eligible to participate in the study. Women with an obstetric fistula who did not consent were ineligible to participate.

2.3. Sample recruitment

Annually, the Evangel Vesico Vaginal Fistula Centre (EVVF) holds a reunion event to which, women with vesico vagina fistula (both new cases of obstetric fistula and those who have undergone repair, successful and unsuccessful) from the community, are invited. Prior to the event, the Centre sends out individual invitations and information leaflets, issues community radio announcements, and displays poster invitations around the Centre and market areas. Family members and spouses of the women usually accompany them to the reunion. The reunion usually lasts for seven days, but women with obstetric fistula can remain at the Centre for as long as they wish to stay.

Prior to the reunion programme, a letter was sent to the director of the EVVF informing him about the study and requesting permission to carry out the study at the facility. Once this permission was obtained, the nurse in charge facilitated study recruitment by introducing the first author to the women at the EVVF. The first author spent some time at the EVVF to familiarize herself with the setting and to gain women's trust. Those who were identified as eligible for the study and met inclusion criteria were then approached by the first author, who provided an information sheet and a verbal explanation of the study in their native language (Hausa). The purpose of the study, its benefits, possible risks, confidentiality and participants' rights to participate or withdraw were all explained [6]. Women were invited to take one week to consider the information and to ask questions from the first author for clarity. Potential participants were then approached again, and those who agreed to take part were asked by the first author to summarise what they understood about the research and who were able to demonstrate their understanding of the project and agreed to participate were then asked to sign the consent form. A Hausa interpreter read the consent form to women who could not read, and those who could not write used a thumbprint; further, the interpreter was asked to sign a confidentiality statement before reading the consent form to the women. Following this process, 15 women agreed and gave their informed consent to

participate in the study.

2.4. Data collection

Data were collected through in-depth, semi-structured interviews that were audio recorded and typically lasted between 45 and 60 min; interviews were conducted in a quiet room at the EVVF by the first author. The local language (Hausa) was used by the first author, who is fluent in it to collect the data and each participant was given a pseudonym to maintain confidentiality. Each interview was in two sections. Firstly, sociodemographic data were collected from the participants and recorded separately [6] (see Table 1). In the second part, the participants were asked to share their birthing experiences concerning obstetric fistula (described as birth injury) following four prompts: i) Can you share your birth experiences that led to obstetric fistula (birth injury); ii) How have you been managing this problem of fistula (birth injury) before you came to the Fistula Centre?; iii) How could this fistula (birth injury) have been prevented from happening to you? and iv) What would you like to change about the care of women in labour to prevent this fistula (birth injury) from happening to women. Audio recordings were transcribed and translated by the first author which allowed the researcher to be immersed in the participants' narratives [6,36]. Comparisons were made between the transcriptions and the researcher's raw field notes. Translated transcriptions were reviewed by the first author listening repeatedly and by an independent translator who confirmed all the transcriptions by back translating to Hausa to ensure meaning had not been lost. To minimise possible researcher bias, the researcher kept a journal of personal reflections following the data collection process and continuously reviewed findings with all the authors throughout the data collection period. To increase the trustworthiness, the first author conducted follow-up interviews with all 15 participants for more clarification arising from the interview (Liamputtong, 2019).

2.5. Data analysis

A thematic approach to data analysis was employed, which initially involved reading and re-reading the transcripts to get a deep understanding of the main issues described [14]; [28]. Then, participants' words, phrases, or sentences relevant to the research question were coded; these codes were then sorted into several sub-themes and their accompanying data were organised in a computer spreadsheet for assessment of the strength of each: the more data the stronger the sub-theme; this process was followed until data saturation occurred. Finally, the sub-themes were arranged/clustered into themes [13,14]. Verification and agreement of the themes were conducted by all the authors.

2.6. Results

Women's socio-demographic characteristics.

