

report

FORMATIVE RESEARCH ON ASSESSING BARRIERS TO FISTULA CARE AND TREATMENT IN NIGERIA

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Acronyms

ANC	Antenatal Care
D&A	Disrespect and Abuse
FGD	Focus Group Discussion
HM	Head Matron
IDI	In-Depth Interviews
MoH	Ministry of Health
OF	Obstetric Fistula
PWD	People with Disabilities
RMC	Respectful Maternity Care
RMNCH	Reproductive Maternal Newborn Child Health
UTI	Urinary tract infection
VHT	Village Health Team

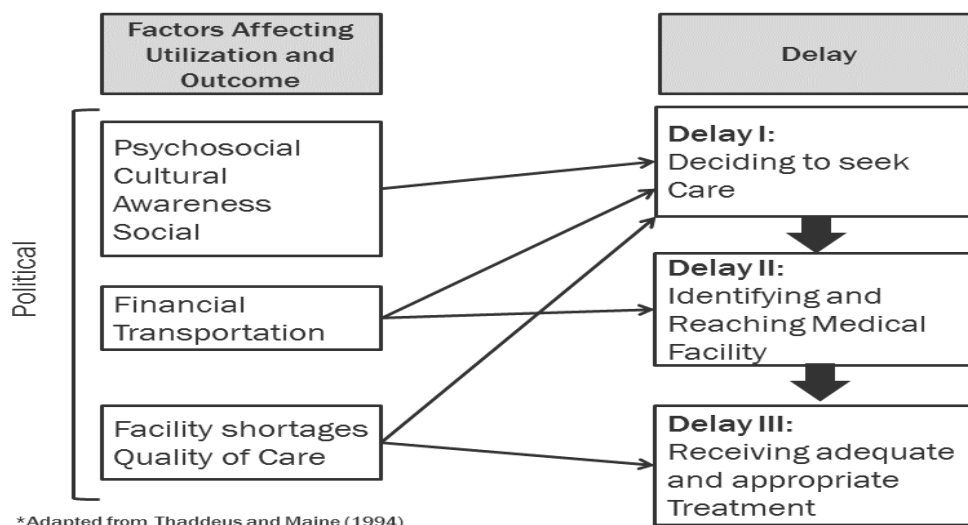
Background

Obstetric fistula affects 1.57 per 1,000 women in sub-Saharan Africa. Although more likely an underestimation, it is nonetheless indicative of a public health challenge, because the gravity of any condition—to an individual—is not necessarily a measure of how many others are in a similar situation. Obstetric fistula is the outcome of prolonged obstructed labor and, in some cases, under-skilled gynecological surgical interventions for procedures such as caesarean sections and hysterectomies that lead to iatrogenic fistulas. Obstetric fistula predominantly affects the lower social economic classes, who are often underprivileged, with little or no income and limited access to the social infrastructure to access safe delivery attended by qualified health personnel.

Women with obstetric fistula face stigmatization, ostracism from their homes, friends and families, and gradual depreciation of their senses of esteem, personal value, and overall outlook in life. Most obstetric fistulas can be corrected surgically, however. Despite its under-equipped and underfunded health system, Nigeria has the technical expertise and infrastructural support for obstetric fistula repair. It is free of charge in many fistula treatment centers across the country, by well-trained practitioners. In spite of this, however, many women still live with obstetric fistula and do not seek care, either due to lack of awareness of the existence of treatment methods and repair and centers, or simply because of economic, social, cultural, and other inhibitive factors.

A systematic review of peer-reviewed and ‘grey’ literature (Bellows et al. 2015) identified 110 studies relevant for understanding barriers to accessing obstetric fistula (OF) care in developing countries. These articles show barriers clustering in nine broad areas—psychosocial, cultural, social, financial, transportation, facility shortages, awareness, quality of care, political—corresponding to the Three Delays Model (Thaddeus and Maine 1994), which categorizes and describes the underutilization of maternity services that drives mortality and morbidity due to: 1) the delay in decisions to seek care by an individual or family, 2) the delay in reaching an adequate health facility, and 3) delay in adequate care once at a facility.

Figure 1. Three Delays Model to Fistula Treatment



To more comprehensively and holistically understand these **barriers** and potential **enabling factors** for alleviation, this study explored the perspectives those involved both in identifying fistula and accessing care, such as family members and other community stakeholders including patriarchs, matriarchs, community leaders, and other opinion leaders. It also examines the cultural patterns, myths, and perspectives related to OF and how they influence women’s willingness and capacities to access surgical care. By understanding these *barriers* and *enablers* in more depth, future interventions can mitigate these challenges for women with OF.

Methods of data collection, sampling, analysis

This study employed a qualitative research design using semi-structured in depth interviews (IDIs) and focus group discussions (FGDs) of women living with fistula, their family members, community stakeholders, and health care practitioners, in two fistula care centers and surrounding communities in the northern and southern parts of Nigeria (Kano and Ebonyi states, respectively).

IDIs included women affected by fistula (including those just repaired, post-recovery, awaiting discharge, and in follow up care), hospital fistula care workers (surgeons, nurses, and matrons-in-charge of operating theatres); and spouses, partners or other companions who accompanied women for treatment.

FGDs with community stakeholders included religious leaders, village or district heads, women’s groups, and traditional birth attendants (TBAs), segregated by sex, in addition to FGDs with women who had undergone fistula repair and were awaiting discharge.

Table 1: Description of Qualitative Data Collection

Sample	Description	Sample size
Women with fistula	Women awaiting repair Women who have been repaired Women awaiting discharged	20
Repaired and discharged women	Women in rehabilitation facilities Women on follow up visits	FGD I: 8 FGD II: 5
Family members of women with fistula	Spouses or relatives of women with Fistula admitted for repair	7
Health service providers	Fistula Surgeons and Nurses Pre-Op/Post-Op Ward Matrons Theatre Matron Guidance Counsellor Program Director	12
Community stakeholders (Women)	Community leaders/Religious leaders Matriarchs Union heads/ Social group heads	FGD I: 8 FGD II: 7
Community stakeholders (Men)	Community leaders/ Religious leaders Patriarchs Union heads /Social group heads	FGD I: 6 FGD II: 7

Data for all IDIs and FGDs were analyzed using an open coding system that allows for in-depth analysis of the data and identification of nuances of meaning, context, and outcomes.

Prior to data collection, necessary ethical approval was obtained from Population Council’s IRB and Nigeria’s federal and state ministries of Health, and were shared with the head of the facilities, for their records.

All participants were briefed on the purpose of the research, their voluntary participation was requested, and they were informed of their compensation (where relevant) and other required elements for obtaining their consent prior to their interviews.

All participants were at least 18 years of age. Although both centers were located in their state capitals, most patients were illiterate and from rural areas. Interviews with women living with fistula were conducted in both facilities, in Kano and Ebonyi, in several languages—English, pidgin English, Igbo, Iki (in Ebonyi), and Hausa (in Kano). Interviews were translated where necessary and subsequently transcribed into English.

Results

Awareness Factors

Barriers

There was broad lack of awareness of obstetric fistula, including its prevalence, causes, and characteristics, and this was a key barrier to women's care seeking, acknowledged by the majority of women and community members as the biggest barrier. Respondents lacked the ability to identify fistula when women experienced it, and furthermore did not know that corrective measures were possible, much less where to go for such treatment. Many women and families did not immediately seek care after discovering the fistula, waiting as many as three weeks, believing that other medical conditions like 'foot drop' were more important.

Most women and community respondents indicated that they had never met or heard of anyone with fistula prior to discovering their own condition. This ignorance leads to the belief that their condition is unique and irreparable, and sometimes leads women to not reveal their condition or seek help. Most women who sought care at facilities ultimately heard of those facilities from other patients or family members.

Providers, however, expressed limited knowledge of centers that repair OF, which sometimes leads doctors to attempt surgery multiple times before referring a patient to another facility, which can be just as deficient in skills necessary for repair. Nearly all referrals to fistula centers were not from doctors but other patients or relatives.

There is limited awareness of OF's causes. Most respondents had no idea it is the result of prolonged or obstructed labor; few were aware of its connection with maternal morbidity. Some respondents believed it was due to a medical accident or doctor leaving something sharp inside them. Some communities (especially in Kano) attributed OF to an act of God, or witchcraft, due to early marriage, or presumed weakness of a woman. This often leads women to initially seek traditional care before medical clinics, however, some women believe fistula is caused by harmful practices of traditional birth attendants (TBAs). Some men feel there is a connection between poor nutrition during pregnancy that may contribute to a fistula forming.

