



Psychosocial experiences of subjects with vesicovaginal fistula: A qualitative study

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ABSTRACT

Introduction

Subjects with vesicovaginal fistula (VVF) are often stigmatized and discriminated against. This may impose on them adverse psychosocial experiences.

Objectives

This study determined the psychosocial experiences of subjects with VVF at National Obstetric Fistula Centre Abakaliki, South east Nigeria.

Methods

Focus group discussion (FGD) was used to explore the psychological and social experiences of 100 subjects with VVF.

Results

Subjects with VVF were faced with myriads of psychosocial problems which included perceived poor social support, helplessness, sadness, suicidal thoughts, feelings of worthlessness, social withdrawal, shame, stigmatization and fear of divorce.

Conclusion

Majority of the subjects (95%) with VVF were rural dwellers and there were several psychosocial problems among them. Proper liaison between VVF treatment centres and mental health personnel should be encouraged. This will improve prognosis.

Keywords: Experiences, Fistula, Psychosocial, Qualitative, Vesicovaginal

INTRODUCTION

Vesicovaginal fistula (VVF) is an abnormal fistulous tract, which extends between the bladder and the vagina and leads to continuous involuntary discharge of urine into vaginal vault.^{1, 2} The primary causes of VVF in Nigeria include prolonged obstructed labour and female genital mutilation among others.³ It is a severely demoralising and disabling condition and affected subjects experience multiple devastating medical, psychological and social problems.⁴

Psychological Consequences

Vesicovaginal fistula has been reported to exert tremendous physical, emotional, financial and social trauma on those affected. Lack of support from the husbands of subjects with VVF, the families and society worsens the psychosocial experiences. The women feel tormented, rejected and despaired.⁵ In a study conducted at Kano Nigeria, Kabir et al⁶ reported that half of the 120 participants were bitter about the condition they found themselves, 33%

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were depressed and 7.5%) were indifferent. It has been observed that women hospitalized for fistula repair enjoyed less support and interest from their husbands and the amount of practical support provided by the family members diminished with prolongation of the illness. They also felt they were a social disgrace to their families and considered themselves treated as outcasts.⁷ Nigerian society greatly honours childbearing. Unfortunately most subjects with VVF lose their babies.⁸ They also may not actualize the desire of having more babies and thus experienced feelings of worthlessness.

Social Consequences

The resulting uncontrolled leakage of urine causing bad odour in gatherings leads to social stigma, discrimination, excommunication and consequent neglect⁶. Childlessness may lead to marital breakdown and eventual divorce. It seems that excommunication would be the hardest consequences to bear psychologically for women with VVF.⁷

While the physical and psychological consequences of fistula are disabling, so too are the social consequences: stigmatization, humiliation, isolation and loss of social support, divorce or separation, worsening poverty, malnutrition and suffering, and ultimately premature death.⁹ Often, the victims give birth to stillborn babies, thus leaving the women childless. And if the fistulae are not repaired, the women remain incontinent and childless, while also suffering abandonment by their spouses on whom they were economically dependent. The constant wetness and the accompanying smell make the VVF patient unpleasant to be around the company of other people. When at last it is obvious that their condition is chronic, they are shunned by friends and families¹⁰ and may be ostracized by their husbands, families and communities.¹¹ As a result of their health condition, women with obstetric fistula may lose their jobs or will not be able to carry out economic tasks they used to do.¹² They also face severe social stigmatization and loss of support from families and communities.¹³

The inability to work might push the woman further into poverty which might affect her social

status. More childless women were divorced by their husbands as a result of their disorder, than were women with living children. It also appears that the rates of separation or divorce increases with the longer period a woman lives with a fistula, particularly if she remains childless.¹⁴ Childlessness, therefore, was thought to be obviously an important social factor in marital breakdown and also the fact that the condition was regarded as incurable.⁷