The 15 participants' characteristics are presented in Table 1. The participants' ages ranged from 17yrs-50yrs. Ten participants (67 %) were married, four (n = 4, 26 %) were divorced and one (n = 1, 7 %) was a widow. Most of the participants (n = 6, 40 %) resided in Kano State (North-central Nigeria) and about half of the participants (n = 7, 47%) had a Qur'anic education, which is non-formal education. Only two participants (n = 2, 13 %) had secondary schooling. The majority (n = 14, 93 %) of the participants were unemployed. All participants (n = 15, 100 %) commenced their labour at home, with the majority (n = 10, 67%) spending 25–96 h in labour while (n = 4, 26 %) of the participants gave birth within 24 h. Most of the women (n = 12, 80 %) gave birth at a health facility, and the remaining (3, 20 %) stayed at home. All the women (n = 15, 100 %) had a stillbirth. Most of the women (n = 8, 53 %) were attended by Community Health Workers (CHEW) at birth. Some were attended by doctors (n = 4, 27%), and the others (n = 3, 20 %) were attended by their relations. No participants were cared for intrapartum by a qualified midwife. The participants whose first birth led to obstetric fistula comprise (n = 12, 80 %) of the sample. Only (n = 3, 20 %) of the participants reported to the hospital for management of obstetric fistula within two years of developing the condition. Most of the participants (n = 7, 46 %) experienced obstetrics fistula for 2–10 years before seeking medical management in the hospital, while (n = 1, 7 %) lived with obstetric fistula for more than 30 years before having

Table 1
Socio-demographic factors of participants.

Socio-demographic factors of participants	Frequency	Frequency Percentage (%)
Age		
<18	1	7 %
18–20	3	20 %
21–30	5	33 %
31–40	5	33 %
>50	1	7 %
Total	15	100 %
Marital Status		
Single	0	0 %
Married	10	67 %
Divorced	4	26 %
Widow	1	7 %
Total	**15**	**100 %**
State of Origin		
Adamawa	2	13 %
Bauchi	1	7 %
Borno	1	7 %
Gombe	2	13 %
Kano	6	40 %
Niger	1	7 %
Plateau	1	6 %
Yobe	1	7 %
Total	**15**	**100 %**
Educational Status		
Primary	6	40 %
Secondary	2	13 %
Quránic	7	47 %
Total	**15**	**100 %**
Occupation		
Unemployed	14	93 %
Employed	1	7 %
Total	**15**	**100 %**
Hours Spent in Labour		
≤24h	4	26 %
25–48h	3	20 %
49–72h	6	40 %
73–96h	1	7 %
97–120h	1	7 %
Total	**15**	**100 %**
Pregnancy Outcome		
Alive	0	0%
Stillbirth	15	100%
Total	**15**	**100%**
Place of Birth		
Health Facility	12	80%
Home	3	20%
Total	**15**	**100%**
Birth Attendant		
Doctor	4	27%
Community health extension worker (CHEW)	8	53%
Relations	3	20%
Total	**15**	**100%**
Parity when fistula occurs		
First birth	12	80%
Second birth	3	20%
Total	**15**	**100%**
Years of living with fistula before coming to the Centre		
<2	3	20%
2–10	7	46%
10–20	1	7%
20–30	3	20%
>30	1	7%
Total	**15**	**100%**

medical management.

Four themes were identified from the data that demonstrate North-central Nigerian women's experiences of obstetric fistula risk factors and their perceived treatment services. Analysis of the insights of women directly affected by obstetric fistula demonstrates that, in their view and experiences, obstetric fistula is a result of poor birthing care practices such as leaving women to birth alone in the room, having to wait in an emergency for the one vehicle in the village, women's lack of knowledge of labour prior to experiencing it, and following native doctors' and sorcerers' treatment orders. The four themes, which are labelled using a representative in vivo quotes from participants, are reported below.

I was left alone in the room.

This first theme represents the accounts some women gave of being unattended by anyone for lengthy periods of time when in labour, only to then be rushed to the hospital after long-existing signs of complications or fetal death.