Early marriage was acknowledged as a possible cause of fistula, but most male participants, while acknowledging that early marriage can contribute to OF, did not feel it is due to physical immaturity, instead due to youth and lack of confidence in asking for help, or attracting attention at medical facilities.

Primigravidas were somewhat ignorant of a normal labor period. While multiparous women were quicker to recognize prolonged labor, their previous birth experience also represented a barrier to seeking care (many assumed they would be able to manage on their own at home), resulting in seeking care too late to prevent fistula. This was especially true in Kano.

Of those who were aware that OF could be treated, some knew it could be done surgically, while others suggested that OF could be repaired with drugs, prayers, or traditional medicine. Male respondents who knew that it could be treated nearly all responded that it could only be done in a hospital. When respondents were aware that fistula could be medically treated, they were still unaware that it could be treated surgically, for free, in government centers, and assumed it carried the same high cost as private facilities.

“What causes it is bad luck, what God allows to happen.”

FGD, community stakeholders, men

“I think it’s a projection from the witches kingdom because why will this happen to me considering the fact that this is my first pregnancy?”

Ebony respondent (3)

“The prophet told me that the woman is the cause of the problem...aunty I believe the prophet because the sickness did not do any of my sisters and even in my husband’s family it has never happened to anybody.”

Ebonyi respondent (8)

“No I have never heard or seen anyone. It was after I came here that I met with one woman who told me that she was here three years ago and was repaired.”

Ebonyi respondent (3)

“Initially we thought she squatted on a sharp object, so we tried treating her traditionally but there was no improvement.”

Ebonyi respondent (3)

“My husband asked for release but they convinced him that I will deliver normally. On the *sixth day* the doctor said the delivery will be through surgery.”

FGD, repair client

“I had not heard before and later, except the woman I told you about. I hid my experience, I didn’t tell anybody.”

FGD, repair client

“They will just be contending with food that is not nutritionally helpful to the child...pregnant women are supposed to eat nutritious food to help refresh her body but there is no money for such here, we are all farmers.”

FGD, community stakeholders, men

“This fistula, there is something that happened first: early marriage. Then they don’t get enough attention where they go for delivery and that brings about problem.”

FGD, community stakeholders, men

Enablers

Women respondents strongly felt that if women were aware that effective treatment options exist, they would certainly make the effort to overcome other barriers and go to a repair clinic. Because women typically hide their condition from their friends and families, they do not get information or suggestions on treatment, so respondents emphasized the need for a widespread and generic approach for awareness-raising and information dissemination.

Antenatal care (ANC) increases women’s awareness that OF can be caused by obstetric complications, and is possible to be corrected. Respondents suggested targeting faith-based organizations with awareness campaigns, as many women initially turn to their spiritual leaders when first experiencing fistula, and these leaders could then help alert women to a diagnosis and direct them to care centers.

Nearly all family members of women with OF demonstrated clear and relatively accurate knowledge of its causes, although this could have been gained from care providers after their relative went to a center and received care.

Ebonyi has good referral systems, where some women were told from the beginning of their care, at rural clinics, that they needed to be seen at the fistula care center.

Medical personnel in both Ebonyi and Kano emphasized their use of radio as a means of spreading awareness about their fistula centers; but only one respondent from Kano indicated it was how s/he heard of the center. Listeners are unable to ask follow up information or clarity over the radio, and lack of consistent electricity in rural areas limits the utility of radios for awareness-raising. Current efforts utilizing radio as an enabler for care have not achieved their anticipated reach in rural areas.

Women and family members also believe that specific efforts are needed to increase awareness that prolonged or obstructed labor is a contributor to OF so women seek medical care earlier in labor, rather than waiting too long and increasing their risk. It was also recommended that medical personnel, at all facilities, be sensitized on the risks of prolonged or obstructed labor, to prevent the cost and trauma of OF, and often repeated and unsuccessful surgeries.

“No I didn’t delay at all I went straight to the hospital when labor started because that was what we were taught during antenatal clinic.” *Ebonyi respondent (3)*

“Even if you go to the hospital in the village, you will be redirected here.” *Ebonyi respondent (3)*

“I think lack of sensitization is the major one because so many people are not aware of this place...I myself have never heard of this place and never knew this kind of place exists...I will tell everybody that cares to listen about this place...they should just look for transport fare and come.” *Ebonyi respondent (3)*

“Health care workers should be trained that once a woman has this kind of problem, she should be referred for expert management instead of trying and causing more harm to the woman...hospitals should come and learn from this place, as to how to be friendly to patients and not hostile.” *FGD, repair client*

“We don’t know who is suffering/has such problem. People in the community should be informed telling them what is fistula, how people get it, what can be done to avoid it and where one can be treated if it eventually occurs.” *Ebonyi, FGD with men, respondent (4)*

“Problem is that we don’t know who is suffering from such sickness, they used to hide themselves. If is from the information sensitization that people who are hiding can now know where to access medication...it is like when HIV came into existence.” *Ebonyi, FGD with men, respondent (2)*

“Using radio is good, especially if it is in in our local dialect, in *izz*, or *ezza*, *ikwo* or *mgbo*...but you cannot ask the radio any questions you did not understand.” *Ebonyi, FGD with men, respondent (2)*

Psychosocial Factors

Barriers

Psychosocial barriers to OF repair are particularly debilitating due to the fact they constitute the cognitive processing of social, cultural, awareness, and other contextual circumstances facing women living with fistula. In the respondents these barriers manifested in the feelings of depression, anxiety, lack of dignity in living, and lack of hope for recovery. A sense of worthlessness results in low self-esteem that ranges from feelings of embarrassment to lack of desire to care for the child born from the labor that resulted in fistula, and is often moderated by women’s social environments and other health conditions.

In every case, women also experienced shock from the discovery of the OF, as most had never met anyone with fistula or were aware of its potential to be corrected, it led to feelings of defectiveness and isolation.

Psychosocial factors are also influenced by women’s fear of what they will experience, as well as the negative experiences they actually have. This was a point acknowledged by all groups of respondents. Fear of stigmatization and isolation prompted many women to try and keep their condition a secret and avoid seeking help or advice. This led to a sense of helplessness in feeling unable to confide their condition in family, friends, or religious leaders. Furthermore, even for women who became aware of medical options to treat their OF, many were reluctant to follow through with treatment for fear that discovery would lead to stigmatization. These barriers to seeking care are also reflected on the issue of clinic location; only two respondents indicated a willingness to receive treatment near home, which may be because of a perceived sense of confidence in higher-level hospitals that are farther away, but which are also due to concerns over confidentiality and that being treated near home may result in people they know finding out about their condition leading to embarrassment and stigmatization.

“I started frying akara but nobody wanted to buy from me seeing me with that kind of child. I went to drop the baby in a motherless baby’s home but they refused to take the child.” *Ebonyi respondent (8)*

“Aunty this is not a sickness that people should know. Nobody knew about my own except my drunken husband who was telling everybody that his wife has this problem.” *Ebonyi respondent (2)*

“I went to the prayer house but couldn’t tell the pastor what was wrong with me [sobbing]. I don’t know how to present it. How will I tell a man that feces are coming out of me? I prayed and cried all through at that church.” *Ebonyi respondent (5)*

“It has secluded me and I always keep to myself. It has derailed me in business, I don’t go to my shop, I don’t go to market...I heard that people started gossiping that it is because I lost my child that am behaving strangely.” *Ebonyi respondent (3)*

“If she is operated at home, a scene will be created. People will be coming to peep and see what is going on. So and so has come and so and so person with uniform, what is going on in this house...this is private and confidential.” *Kano respondent (7)*

“She will not participate (in social gatherings)...she will be hiding herself...she will not like to go out in the public because of the embarrassment.” *FGD, community stakeholder*

Enablers

Providing psychosocial support for women affected by fistula involves relatives and communities understanding and responding empathetically to the stress felt by suffering women, as well as having better understanding about fistula. This can then enable them to help women to manage their condition in the household and being supportive of care-seeking, while reducing attached stigma associated with the condition.