According to an Ethiopian study of 78 previously married women with fistula repairs, majority (59) of them were divorced while the remainder (19) were abandoned by their husbands.¹⁵ In Zambia, a study on women with VVF receiving care at Monze Hospital reported that three-quarters of women with fistula were married, 15.1% divorced, 7.5% single, and 1.7% widowed. Among the 45 women who were no longer living with their husbands, 31 (67%) stated that this was due to their fistula.¹³ In Niger, fistula accounts for 63.3% of all divorces.¹⁶ A Nigeria study of 31 fistula patients reported that the divorce rate, even after repair, was 55% and 87% of these women had a still birth.¹⁷

In Guinea, women who developed VVF often suffered stigma, abandonment, loss of self-esteem, and varying degrees of social isolation. They were considered perpetually unclean as sometimes they were even excluded from food preparation, social events, and prayer ceremonies.¹⁸

In Nigeria, where childbearing is central to women's status, the loss of both a child and the role of motherhood are devastating. Subjects with VVF therefore face social isolation. Social isolation reinforces the woman's belief that she is to blame and has brought shame on her family. Therefore, this study explored the psychosocial experiences of subjects with VVF at National Obstetric Fistula Centre Abakaliki, South east Nigeria.

METHODS

Study Setting

This study was done at the National Obstetric Fistula Centre (NOFIC), Abakaliki, Ebonyi State Nigeria. The centre has a total bed capacity of 90. The catchment area of the centre is the South east geopolitical zone



of the country but receives women with fistula from all over the country. Treatment of VVF is provided free of charge at the centre.

Ethical Approval

Approval for the study was obtained from the Institutional Review Board of National Obstetric Fistula Centre. Written informed consent was also obtained from each subject.

Instruments of Study

Socio-demographic and Clinical History Questionnaire

This was designed to obtain the socio-demographic characteristics and clinical history of subjects which were age, marital status, parity, place and mode of delivery, age at onset of fistula, fistula duration, ethnicity, marital status, level of education, occupation, duration of labour, obstetric outcome (whether live birth or still birth), cause of VVF (from subjects' medical records), any social complications (divorce, ostracized), extent of social support from friends and family members.

Qualitative Interview

The qualitative interview was done through Focus Group Discussions (FGD). This involved in-depth group interviews in which participants were selected based on sharing of common experiences.

Procedure

Subjects were women diagnosed as having VVF for more than 3 months and receiving treatment at NOFIC Abakaliki, Ebonyi State Nigeria. Women who had any other form of fistula like rectovaginal fistula were excluded. Consecutive attendees to the centre who met the inclusion criteria and spoke English or Igbo languages were recruited. FGD was used to explore the psychosocial experiences of the VVF subjects. There were 9 groups composed of 11 subjects and the sessions lasted for one hour. All the FGD sessions were conducted at the conference hall of the National Obstetric Fistulae Centre, Abakaliki. A Social Worker in the centre, served as the assistant moderator/transcriber of the sessions. Participation was voluntary. All the discussions were tape recorded with the consent of the subjects.

RESULTS

Socio-demographic Characteristics

The socio-demographic characteristics of the subjects are shown in Table 1.

Social Support Available to the Subjects

Thirty three (33%) of the subjects reported having some kind of social support while sixty seven (67%) had no social support ($X^2 = 15.911$, $p < 0.001$). Figure 1 is a Bar chart showing perceived levels of social support

Results of Qualitative Data

Analysis placed emphasis on the interpretation, description and recording of what was said. Relevant themes were developed for coding and sorting of data. Themes addressed both general feeling about having VVF, causes of VVF, social support available to the subjects as well as the psychological and social consequences of living with the condition. Confidentiality was maintained by coding subjects as participants 1, 2, 3, 4, 5 and 6 etc.

Theme 1. Perceived Causes of Vesicovaginal Fistula

Across the focus groups, some participants reported that VVF could be as a result of being unlucky with pregnancy. Some reported that VVF is a curse from the gods. Some of the subjects believed that the woman may have been involved in infidelity resulting in the gods punishing her. However, there was a general agreement among the participants that VVF is as a result of delivery process. Some of the subjects lamented about their suffering during labour that may have resulted in their problems. Participant 12 said "if only I was not allowed to labour for four days in the house, I would not have had this problem".