One participant described a scenario in her labour where this occurred:

'' I was left alone in the room [when] the native doctor [TBA] went out and brought different types of shrubs and herbs… [he then] gave them to me. ''FJ.

'' I had three-day labour alone, from Sunday to Tuesday, my husband was not around. I asked them to call my parents or take me to the clinic since they had nonchalant attitude. This was the argument while I was still talking until I could not talk, understand what happen or how I was taken to the hospital'' HM.

Some of the women who were able to make it to a village health clinic stated that they were turn back to birth alone at home because there was known staff on duty, as one participant said;.

''He [TBA] stayed and examined me for sometimes before he left, saying that I can deliver duly. But I could not deliver, the doctor [TBA] just left me alone while in labour and they did not take me to the hospital until Saturday midnight that they took me to the hospital. When we reach the hospital [village health clinic], you know during weekend there were no staffs on ground. Then they say they will not admit me, then I was taken to a private hospital, and they too declined admitting me'' FM.

Waiting for the one vehicle in the village.

The second theme is about how living in a rural area means the absence of local hospitals or health clinics close to the women and a lack of transportation, as well as poor access roads linking country communities with major towns where hospitals are situated. The situation becomes increasingly difficult during the rainy seasons. One participant explained;.

''There was one vehicle in our village…. Yes, only one, apart from that, there are … carts, the type that cows pull. The vehicle normally leaves the village very early in the morning to where he conducts his business and that day was Wednesday, they said he has gone to the market, and the only thing we can do was to wait for him to come back so he can take me to the hospital. Can you imagine leaving a woman in labour suffering, saying that you are waiting for a vehicle whose owner does not even know that you are waiting for him, that nothing will happen until he comes? And that was what happened. We waited until around ten (10:00 pm) o′clock in the night '' HY .

In addition to lack of transportation availability, many of the women could not afford the transportation fees to access the healthcare facility even when a vehicle was available:

'' The transporter will not even carry you because you do not have the money that will take you to the hospital…how can she get to the hospital? when she cannot have a penny to go to the hospital?'' FA.

Another participant explained in detail,

'' You have been in labour at home for two days, some five days, some even a whole week, everyone is tired, your husband does not have the money to hire transport, coupled with the fact that some transporters are very expensive, that is why VVF will keep increasing in Nigeria'' RY.

I never knew about labour until that very day.

Theme 3 represents how lack of knowledge about labour and the process predisposes many women to fistula occurrence. A number of participants could not identify early labour symptoms.

One participant says: *''I never knew about labour until that very day. I started feeling some pain; it will come again…and subside '' HU.*

Another participant professed complete ignorance's regarding labour as she narrates her story:

''My stomach started to pain me around 12 o′clock in the night. When the pain started, I woke my husband up and told him that my stomach is paining. He asked if it was labour and I said I do not know. He said, what can we do in the night like that? I suggested that we wait until morning and see. We were there just like that. As that was going on, I felt like I am going to pass stool, so I stepped out, as I was squatting, the child came out ''NN.

A lack of knowledge concerning the onset of labour was demonstrated by one participant as she stays a long period at home until she became exhausted.

''Since that Sunday when the pain started and I was still conscious to speak, I asked them to go and call my grandmother but they objected; I told them[relatives] my stomach is aching I never know it was labour. From Monday up till Tuesday, I was no longer myself, in fact, I could not recognize the one close to me'' RH.

We kept following the native doctors and sorcerers.

In the final theme, the lack of knowledge women has about where to access medical care to either aid labour or for a fistula cure once it has occurred is made clear.

The cure for labour dystocia proposed to one woman was described as follows:

''…the native doctor [TBA] went out and brought different types of shrubs and herbs… [he then] gave them to me. I kept drinking. He poured water on my body as I was drinking the herbs. After that, he came and was putting his hands into my vagina saying that he wanted to pull out the baby from my womb, but the baby never came out'' FJ.