Respondents believed that increased psychosocial support is key to women’s treatment and recovery, and that if psychosocial support were present then fewer women would feel the fear and stigmatization that prevents them from seeking care. Creating an enabling psychosocial environment would involve participation from the range of factors in women’s contextual circumstances, including their interactions with family, friends, spouses and partners, and religious communities. Each of these groups can play an important role in supporting the morale of women with OF; for example, the spiritual and emotional confidence women had in their religious leaders can play a powerful role in alleviating their emotional pain if these leaders were supportive and informative. Likewise, women who experienced acceptance by a partner also had much different psychosocial experiences than those who were rejected, which plays a role in how and when they seek care.

Women who came to the facility typically received a short ‘health talk’ about their prognosis, which all found to be reassuring and calming. Coming to the facility also seemed to cultivate a newfound sense of community among the women once they discovered that there were other women living with fistula, that their situation was not strange, and that they were sometimes in better conditions than they could have been. It was suggested that sensitization of medical personnel and improvement to the referral system could reduce the psychosocial trauma women experience after being subjected to multiple unsuccessful surgery by untrained providers who lack awareness of treatment centers.

“I have seen people who were operated, many of them came here and they are well now, that is why I have confidence that I will be well too. I was worried because people in the community have been saying that people don’t get well.”
Ebonyi respondent (7)

“All the patients here are suffering from the same sickness so we share our experiences...what I learnt is that fistula is not a disease...my case is even a *moi moi* [simple] case compared to what I have seen here. I carried my own for four months but a woman that has lived with her own for twenty years.”
Ebonyi respondent (3)

“Women with this kind of problem need encouragement, her family members should encourage and let them know that one day it will be fine.”
Ebonyi respondent (8)

“That is very important because it is an experience you want to hide inside yourself, not knowing that...”
Ebonyi respondent (1)

Cultural Factors

Barriers

Cultural dimensions such as gender roles, family dynamics, age dynamics, and influence of external family and traditional beliefs can all act as barriers that affect women’s decisions to seek care.

Women have limited role in making family planning decisions, let alone in deciding to seek obstetric care. This was especially true with multiparous women. For almost all respondents the decision to seek obstetric care was made by their spouse; where the spouse was absent, the decision was made by the parents or parents-in-law. This was frequently the case in the north of Nigeria, where women often go to stay with their parents during childbirth. In this case it is their fathers who make the medical decisions. Most of the few women who sought to make the decision without their spouse were financially obstructed by them from seeking care. Imbalanced gender roles were the foremost cultural factor that was cited by female respondents. There is the feeling that women are replaceable and that there can be indifference and even hostility towards specialized home and healthcare needs for fistula.

One significant obstacle in cultural gender norms as a barrier to care is the fact that few men acknowledged that cultural norms are a significant barrier at all. Men in the FGDs seemed to think these instances were rare. However male respondents did emphasize that the lack of access to skilled obstetric care was complicated by a poor sense of urgency on the part of pregnant women’s care givers. Such women were kept at home until it was sometimes too late to prevent serious complications or morbidity.

The decision to seek medical care was sometimes delayed because of cultural beliefs about giving birth at home being a sign of strength, leading to a too-long delay in seeking care while traditional remedies were tried and failed to facilitate delivery. But as opposed to being a generalized cultural phenomenon, some of these cultural positions were rooted in specific family customs of avoiding hospitals. In addition, religion and superstition play roles as barriers; religious centers were often a first stop for families when they discovered OF and could not find an explanation, and played a role in the initial decision to seek care or not, with things like prayer being first suggested as a remedy. Even when some religious leaders suggested medical care, the fact that there were conflicting messages coming from different leaders led to delays and indecision for women and their families. It was also noted that, though rare, some faiths and spiritual beliefs which do not believe in modern medicine were cited as reasons not to seek fistula care. And because superstitious beliefs are also present, they can obstruct seeking hospital based care because they attribute the cause of OF to be “witchcraft” or “an act of God”, rather than a medical condition. Male respondents were aware of superstitious beliefs as to the cause and cure of fistula, although they disregarded the traditional remedies to which they acknowledge women sometimes resort.

While not explicitly stated, female participants implied that women are of lesser value, and because of this their health and welfare during labor and delivery was not a high priority and care is delayed until the last minute. This trend was particularly revealed in discussions about early marriages, in which participants relayed that the question of delaying pregnancy until the girl was mature enough is met with suspicion and dismissal.

“I never wanted it. I have given birth to eight children...when my husband came up with the discussion of having another child I refused...friends and family intervened and it was resolved that I was still young and should have more children...I am really feeling bad about the way my husband treats me despite the fact that he is the cause of the problem.”
Ebonyi, respondent (2)

“If they want to bring a woman to hospital, they won’t bring her till either the head is out or the leg is out...whether they want to do CS or not, you will find that the work has already been done inside.”
FGD, community stakeholders, men

“I was seriously sick, I wanted to register for antenatal but he refused. He threatened that if I take even paracetamol, he will send me out of his house.”
Ebonyi, patient (2)

“[Sisters] are the ones who decide what happens in our family...they will tell you that if you disturb their brother, they will make life miserable for you because he is the bread winner...you can’t really do much.”
Ebonyi patient (4)

“They said it is not a must that we come to the hospital...his parents went and carried a medicine man...he mixed some concoctions and gave me and he also looked there [examined extent of labor]. I continued drinking the concoction up to the fourth day.”
Kano respondent (1)

“The doctor said I must undergo an operation. I went home and met with one pastor who told me not to go for the operation because I will die if I enter theatre... finally went to see another pastor who now told me to go ahead with the operation.”
Ebonyi respondent (8)

“Some rural women, when they are pregnant the mother-in-law herself would be dealing with the woman saying that during their own time they don’t deliver in hospital. They used to deliver at the back of the house.”
FGD, community stakeholders, women

“The only cultural something that can happen is only when a woman commits adultery, if she sleeps with other women, she will experience hard labor...people will ask her what she did...I don’t think there is any belief in our tradition that exist where women cannot seek services at hospital.”
FGD, community stakeholders, men

Enablers

Cultural norms have long and complex roots and can represent some of the most intractable barriers, especially gender and family norms. Reducing these barriers to empower women to decide and reach care necessitates a removal of power from the male or in-law sphere, and thus requires their participation and support. There were indications that this was present. For example, for younger couples, family planning decisions were mutually agreed. It may be that increasingly progressive modern ideas are becoming the norm with younger generations, and that the more young couples there are in communities, the more influence their own couple-dynamics can have over group norms.

Based on the experiences of respondents, increasing decision-making power for women would require a combination of spousal and family support, but it was interesting to note that the majority of women did not cite the need for additional family financial support. This may be due to the fact that women did not imagine their families could afford more financial support, or it may be that when the spouse or parents sanction a medical decision, the financial support goes along with it. However this may suggest that were women to gain more decision-making power, it would then be necessary to secure the same financial support for their decision (or a greater degree of financial independence).

Increasing women’s decision-making power could also require improvement in education and basic literacy for women to access resources independently and privately, rather than through word of mouth. The question of women’s education is also linked to the question of early marriage, as the two are often mutually exclusive. It was recommended by participants that this is a key role that parents can play: to discourage early marriage until girls are mature enough for childbearing, which would then enable them to stay in school for longer. A degree of family support for the health of women was already present, and could be drawn on to extend the support for women’s decision making; all participants noted that once the decision was made by the family for the woman to seek care, they were taken to the health facility without delay.

Spousal support was frequently noted as playing a key role in women seeking care, and many spouses were indeed supportive of them; this support must be extended further to women’s ability to decide care for themselves if women are to gain more agency in their own health decisions. Although it was observed that while the patriarchal nature of Nigeria promotes the spouse’s dominance and involvement in choosing whether to seek care, it may also be that the spouse is the first person a woman confides in when deciding whether to seek care, his support is the determining factor. This would suggest that some men may be more amenable to empowering women to choose care than previously thought. Indeed, one woman made the decision to seek care herself, and was fully supported throughout the logistical and financial process by her husband.

Because religious leaders play such central community roles, it was recommended that religious leaders, as highly influential people in the community, can help make proactive efforts in support of women with OF by educating and encouraging their congregants to be compassionate and helpful.