Theme 2. Feelings about Having the Disease

Many subjects felt confused and could not explain the nature of the problem. They generally felt deeply worried and anxious. One of them put it this way "I was deeply worried and anxious. I could not sleep and had no appetite". Another felt as if her world has come to an end and queried what kind of problem VVF could be? Many felt that they were alone with the condition and wondered why it must be them. However, some participants felt differently. One said



she did not feel too bad. "Though I felt bad initially, I encouraged myself because I saw it as one of the challenges that could come to human beings. I did not do any bad thing by getting pregnant for my husband". Another subject echoed optimistically. "I have always been hopeful, because it is only death

that does not have a solution". Many lamented the economic loss they have undergone. They no longer carried on their farming activities as usual. They were not free to mix up or felt free to visit friends and loved ones as before.

Table 1 Distribution of Subjects According to Age, Marital Status, Family Type, Religion, Place of Residence and Educational Status

Age		
Mean Age		36.36±10.9
Age Range	N	%
16-25	14	14
26-35	40	40
36-45	27	27
≥45	19	19
Marital Status		
Married	71	71
Single	8	8
Separated	9	9
Divorced	5	5
Widowed	7	7
Family Type		
Monogamous	37	37
Polygamous	63	63
Place of Residence		
Rural	95	95
Urban	5	5
Religion		
Christianity	98	98
Islam	1	1
Traditional	1	1
Educational Status		
No Formal Education	54	54
Formal Education	46	46

Theme 3. Perceived Social Support available to the Subjects

Poor social support was available to subjects with VVF. Majority of the patients were noticed to be abandoned by their spouses. Support from their relatives was mainly in the form of material provisions which was often insufficient. Appreciable

support came from health workers in the form of encouragement and consolation. A greater number of the subjects (67%) confirmed lack of social support from their spouses. Some said that their husbands neglected them and refused to attend to their needs while others said that they were divorced and excommunicated.

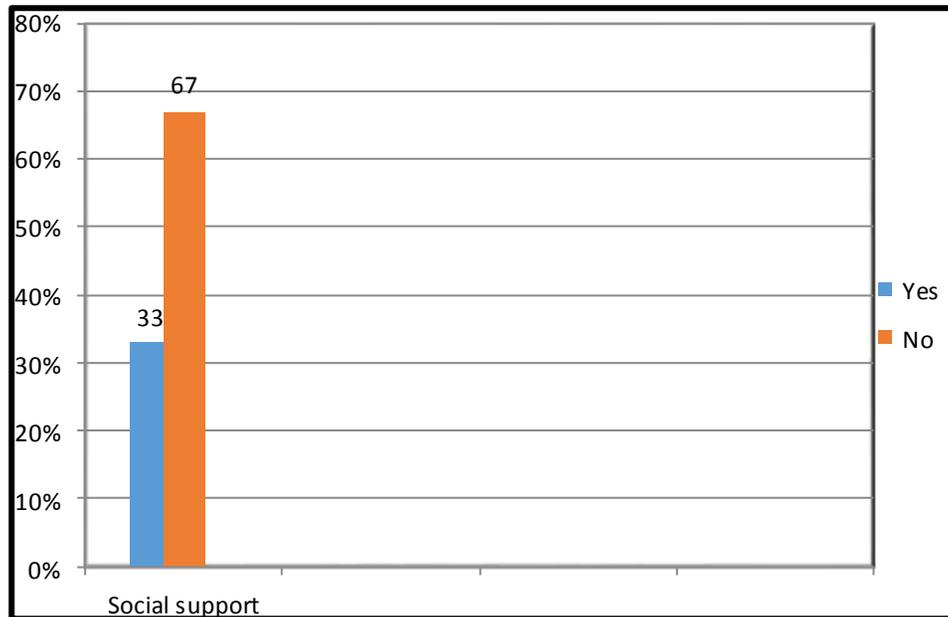


Fig 1 Bar Chart Showing Perceived Levels of Social Support

Theme 4. The Psychosocial Experiences of Women with VVF

The Focus Group Discussions showed that subjects with VVF experienced the following psychosocial challenges- helplessness, sadness, suicidal thoughts, stigma and blame, feelings of worthlessness, fear, shame and social withdrawal.