Another participant shared the general perception in the community that fistula can be cured by using alternative medicine:

''Someone told my husband that what we need to do is to buy the head of a lamb, wash it without removing the skin, it is to be cooked like that with the fur. That is what they were to give me to eat, it is that fur that will go and block the place where the urine is leaking from'' HY.

This belief was also reported by another participant:

''We kept following the native doctors and sorcerers. They keep giving us roots and different types of native medicine. Sometimes they will give us a ram's head and tell us to cook it with a certain medicine they give us, without salt or any seasoning. They will ask us to cook the ram's head without removing the fur or the skin saying that if I eat it, I will get rid of that leakage'' FA.

3. Discussion

The findings from this study demonstrate North-central Nigerian women's own accounts of their experiences of obstetric fistula risk factors and their perceived treatment services. Analysis of the insights of women directly affected by obstetric fistula demonstrates that, in their view and experience, obstetric fistula is caused as a result of women birthing alone in the room, waiting for one vehicle in the village, lack of knowledge about labour until that very day of birthing and women's following the native doctors and sorcerer for treatment.

Our study revealed that the majority of the participants experienced poor birth practices at home as labouring mothers were left to birth in the absence of trained midwives, skilled birth attendants, or in some cases, anyone at all. This is reflective of the birthing culture in the region where this study was set: women labour at home, often alone, and often for an extended period before referral to a hospital; in some cases, they are never referred to the hospital even when complications are evident. Some of the cultural beliefs and practices evident in our study included birthing with unskilled birth attendants such as traditional birth attendants rather than qualified midwives, and this has been reported

previously [2,15]. Other research conducted in this context have also found that women are commonly expected, often by relatives, to wait at home and birth with unskilled birth attendants who have little or no physiological understanding of labour and birth [2]; [17]. However, a study conducted by Molzan Turan et al. [27] found differently: in the Ethiopian healthcare system, TBAs' role is acknowledged as that of a volunteer worker, and these practitioners only attend to women under the supervision of health extension workers; although their role and relationship have not been clearly defined [35]. Recognising the limitations of TBAs, Amodu et al. [3] suggest that regulating and monitoring their practice could be a starting point for the eradication of fistula, however, it is recognised that a lack of low-cost maternal care or free midwives' services at healthcare clinics may be the overarching reason for women being kept at home in the hands of relatives or community members [2,3]. A study conducted in the Cross River state of Nigeria to understand the effect of providing free maternal health care in pregnancy showed genuine increments in the number of women choosing to birth in the presence of skilled birth attendants following the removal of the direct cost to service users of maternal health services [19]. It is also recognised that to be able to offer free skilled birth attendants, an adequate skilled birth attendant workforce is necessary: five years ago, Amodu et al. [3] put forward that an increase in healthcare personnel in northern Nigeria was needed and our study suggests that this is currently still the case. Quality improvement in maternal care through the training of more midwives, as well as creating enabling communities for easy access to midwives' services, are crucial in mitigating the number of women birthing alone in the room in the absence of skilled birth attendants. Increasing political commitment and healthcare budget allocations are also noted by experts on this topic to be essential if the obstetric fistula is to be forgotten [3,4].

We also found that women were waiting for one vehicle in the village, suggesting that almost all the participants experienced transportation barriers, sometimes for financial reasons, in accessing health facilities. Degge et al. [18] has described the lack of transportation for women in labour as structural violence against women. More specifically, poor road infrastructure and natural geographical obstacles, combined with a lack of finances, conspire to limit access to skilled health care to prevent fistula occurrence in women [3,11]. Some of the women in previous studies who made it to primary health care discovered that there were no components of emergency obstetric care in primary health, and had to walk further and often for long distances before having access to appropriate healthcare for their condition [24, 27]. Women attribute a lack of essential emergency services as an indirect cause of obstetric fistula including delay in referring women to a health care facility with emergency services in a study conducted in Uganda; a lack of essential emergency obstetric services in the cases of an emergency, including a lack of a functional referral system, were reported by these researchers [5]. Picking up on these factors, Mselle, and Kohi, [29] have proposed that reducing obstetric fistula requires investing in healthcare and emergency obstetric services such as the provision of pregnancy-related vouchers for women to access skilled services and transportation.