“It was me. I told him we should go to the hospital, he did not argue.”	<i>Kano respondent (8)</i>
“Na my husband n aim decide. My husband tried. E dey carry me go up and down different hospital.”	<i>Ebonyi respondent (5)</i>
“My husband was the one, because when the doctor discharged us and told us about this place in Abakaliki, he started making calls because we have never been to Ebonyi state. He also tried to raise some money.”	<i>Ebonyi respondent (3)</i>
“The Islamic leader and the titled men should talk to the people and they will listen more. Since God has said wake up so that I will help you, so move to where you will be assisted, then God will help you.”	<i>FGD, community stakeholders, women</i>
‘The assistance that parents can offer is to train the child to be mature before she is given in marriage. Let them not think she has found a husband and marry her off, thinking she is lucky. This luck can bring her trouble.’	<i>FGD, community stakeholders, women</i>
“It should be preached in the prayer house...that is the biggest step...community leaders and heads of mosques must first sit down and talk among themselves.”	<i>FGD, community stakeholders, men</i>

Social Factors

Barriers

Social barriers are a critical impediment to women’s fistula care, as not only are they themselves impediments to women admitting their condition, asking for help, or seeking care, but the resultant stigmatization and isolation also play a significant role in constructing psychosocial barriers (embarrassment, lack of self-worth).

Social barriers that include negative or abusive reactions of husbands, relatives, and community members not only constitute a lack of emotional support (what one might call a “passive” impediment to women seeking care) but can also be active impediments to care seeking. When a husband or family member reacts with disgust

or shame at a symptom of fistula, it can compel a woman to keep quiet about the seriousness of her condition, for fear of further stigmatization should her condition be known, precluding the necessary next steps of care.

Most respondents noted that husband's behavior towards discovering their wife had OF was unsympathetic and unsupportive (though there were several examples of supportive spouses). Husbands who were not supportive were also frustrated with the problems or obstacles the fistula presented for having sexual relations with their wives, which further strained the relationship and decreased support. Some women reported that their husband had shunned them, barred them from the home, or divorced them. It was noted that every respondent in the post-repair follow-up FGD emphasized spousal abuse, forced separation, and abandonment. Not only does this result in the woman lacking the emotional and financial support of a partner, but the trauma of this adds to the psychological burden as well. In such cases of spousal abuse, they experienced the additional obstacles of having few financial resources, having no physical help with the condition, and sometimes the burden of a disabled child which resulted from the prolonged labor that led to the fistula.

Some women reported stigmatization from family members, especially if the woman was older and had had multiple children. This was especially the case in Kano. Most respondents reported that women avoided sharing their condition with their relatives unless it was unavoidable, or if their husband told them. Stigmatization from members outside the household was also significant. Respondents experienced rejection from friends, community members, religious centers, and among strangers.

Interestingly, the question of social barriers of rejection by family and friends was somewhat undercut by community members' own responses; in nearly all cases, there was no indication of awareness of the women's stigmatization or family members' unwillingness to be supportive. This is perhaps explained by the fact respondents were themselves family members of women with OF, and may have been reluctant to self-incriminate. Family members present for the interviews were possibly there out of desire to serve as a companion for a women with OF or to inquire about her wellbeing and were part of a supportive community contingent.

"My husband hates me so much since this problem started...In fact I am like a widow...he banned me from entering his provision store...[and] married another wife who enters there with him."

Ebonyi respondent (2)

"Like when they do a ceremony, you will not be invited. Things will be happening, like if one cooks, they will not want to eat, all these kinds of things."

Kano respondent (5)

"I started frying akara but nobody wanted to buy from me seeing me with that kind of child. I went to drop the baby in a motherless baby's home but they refused to take the child."

Ebonyi respondent (8)

"When I stay with him he may feel like us being together as husband and wife, so it made me not to be entering his room anyhow. I may enter that place and it is time to wet the bed."

Ebonyi respondent (1)

"Some men are very mean. Even if you are shouting, they will not hear. When you die, they will go and marry another woman...we women suffer these things."

FGD, community stakeholders, women

"The woman's husband threw her out of the house saying she must have offended the gods...nobody goes to her house...the woman died some years ago. The man refused to come and take his son [so] that the gods will soon kill him like his mother."

FGD, post-repair client follow up

"Some of them, when they bring their wives to the hospital they are told to go and buy drugs. They will leave never to return again, leaving the woman for her parents."

FGD, community stakeholders, women

"They will be running away from you. They will not [be] near you. They will be saying this woman that water is running out of her body. Anybody that wants to help will advise you to go to hospital."

FGD, community stakeholders, women

"To cooperate with that person, even to eat what that person is eating will be difficult for you because every time she will be smelling...even in meeting when you sit down with that person, you will carry your chair and commit."

FGD, community stakeholders, women

Enablers

A number of women were however shown support and empathy by their spouses when they told them of the condition and throughout the repair process. Younger women, especially newlyweds and first pregnancies, were shown more empathy from families and in-laws, especially in Kano state. Further, not all respondents were faced with stigmatization, especially from their spouses. It may be that building on the sympathies that permit some women support but not others may be a fruitful starting point for sensitizing the community at large about supporting all women with OF.

Among all women, it was emphasized that family and spousal support is a key enabler of seeking care, and especially during the healing process. Emotional support and assistance in performing household chores were particularly noted.

“He was not, he was not regarding my condition and he did not show me any discrimination.”

Kano respondent (5)

“The family should help in duties like fetching water and lifting heavy loads. If you cook with firewood...anything that will make the repaired patient push themselves, the family should help.”

Ebonyi, discharged patient FGD, respondent (5)

“Women who had this problem should be supported with skill and government should mandate their family members to help them...I did this surgery two times just because nobody was there to help me with home chores. My husband doesn't help.”

Ebonyi, discharged patient FGD, respondent (3)

Financial Factors

Barriers

Financial costs fell into three categories: care at home, transportation costs, and costs of ongoing care at facilities. The costs were primarily noted as being barriers when ongoing and repeated medical intervention occurred. Some families experienced significant financial barriers, some none at all (at least for the first attempt at treatment), and some began to face financial barriers if the costs were ongoing; that is, if the woman had to be repeatedly seen by a doctor, had multiple failed surgeries by unskilled staff, and had to travel multiple times to health clinics. This was due either to financial inability, or a lack of willingness by the husband or family to pay for costs beyond a certain point.

The cost of caring at home was so significant for many women that they lacked anything left to take the next step of accessing medical care at a facility. These costs included the cost of cloth napkins, pads, adult diapers, personal caregivers, separate bedrooms or living facilities, and house help if the woman was no longer able to do her household tasks or business. The latter point was especially significant when it meant that the family's household income was diminished.

Cost of transportation as a barrier varied according to respondent location. In Kano the cost was not as high as in Ebonyi, likely because there are more fistula care centers in the north where Kano is located, whereas women had to travel significantly farther to reach the Ebonyi center.

Sometimes it was the perceived cost of treatment that was a barrier to seeking care. When families who were unaware that government fistula treatment is free in Nigeria believed the cost to be high, this could be a deterrent to seeking out the care at all. Some women were forced into desperate situations to pull together funds for treatment; one borrowed a significant amount of money from a village cooperative association using her five year-old daughter as marriage collateral.

In discussing costs of ongoing care at treatment facilities, it is useful to point out the characteristics of both facilities. Medical treatment of OF is free at both facilities. However at Kano center, only the actual surgery was free; clients are obliged to pay for food, water, medication, and toiletries. The Ebonyi center is better funded by the federal government (although inadequate to meet all of the center's needs). Nevertheless women are provided with not only free surgery but also food, water, sheets, buckets, and drugs. But even fully free treatment at Ebonyi did not dispel the financial barriers that occurred when, unaware of their medical options or free services available, families had unsuccessfully attempted surgery elsewhere or had gone to private expensive medical facilities, some of which were dishonest and charged the clients more than agreed upon once surgery was complete. Further, it was pointed out that families who lacked awareness of free services would reasonably expect the care at government facilities to cost just as much as at private facilities.