Helplessness

The subjects reported that the continuous leaking of urine caused a lot of discomfort to them. The uncontrollable leaking of urine made them feel helpless and depressed. Subject 3 who was awaiting treatment clearly stated: "I always wet my bed and clothes day and night. It irritated as the sores were not healed; I have developed rashes which were always itching. Someone advised me to use pads but I can no longer meet the cost. It is really painful because I cannot do anything about it and I am now straining anyone who cared to help." The women also associated their dependency with a child's status and that also led to feelings of helplessness, as participant 4 described her situation: "I have turned back into being like a baby. I have to depend on my parents or relatives and neighbours and could not carry out many activities on my own".

Sadness

The subjects reported that they felt sad most of the time and were rarely happy. The sadness resulted from the discomfort caused by the condition. Subject 27 clearly stated that: ".most of my relatives and neighbours did not know about my problem and I have suffered a lot. I wet my bed every night and it was difficult washing my blankets every morning. My life has been full of unhappiness and misery. I feel very sad it happened to me. Nothing can console me". Two other subjects asked rhetorically "do you know what it means to be excommunicated?"

Suicidal Thoughts

Some of the subjects had suicidal thoughts. One of them wished she was dead because she reported being worthless and a family liability. Another woman felt like taking her life because she felt she had lost her motherhood. Subject 1 said: "I don't even know the reason why I am surviving because I have lost my child and my husband cannot have sex with me. I feel so worthless and sometimes I become so down to the extent that I feel like taking my life". Subject 4 reported that she could no longer take care of her children and family. That made her feel she was no longer useful in this world and therefore believed that if she died she would relieve her family of burden. Many felt the discrimination,



rejection, and the societal stigma was too much for them to bear and the best thing was to end up their lives. On the contrary, one woman was hopeful and believed that she could still make it in life. This showed that she had accepted her fate and was optimistic that there is still more to life. Subject 72 said that: "I believe that this is not the end of the world. If I get treatment and get cured I will go back home and start my new life, maybe I will even become a better person."

Stigma and Blame

The loss of a child during birth was reported to be traumatizing and produced intense feelings of guilt feelings and self-blame. Women who participated in this study reported that their relative (especially from the husband's side) would blame them for not using traditional herbal medicines during pregnancy. The herbs were meant to loosen the vaginal muscles and therefore reduce birth complications. Therefore some women who participated in this study even blamed themselves for causing the death of their babies. Subject 33 said: "My in-laws seem to be putting the blame on me because no one in the family has ever developed this problem, I do not even know what they are thinking of me. Only my family supports me somehow but, how can I live happily with my husband when my in laws are putting the blame on me. They say if I had used the herbs that they gave me properly there could not have been any problems. I wish there could be someone to convince them that it is not my fault". Self-blame was also evident among the participants as subject 2 confirmed: "If only I had drank all the holy water that my mother brought from the Prophet, I don't think I could have had this problem. Somehow I think I killed my baby".

Feeling of Worthlessness

Due to their physical condition, the subjects reported that they were no longer able to carry out daily activities like household chores which made them feel worthless. Some complained that they found it difficult to walk and the pain from their sores did not allow them to do their normal duties. Subject 51 reported: "I have developed a condition which they call foot drop and the sores are so painful that it is very difficult for me to carry out my normal duties as

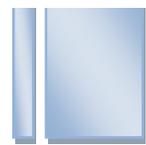
a mother. It sometimes makes me feel worthless because my mother is the one who is now cooking for my husband and doing most of the duties that I am supposed to do. My husband sometimes does his own laundry and it seems I am just being a burden to him".