Further contributing to the development of an obstetric fistula was that many women in our study shared that they had no idea about labour before they experienced it. Most participants were first-time mothers who were devoid of any knowledge of their bodies including signs and symptoms of labour. As a result, they laboured for a long time at home, often without contacting a skilled birth attendant. Additionally, the traditional birth attendants or family members attending to the participants at birth are perceived to have poor physiological knowledge of the health consequences of complicated labour. Our findings, align with work previously conducted where both the mother and the birth attendants have little to no knowledge of appropriate labour management or knowledge of signs and symptoms of labour [8,40]. Several reasons have been put forth as to why women do not acquire adequate knowledge of birth preparedness during their antenatal care visits [29]. One of them is if women were given substandard information, women never attend antenatal services or women attend but never allow their knowledge to inform their practice. The major elements of birth preparedness include making plans on how to reach an adequate healthcare facility, including birthing with some skilled birth attendants. However, Banke-Thomas et al. [8] mentioned, strengthening research that focuses on identifying information gaps that explore the best way of disseminating information for behaviour change for women will be an essential programme to prevent obstetric fistula in urban and rural communities.

Finally, our study mentioned that women were following native doctors and sorcerers for treatment of their fistula. Poor health literacy together with poor awareness of where to seek treatment put the participants in this study at risk of inappropriate cures for their fistula. Many fistula sufferers are living with their fistula not knowing where to go for treatment [33]; [39]; [42]. Fistula sufferers and their caregivers sought treatment in varying places including native doctors, herbalists and TBAs [33,40]. Women's poor awareness of where to seek appropriate healthcare for fistula is likely a reflection of their low educational status and social value [2,15]. Raising community awareness of the availability of surgical treatment of obstetric services may reduce the physical and psychological burden of women living with obstetric fistula. Nwala et al. [33] reveal that there is a lack of awareness of obstetric fistula including the availability of repair services at the community level even among family members.

4. Study strengths and limitations

This study provides previously unreported information on women's experiences of obstetric fistula risk factors including their perception of treatments and health services in North-central Nigeria, however, the data collected are specific to one region of one country only, so are unlikely to be generalizable. Nonetheless, the findings add to the body of knowledge on this topic and provide useful insights into the issue of obstetric fistula.

5. Conclusion

The findings from this study highlighted the depth of women's experiences from the devastating complication of childbirth injury in North-central Nigeria. Analysis of insights from women directly affected by obstetric fistula demonstrated that, in their views and experiences, women were left alone to birth in the room, women waiting for one vehicle in the village, lack of knowledge about labour until that very day of delivery and following the native doctors and sorcerers for treatments were majorly responsible for their fistula status. It is hoped that the findings of this research will give insight into the causes of this devastating complication of childbirth and that they serve as a call to action in areas of service provision, policy development and the creation of community awareness to enhance positive maternal outcomes in the area of healthcare.

Details of ethical approvals

Ethical approval was obtained from Edith Cowan University Human Research Ethics Committee; approval number 2020–00971. Ethical approval was also granted by Bingham University Teaching Hospital Jos, Nigeria approval number NHRec/21/05/2005/00705.

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CRediT authorship contribution statement

LB conceived the study and wrote the study protocol with input from

DI, EA and SB. LB recruited participants and collected the study data. LB, DI, and EA, analysed the data with input from SB. All authors commented on manuscript drafts and approved the final version.

Conflict of Interest

None declared. Completed disclosure of interest forms is available to view online as supporting information.

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We would like to convey our appreciation to all our participants for sharing their stories and to the managing director of the Fistula Centre We would like to convey our appreciation to all our participants for sharing their stories and to the managing director of the Fistula Centre, Bingham University Teaching hospital.

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