“When I was brought here, he (husband) bought the things needed for the operation (CS). After buying these things and some drugs, he did not buy anything again...I have been suffering on the matter of buying drugs except when our relation visits us.”
Kano respondent (7)

“Poverty is the main factor. There is no money to feed your family, talk less of giving your wife for antenatal delivery. We don't even have for ANC.”
FGD, community stakeholders, men

“The problem is that we are faced with serious financial challenges. I am not working and even the little business I was doing before this sickness started I couldn't do it again because this sickness made life miserable for us.”
Ebonyi respondent (4)

“The money wey I borrow I collect am from meeting...I borrow N10, 000, they take 2000 [upfront interest]...if I go and come back I never bring the money dem go take my pikin give am to marriage...dem give me one month.”
Ebonyi respondent (8)

“Before the surgery we agreed on N100,000 but as he went to that place what we saw is not as he thought so he now increased finally when they discharge they give us N180,000 bill.”
Ebonyi respondent (1)

“They think they will spend money. The way they spend money on traditional remedies, it would have been better if you come to hospital, the money you will spend here compared to the money you will spend outside.”
FGD, community stakeholders, men

Enablers

Most respondents emphasized that financial support was an important enabler of care and a primary barrier in their perspectives, ranging from lack of funds for adequate nutrition, rest, and prenatal care during pregnancy, to lack of funds for skilled medical care during delivery, to inability to pay at treatment centers for OF. There was no particular vehicle for financial support identified, but it was clear that the good federal funding was a significant financial enabler for women to seek and obtain care at the Ebonyi center.

It was suggested that the government can enable care by reducing financial barriers by subsidizing or eliminating the cost of skilled obstetric care in the first place. Since many women's OF is the result of delayed or poor obstetric care during prolonged or obstructed labor, they felt that reducing financial barriers to facility based childbirth itself would reduce the incidence of fistula, thereby reducing the need for women to seek fistula care and the need for the government to pay for fistula care. Reducing the financial burden of all steps of prenatal, obstetric, postnatal, and fistula care would prevent women from avoiding the hospital, and avoid drastic scenarios like the one that one respondent described how some women flee the hospital rather than being forced to pay.

“I did not pay anything, it still amazes my husband...the reason he insists on coming is to come and discuss the hospital bill because he doubts if there is any free hospital in Nigeria...may God bless you people.”
Ebonyi respondent (3)

“Federal government will look into this our hospital...let them reduce this money because this money makes some people to stay at home and die.”
FGD, community stakeholders, women

“Okay you will see some people after delivering, they will just leave everything they used to come to hospital, carry their baby and put inside basket and run away because no money to pay.”
FGD, community stakeholders, women

Transportation Factors

Barriers

Cost of transportation was frequently highlighted as a barrier to care. This was more so the case in Ebonyi, where women and families had to travel greater distances to reach the care center, which is uncomfortable and stigmatizing for the woman in and of itself if she must take public transportation. The farther women must travel for care, the more costly it is; the more time she must spend away from her family and business. This is also compounded when the women’s lack of awareness of government treatment centers and their free services compels her to seek care at unequipped or unknowledgeable facilities, leading to multiple travel times to clinics. In Kano, where there are more government fistula care centers, this was a less frequently cited barrier to care, although the lack of awareness and subsequent repeated attempts at care does make transportation inconvenience and a cost barrier.

Some transportation barriers contributed to the development of the fistula in the first place; some women were delayed in obtaining transportation to the hospital during labor, whether it was due to the transportation being infrequently available, or because they could not walk or otherwise reach the motorable roads to access transportation to the hospital. Poor road networks or poor quality roads (that wash out in the rain, for example) were cited by men as being a particular transportation challenge, for bringing the woman to a hospital whether she is in childbirth or seeking treatment for OF.

“For some people there is no transport, like our place e dey very far...they don’t have transport fare...some people the long distance will hinder them so we also beg you people to bring please this kind of hospital to our place.”
Ebonyi respondent (2)

“When the doctor referred me, I told him I don’t have money. He even gave me the N5000 to transport myself to this place.”
Ebonyi respondent (4)

“It was just the lack of money that hindered me from seeking care for eight years. We were looking for traditional treatment because of lack of money to come here...yes no money to come here. My husband hadn’t, and his father hadn’t, my father had to sell some things for us to come here.”
Kano respondent (5)

“We were on our way to hospital because there was no ready means of transport an unskilled birth attendant spread a mat on the floor. As I was pushing the baby I saw something like a ball coming out of my body and later followed by urine.”
FGD, post-repair client follow up

“In some villages, between them and the hospital, the roads are terrible...you need to carry a pregnant woman in pains whether she is near delivery or with complication before she is brought into the hospital...or on motorcycle.”
FGD, community stakeholders, men

“There is no nearby hospital, no nearby health center...the only place where they can go and obtain card is in Abakaliki.”
FGD, community stakeholders, men

Enablers

In general, all respondents agreed that once their families and spouses agreed they should be seen by a medical clinic to receive treatment, they were promptly transported to a clinic. Thus, family willingness to support, pay for and organize transport is a way to overcome some transportation barriers.

It was recommended that communities work to reduce transportation costs in general so that it is not so prohibitive for low-income women. It was also indicated that increasing the frequency and availability of transportation would also help prevent incidents of fistula that resulted from women being unable to access transport, or delayed in accessing transport to the hospital during labor.

For those in rural areas, walking great distances to even access commercial transportation to a hospital is necessary, in addition to paying for the commercial transportation. Nevertheless, where there were vehicular roads, husbands or relatives made the effort to procure a vehicle, first to the home, to take a woman for treatment. There are also examples of helpful individuals who gave rides to women who were walking. It is clear that good, vehicular roads reduce transportation barriers for women. Establishing more rural treatment centers would also help reduce the transportation barriers for distant or costly travel.

“I say make I waka find motorcycle come go hospital...so na some people wey see how I dey ground for road, na dem carry me go hospital.”

Ebonyi respondent (8)

“The center should be in rural area or community by community so that it would be easier for them to go because to go to the town, some people are scared.”

FGD, community stakeholders, women

Facility shortage factors

Barriers

Facility shortages comprised both a lack of human resources as well as lack of material resources. These barriers are significant both in terms of the quality of medical care women receive as well as the quality of post-surgery support and counseling women and their families receive. It also impacts the extent of community outreach a facility is able to engage in. Fistula repair care not only requires adequate numbers of specialized surgeons to be able to examine and treat various levels of tears, but also a supportive nurse-counseling staff to counsel patients pre and post repair. Recovery takes a longer time, requiring longer hospitalization and follow up services, and facility shortages negatively influence the quality of all these elements.

Staff shortages can lead to overwhelmed and overburdened caregivers who then provide a lower standard of care. In one instance, a patient continued to return to the hospital on a daily basis to have her open wound from caesarean section dressed and cleaned. For this patient, it took four to five days to get the wound sutured because the doctor to do so was constantly tied up with other emergencies. One of the challenges at the Kano center was the lack of resident doctors at the facility because of poor funding. Therefore the center relied on the generosity of volunteer surgeons who visited the center from time to time to perform these surgeries. This approach had significant implications for many other elements which surround the overall provision of care; elements such as pre-operative care and investigations and post-operative care. In addition, it had implications for the scheduling of surgeries and patient waiting times as there were no standard timelines because the flow of work was totally dependent on the volunteer surgeons and their own schedules.

So, while in the Ebonyi center respondents did not spend more than two days in the pre-operative ward, except for other pre-surgery indicators such as anemia or high blood pressure, ‘healthy’ respondents in the Kano center sometimes spent two to three weeks awaiting surgery. These long waits further increase costs of daily living in addition to the ongoing facility care for patients and their families.

Supply shortages were even seen at health facilities with skilled personnel. Some respondents who reported early enough to facilities during labor and were attended to by skilled doctors were then confronted with poorly equipped delivery rooms. This was predominantly experienced in relation to theatre equipment and in some cases power supply to conduct vaginal deliveries.

“They had four deliveries that night with only one bed and one old lantern. When I was pushing, the lamp went off and I gave her my Nokia torch phone to help us with light. Then another lady came and they put me on the ground so she could use the bed.”
Ebonyi respondent (4)

“Apart from the delay in carrying out the operation on time after the long stay here. Frankly it is not just me alone, many of us here suffer lack of money...if there is any way they can assist us so that this long stay in the hospital before the operation can be avoided, we will appreciate it.”
Kano respondent (8)

Enablers

Even though arrival at medical facilities still meant that women were delayed in receiving services at facilities with shortages (this was especially the case in rural areas), none of the participants criticized the reception and treatment that women received in hospitals toward the end that it was in some way abusive. In fact the efforts of practitioners were praised especially when the burden of responsibility on each staff was considered. Respondents were typically sympathetic to the plight of facilities with staff shortages, and commended the practitioners at the public delivery facilities and expressing concern for their work burden. The concern and sympathy demonstrated by some respondents in response to the facility staff shortages may in and of itself help alleviate the emotional burden of these shortages on both the staff and the patient. The increased goodwill this could engender may at least alleviate some of the sense of trauma and abandonment women feel.