Fear of Divorce

Some of the subjects reported that they were afraid that they might get divorced by their husbands who were the only source of comfort they were left with and thus reflecting their vulnerability. One subject said: "I am now afraid that my husband may find the leaking urine distasteful and might look for another clean and fertile woman. I do not want to lose my husband; he is all I am left with because my child died during birth. I wish the fistula surgery would be a success so that I can go back home a clean woman". Some were anxious and even feared that the condition might be untreatable due to the size and pain of the wounds. One participant clearly stated: "even though the matron is looking after us very well and is giving us hope, I am afraid that my condition may not heal completely because of its severity". However, some were hopeful that the surgery would be a success as participant 13 clearly stated that". Although this problem has caused me distress, I am now hopeful that I will get cured and get back to my normal life because treatment has already started; they gave me antibiotics and medication to control the pain and continuous infection while I am waiting for the fistula surgery".

Shame

Subjects revealed that having VVF made them to feel ashamed. Shame was associated with messing oneself in the presence of own children and other people. They also felt that they were burdening their children with doing all the work and even cleaning their mess. Participant 14 reported: "before I came to hospital I felt ashamed of myself because I always soiled myself in front of people, it seemed I was also failing my other two children when they had to clean my mess and when I could not carry out my roles as a mother".



Social Withdrawal

The subjects in this study reported that they experienced social withdrawal. During the interviews subject 1 stated that: "I always told myself that I should remain in my home as much as possible. I no longer went to church gatherings like I used to do, which are all because I know I would not withstand the shame of soiling myself in front of everyone". However, those who attended social gatherings like funerals were always quick to leave as evidenced by a statement from Participant 83 who clearly stated that: "I attend funerals because everyone is expected to do so but I am always quick to leave before everyone notices my problem. Those who know my problem would be staring at me with "talking eyes" of which that makes me feel very uncomfortable".

DISCUSSION

Socio-demographic Characteristics

Majority of the subjects (95%) with VVF were rural dwellers. More than half of the participants (54%) had no formal education while 91% were subsistence farmers and artisans. Similar low literacy levels and poor socio-economic status of the subjects have been reported in previous studies.^{19, 20} Education gives young women better access to gainful employment. It also reduces the incidence of high-risk pregnancies, unwanted pregnancies, and abortions by increasing contraceptive use and reducing fertility. As girls stay in school longer, the average age at marriage tends to rise, as does the average age at first birth, especially when family planning services are promoted, readily available, and accepted by the women.²¹

Psychosocial Experiences of Subjects

Majority (67%) of subjects in this study reported not having social support. Participants in this study tended to see themselves as worthless, unwanted, a burden to the society and incomplete. Subjects were expected to work for their families but consequences of VVF may make this impossible. These findings are in line with studies by Nicol,¹² who found out that women with obstetric fistula felt that they were useless to their husbands because they had failed in their duties as mothers and wives with feelings of worthlessness.

Failure of the subjects with VVF in this study to manage their roles fully as women, or participate in social economic activities made them lose their identity as women, wives, friends, and community members. The subjects may have become socially withdrawn as a result.

In this study some subjects with VVF reported failed sex lives. They had strong negative feelings over their inability to have sex with their husbands and partners. Subjects in this traumatized state experienced shame.

In Africa, safe delivery of a healthy baby is always an occasion for great rejoicing.¹⁵ Women with obstetric fistula may deliver stillborn babies in addition to the offensive odour as a result of leaking urine. Arrowsmith et al²² noted that women with obstetric fistula faced serious social problems like stigma, and some women may be labelled as witches who have eaten their own children. Also, a study that reviewed the causes, complications and outcomes of vesicovaginal fistula in Nigeria reported that stigmatization, divorce and social exclusion were common complication.²³ Participants in this study during the FGD expressed being subjected to lots of stigmatization in society. This study also showed that subjects with VVF experienced fears. Some subjects expressed fears of losing their husbands.

CONCLUSION

Majority of the subjects (95%) with VVF were rural dwellers and there were several psychosocial problems among them. Proper liaison between VVF treatment centres and mental health personnel should be encouraged. This will enhance improved prognosis.

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