However, in some cases, this kind treatment and goodwill was maintained only as long as the woman was able to pay her bills. Because women who cannot pay their bills are detained, ensuring that women are financially able to pay for their costs of care will encourage any concern that they will be ill-treated at facilities despite facility shortages.

“Honestly me myself I saw how they were. Till I left the hospital, I used to pity them. I see how they work, they don’t have rest at all...the work is too much or the staff are not sufficient for the labor ward and the theatre.”
Kano respondent (5)

Quality of Care factors

Barriers

Poor quality of care is closely linked to facility shortages. When facilities lack adequate supplies, infrastructure, and personnel to provide required services, the quality of service suffers. This can manifest as women waiting long periods to be seen by the skilled providers who are too few to manage the client volume; patients lacking basic amenities like beds, bedding, medication, and food; lack of post-operative counseling.

Most often, participants cited poor quality of care as stemming from unskilled or undereducated providers conducting poor obstetric interventions. From the outset, this low quality and lack of faith in medical care was itself a barrier because it deterred women from seeking obstetric assistance during prolonged labor. Furthermore, once women attended facilities to deliver their babies, unskilled surgical intervention (including cesarean sections and episiotomies) contributed significantly to the outcome of fistula in some respondents. Even when women made it in time to the health facility, when they were faced with incompetent care, many went through the ordeal of being referred from one health facility to another, prolonging the labor process.

Furthermore, some providers lacked knowledge of appropriate labor durations, which resulted in women's prolonged labors of exceptional amounts of time. Some hospital facilities, due to shortages, had only one attendant on staff who, in most cases, did not have emergency obstetric care (EmOC) training, leading to further repeated referrals. These negative experiences degraded some women's faith in the medical centers, which could have deterred care-seeking for the resultant fistula. In some cases, the doctor overseeing the woman's delivery made several unsuccessful attempts to repair the fistula before referring the woman elsewhere.

Under-skilled providers also obstructed women's care for the actual fistula by enabling unstructured and inadequate referral systems. Often respondents were faced with attending a facility that had low awareness of OF, its surgical repair options, or that there were specialized facilities to which they could refer their clients. Respondents cited receiving inadequate surgical procedures and remained at a loss as to where to seek more skilled and specialized care. This resulted in repeated referrals to facilities that were often as unhelpful as the previous one. These kinds of situations exacerbated the circumstances by further traumatizing the woman and drawing down her bank of personal and financial resources to seek proper treatment.

There were also issues of stigmatization, in which hospital staff and caregivers were unaware of OF or insensitive to the needs of women suffering from it, and treated women poorly for it. There were reports of corruption and dishonesty, with women asked to provide money for medical services, and when they did they were then informed that such procedures could not be carried out in that facility and they would need to go elsewhere.

"I started having labor at home. I had it a whole day at home, then early the next day we went to Kenyiah hospital...we slept at Kenyiah hospital. The next day they signed and referred us to Minjibiri, we slept there again and the next day they referred us here."
Kano, respondent (2)

"During the time they were fixing the drip that they observed the head of the baby coming out that the cord held the baby and she asked the second nurse to call the doctor...while that nurse went to call the doctor, the nurse inserted a scissors into my vagina to cut the cord and that is where the problem started."
Ebonyi, respondent (3)

"That day she went to doctor, the doctor told her to endure, that she will deliver by herself. So she continue to endure...she stayed for three days...the problem is from the doctor. He allowed the girl to suffer long."
Ebonyi respondent (1)

"I've been waiting four weeks now before operation."
Kano respondent (3)

"They gave me cut and doctor told me it resulted to the fistula. When they saw my body and noticed that I had come up with this ailment, I was placed on drip."
FGD, post-repair client follow up

Enablers

Interestingly, every respondent rated her care at a fistula treatment center as excellent. This could reflect women's low expectations due to previous negative experiences and inadequate care at non-specialized care centers. Regardless, it was observed that both facilities were kept very clean, that amenities were available (although they cost at the Kano center), and orderlies are available to clean patients. Many patients found the facilities' amenities satisfactory, especially compared to what they are accustomed to at home.

At both centers, all respondents attested to genuine empathy from the nurses, doctors, and other support staff. When questioned about issues of abuse, abandonment or disregard, all patients, without exception, stated that this had never occurred but rather, because of the attitudes of personnel, especially the nurses and matrons, their fears and concerns were allayed almost as soon as they arrived, which provided significant psychological relief. This conduct was particularly appreciated by respondents who had suffered significant stigmatization and ill treatment from friends, communities, and health facilities previously visited (including the ones which had cost money).

The positive and encouraging reception at the fistula centers also improved client awareness; many respondents, men and women, indicated learning a great deal about fistula through this orientation. The reception at Kano facility was weaker than at Ebonyi, due to system deficiencies, but Ebonyi's interpersonal treatment was no less as accommodating.

In other facilities, medical staff competence and self-awareness contributed to some women's immediate corrective care, particularly in cases of iatrogenic fistula, which women received during obstetric surgical interventions. In some cases, doctors felt obligated to repair their mistakes or obliged women who requested it. In Kano, women who gave birth at the Murtala Mohammed Hospital were referred to the fistula center in the same facility.

Because the primary client complaints about quality were due to shortages, increased federal funding for facilities may contribute significantly to improving quality of care. Respondents also recommended that medical practitioners, especially those at non-fistula clinics (often the first point of medical contact for respondents) be sensitized to the experiences with women with OF and offer kinder and more understanding services and referrals. Respondents also indicated that a way to improve their care experience would be to have a clear idea of how long they would have to remain at the facility. This would enable them to plan their budgets rather than having to worry about an open-ended hospital stay and its associated expenses.

Due to the additional and more complex quality of care issues that prevailed in the non-fistula care centers (low provider skill, broken referral processes, dishonest practices, stigmatization of patients, and low obstetric skill which contributed to women's OF in the first place) it is clear that increased and improved obstetric/midwifery training is sorely needed and would significantly reduce the barriers presented by low quality of care.

"At least I will bathe and sleep in a clean place."

Kano respondent (5)

"When we came to this place...we came with stove, mat and food stuff. As we were going to the ward, they called us and said those things are not accepted here...that we don't even need caregivers...I don't have any problems since I came, they give us food three times a day...the nurses make us happy."

Ebonyi respondent (3)

"The treatment from them is very good aunty, honestly I am ready to stay here for another one month in this kind of environment!"

Ebonyi respondent (2)

"I am surprised that this kind of place exists in Nigeria. As they told me it is free. I thought...even in a place where you pay your money, if you go there they don't even give you attention talk more of where it is free."

Ebonyi respondent (1)

"When I came, I was looking so hungry and dirty. I was crying before one nurse came and calmed me down...The nurse called another nurse that was wearing blue clothes to give me food. My stay in the hospital is a great experience I will never forget because the people working here are different, they treat us like princesses."

FGD, post-repair client follow up

"When you come, they should give you a definite date for you to go and come back because due to maybe lack of money...people come from distant places and their money finishes because you are constantly spending."

Kano respondent (8)

"Before we did not understand about this condition and we thought that the continuous drinking of water would make the leaking to increase, we did not even know that it was a remedy till we came here."

Kano respondent (2)

"Health care workers should be trained that once a woman has this kind of problem, she should be referred for expert management instead of trying and causing more harm to the woman...hospitals should come and learn from this place, as to how to be friendly to patients and not hostile."

FGD repair client

Policy and political environment factors

Barriers

The policy and political environment and associated governmental structures in Nigeria can affect how fistula care is administered and structured, its funding, and accessibility through physical infrastructure. One of the greatest barriers is inconsistent application and enforcement of medical training standards (and associated subsequent low quality of care provided by providers with limited skills and awareness). Respondents emphasized the challenge that unlicensed or untrained medical practitioners pose for the health and safety of women seeking care for OF, as they are seen as preying on desperate patients who cannot reach or afford the costs at larger hospitals or fistula centers. The need for closer rural hospitals was again emphasized, with respondents stating that even though many knew that some patent medicine practitioners were not qualified, they were left without much choice, as they could not afford the high costs of traveling to hospitals in urban areas.

The funding system is inadequate due to the complexity of costs and challenges associated with fistula; respondents emphasized the need for increased government funding for the cost of fistula care in the home, cost of transportation, cost of basic amenities in the Kano center, and costs of recovery and reintegration into society.

“Government should help us. Some people from the big city bring gifts. I got a wrapper since they felt that this condition needs us to be clean...the money to buy things is a challenge because our money often finishes.”

Kano respondent (8)

“That is very important because it is an experience you want to hide inside yourself not knowing that.”

Ebonyi respondent (1)

“Government should come and screen those quack patent medicine shop called chemist and doctor...they claim they can supervise delivery which they are not qualified to handle, their license and certificate need to be investigated.”

FGD, community stakeholders, men

Enablers

Respondents already consider the existence of repair facilities as indicative of the government’s concern and engagement with women living with fistula. They advocated for more commitment to build more centers in rural areas to reduce the distances some patients have to travel to an appropriately specialized facility. One respondent also suggested a penal system for family members who do not offer the required level of support to women with OF.

Nearly all respondents emphasized an important role for the government is to raise public awareness of fistula, including mass media channels. It is felt that that these avenues will yield more results and reach more people; not only through radio or television advertisements, but in churches and other religious structures that play a significant role in women’s social interactions, relationships, and support networks. Respondents also emphasized the need for grassroots awareness campaigns, using local dialects to facilitate better understanding and engagement by rural audiences.

Finally, respondents called for relevant regulatory institutions to institute stricter codes of practice for patent medicine stores and other lower level facilities, with many examples of women who had lost their lives due to such practitioners.

“The role that government is supposed to play is that they have bring out this place for help, let it continue this one is very far from people. As I said so many people might not find it easy to transport themselves.”

Ebonyi respondent (1)

“They should make the laws that will protect the right of women that has this problem, and the law should include how they expect your family to treat you and the community at large.”

FGD, post-repair client follow up

“If the government can help us get some people that will go to the villages or community and teach them...Let them send people that will explain in our own dialect so that they will understand. And tell them ‘this place is free.’”

FGD, community stakeholders, women

“They should be told, everybody with this kind of problem should try and come to the hospital...above that, this treatment is free and you can be well again and you can still go back to your marriage and even give both.”

FGD, community stakeholders, men

Healing and reintegration factors

Barriers

Healing after OF repair surgery and reintegration into a family and community require individual and societal contributions. On the individual level, women’s confidence in their quality of treatment, care by practitioners at the facility, confidence in their self care, and sense of community with other repaired women are all key for recovery. At the societal level, a woman’s ability to find or return to work, and the reactions of spouses, relatives, in-laws, friends, and strangers all affect how a woman reintegrates.

Coping with the daily costs of fistula in addition to the often high costs of eventual treatment can leave many women without financial resources. These can be compounded if a woman is rejected by her husband or lost work or business. A life without financial resources is difficult, especially when painkilling drugs for recovery is beyond a woman’s means, and lessens women’s abilities to rekindle relationships and feel like active, participatory members of their communities again.

Women were also faced with recuperating from the social losses of rejection by their husbands, in-laws, relatives, and communities. Even when repaired, if a woman returns to a husband who still rejects her, or a community that still shuns her, her chances of reintegration are decreased. Lack of public awareness, understanding, and support for obstetric fistula presents barriers for women at all steps of the illness, treatment, and recovery process.

“Honestly we need assistance to help us restore our health...because of this condition, most of us have been divorced by their husbands...some of us don’t have fathers just mothers and they don’t have handwork.”

Kano respondent (3)

“There is a great need for financial support because the period of this sickness takes everything you have. Like myself, I was moving from place to place, from one herbal home to another...I was in pieces every day without any income.”

FGD, post-repair client follow up

“Once this happens nobody wants to associate with you again. The person is treated like an outcast, if such a person does not have financial support that means the person will go and die.”

FGD, post-repair client follow up

“Some men don’t have patience. Because of their urge, you will see that what is being avoided will end up happening.”

FGD, community stakeholders, men

Enablers

Psychosocial support for women recovering from OF was emphasized as a key element to their healing and reintegration within their communities. From the moment of reception at the fistula care centers, clients reported that the kind, sensitive, and informative staffs contributed greatly to reducing their mental stress and encouraged them that their situation was reparable and that they could gain their lives back.

Furthermore, the development of a sense of community among the patients at the fistula care center was cited as an important stepping stone towards recovery and reintegration. In discovering that the condition was not unique, they found validation and often reassurance that their situation was not as bad as they had previously thought.

Respondents also recommended government financial support for reintegration that would help mitigate lost income, such as support and development of job training and skills acquisition and enhancement. Because the degree of social isolation and disconnections that women with fistula often face, reintegration into society is a challenge, especially when they do not have any viable economic skills or jobs. They further emphasized the need for civil and legal protection.

The role of men in the recovery process was highlighted as crucial, as they can be a valuable source of psychosocial support. Respondents suggested that men should be included at the beginning of the care delivery cycle so they not only support women through the surgical process, but through the recovery process at home, especially during the recommended abstinence period.

“The nurse told my sister that day to calm down because soon this sickness will be a thing of the past. That she should stop thinking about it because she is not the only one with this problem in the world.”

Ebonyi respondent (3)

“Government should support them with skill since they are told not to do strenuous jobs. If they can be engaged in less strenuous activity it will be good. You can’t say that government should pay them monthly salary, it is not realistic.”

FGD post-repair client follow up

“As they are talking to the women, they should also be talking to the men. The men are the major cause of it. It is as if a woman has committed a crime because she is pregnant.”

FGD, community stakeholders, women

“They should not isolate her, when she comes to a social gathering people will be closing their nose...continue with this kind of free service...they should also give us money...I suggest they should get police to arrest any family member that has refused to help such woman...my husband will be the first.”

Ebonyi respondent (2)

“The government should support us financially because this sickness is not easy at all...They need serious financial support as that will help them buy detergent for those steady washing of pieces.”

Ebonyi, respondent (6)

Discussion

Barriers and enablers of fistula repair access and care are clustered around **awareness, psychosocial, cultural, social, financial, transportation, facility shortage, quality of care, policy and political environment, and healing and reintegration** factors. These findings reinforce and add to the nine factor clusters identified in a systematic review of the literature (Bellows et al. 2015). Women are also concerned about healing and reintegration, an additional factor or potential barrier they have to overcome in Nigeria, suggesting that decisions about access reflect whether or not women believe in the cost-efficacy of repair, including a facility's ability to deliver holistic care incorporating physical, sexual, psychosocial, and economic rehabilitation to "normal life." While women affected by fistula, their families and communities, care providers, and their managers concur on the range of factors affecting care access, their relative influence remains difficult to measure. The fact that some women, however, are uniquely positioned and knowledgeable about repair options (those who heard about fistula centers on radio or word of mouth and promptly sought care), motivated (internally or by spouses or other family members), and with sufficient resources for travel and ancillary costs, is encouraging and suggests that certain barriers and enablers may exert stronger influences than others.

As seen in the quotes of our respondents, many factors affect one other in addition to the overall issue of access to repair, in both direct and indirect ways. Related and cross-cutting barriers often involve poverty, early marriage and limited education, gender dynamics within households and communities, and women's agency for making choices about their reproductive health. The underlying poverty of women and their families limits their financial access to quality obstetric care, let alone fistula repair care. Married women's limited power in their households impedes their agency for care seeking decisions. The shame associated with fistula is debilitating and often only overcome if a family member mitigates it with financial, psychosocial, and social support. The dynamics of women's agency and empowerment against (and within) socio-cultural norms for "leaking women" and the implications for their sexuality, role in society, and surgical care may vary by education and financial statuses. These related and cross-cutting factors amplify existing awareness and transportation barriers for those in remote areas who are less exposed to radio communications that advertise repair centers and who are dependent upon local referral mechanisms.

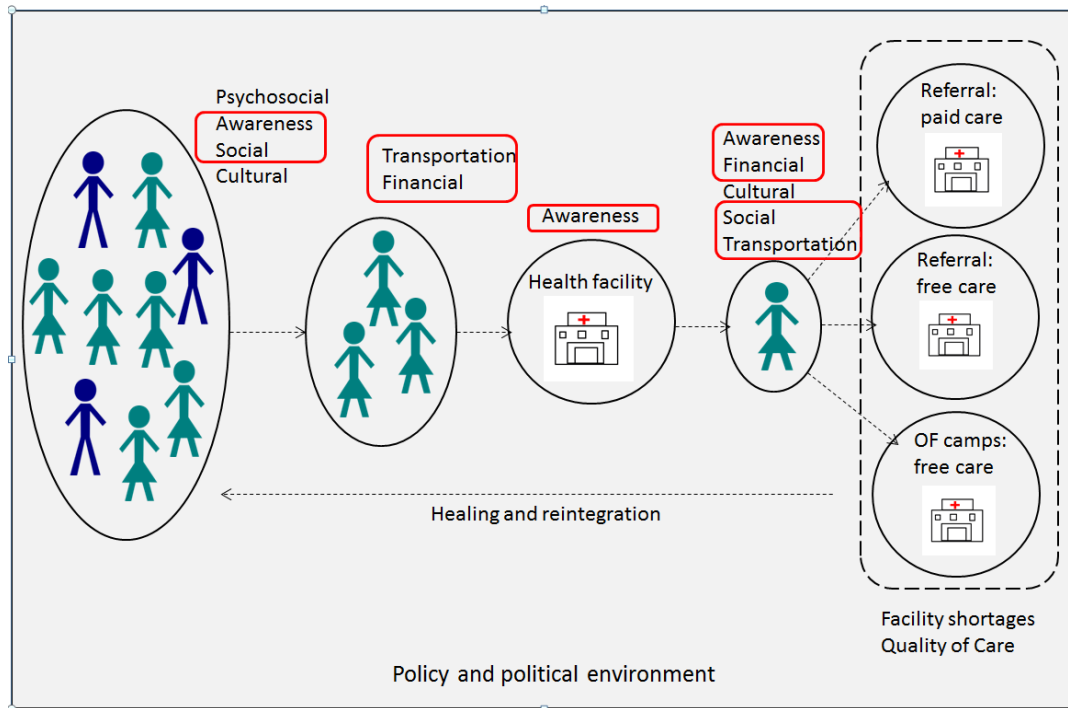
The importance of care quality and referrals emerge as key for determining access—for both prevention and treatment. While the quality of care at both repair centers is perceived as generally 'good' compared to routine maternity care, logistical and financial challenges for adequate treatment often fall short due to high demand and overwhelmed facilities. Fistula prevention through promotion of skilled birth attendance and early antenatal care readily emerged from the data. Limited provider knowledge and behaviors at lower level facilities also present factors at the first point of contact for women living with or at risk of fistula. The fact that many women were not told about their condition despite delivering in a facility, or were neglected during childbirth, poses concern and has implications for increasing provider awareness about fistula screening and referrals.

Conceptual framework

Figure 2 (next page) illustrates the theoretical process by which these factors lead to the reduction of women living with fistula in communities to those able to access successful repair from the formal health system. At the population or community level, where a certain proportion of Nigerian women suffer from fistula, awareness, psychosocial, cultural, and social factors influence their readiness and willingness to seek care, while finances and transportation affect their abilities to do so. Most women first seek care at lower level health facilities, where providers exhibit varying degrees of awareness of fistula screening and repair. The full range of demand side factors (awareness, psychosocial, cultural, social, financial, transportation) further influences whether a woman reaches an appropriate referral point for fistula care. Supply side factors, including facility shortages and quality of care, subsequently affect whether a client receives adequate care. At each stage, there is notable attrition.

The policy and political environment in Nigeria, including the funding commitments of the government, donors and other partners, and the structure and schedule of fistula care centers, determine how repairs are sought and received. The healing and reintegration of women with obstetric fistula further influence both the attitudes and actions related to fistula in communities.

Figure 2: Factors affecting fistula repair access



Given the range of barriers to repair access in Nigeria and the positive policy language for promoting awareness, and social, financial and transportation support, a deliberate discussion of these formative research findings suggests a need to focus in these areas (circled).

Data limitations and future research

The formative research provides a comprehensive mapping of the broad issues facing women living with fistula in Nigeria, including their knowledge, the care landscape, and socio-cultural and economic dimensions. Although this report reflects a scoping exercise—an inductive approach that draws upon the framing in systematic literature review and maintains goals of behavioral explication—the richness of the data warrants further analysis using additional theories of health behavior, gender, and health systems. The transcripts show that women’s willingness to engage in group discussions may vary by region, setting, and timing (pre- or post repair).

There are still a number of areas that merit further explication. Having identified a range of barriers to repair access that appear fairly consistently in our Nigerian sample, a diversification of methods should assess their relative influences on access to repair care. Disaggregated analysis of each delay and the overall time for repair would provide nuanced understanding of the care seeking process, with implications for programming and research. A barrier-enabler index would allow assessment of the relative influences of each barrier. In addition to women affected by fistula, male partners, family members, and their surrounding communities are integral perspectives for monitoring shifts in socio-cultural norms—which apparently began through *Fistula Care Plus* radio spots and community awareness activities. A barrier-enabler index, coupled with quantitative and qualitative assessment of social norms, women’s agency, and trust for repair camps, would strengthen an understanding of the importance of each factor. Given the limited scope of this formative research, the findings

about lower level providers warrant investigation. Exploring the experiences of providers at lower level health facilities, who affect both prevention and referrals to fistula treatment centers, will provide a better understanding of the first and second delays to accessing care.

Formative findings suggest, in designing the next phases of implementation research, collecting data on socio-demographics, barriers and enablers, prevention, access to care, treatment prognosis, and reintegration to “normal life” is necessary. A conceptual model, starting with Figure 1 (page 1), that illustrates the problem, proposed solutions, and informing the study design, could be adopted. At present, we recommend a layered intervention at the community and (lower) health facility levels that reduces transportation, awareness, and financial barriers to accessing fistula’s preventative care, detection, and treatment. The intervention will 1) develop and deploy a mobile screening and voucher-based referral system that promotes women’s and communities’ knowledge of fistula, 2) develop and validate an index to assess respondent barriers and enablers to fistula treatment, and 3) increase lower level provider ability to screen and refer obstetric fistula cases as well as promoting respectful maternity care. To evaluate this intervention, a mixed methods approach would strengthen the study’s intervention development, implementation, and evaluation. The quantitative arm will draw on a screening algorithm and ascertain data on patients in the referral system over time. The qualitative arm (both IDIs and FGDs) will enable an understanding of intervention development, experience with the referral system, and further explore healing and reintegration. FGDs, pre- and post intervention, will assess changes in attitudes that can be attributed to the awareness building activities of the referral-voucher system, as well as its overall usability.

Recommendations for policy and practice

- Adopt targeted approaches for addressing fistula, given the relatively small population that suffers from it, as well as its 'identifiable' and stigmatized nature.
- Encourage referrals to fistula centers of excellence and specified wards (at particular days and times) within general facilities.
- Work towards developing centers of excellence for fistula repair or establishing regularly partitioned areas in regional hospitals for more efficient, routine care.
- Increase and coordinate the timing of volunteer surgeons (as in Kano) to maximize frequency of fistula repair across the country.
- Provide financial and transportation assistance to patients and their accompanying family members.
- Integrate fistula into health education programming for youth and generally in communities through appropriate liaisons and different sectors (such as education).
- Enhance fistula awareness in lower level provider cadres.
- Support and emphasize fistula prevention by promoting antenatal care and timely access to facility delivery and emergency obstetric care.
- Promote respectful maternity care to prevent obstetric fistula and promote future care seeking for fistula repair.

References

- Bellows, B., R. Bach, Z. Baker, C. Warren. 2015. Barriers to Obstetric Fistula Treatment in Low-income Countries: A Systematic Review. Nairobi: Population Council.
- Uganda Bureau of Statistics (UBOS) and ICF International Inc. 2012. Uganda Demographic and Health Survey (UDHS) 2011. Kampala and Calverton, Maryland: UBOS and ICF International Inc.
- Thaddeus, S. and D. Maine. 1994. "Too far to walk: maternal mortality in context." *Soc Sci Med* 38(8): 1091-1110.
- Government of Uganda, Ministry of Health, National Obstetric Fistula Strategy (NOFS) 2011/2012–2015/2016 (policy document)
- Government of Uganda, Ministry of Health, Health Sector Strategic Plan III (HSSP-III), 2010/2011–2014/2015 (policy document)