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Re-Integration of Women Who Had Repair of Obstetric Fistula – a Pilot Study

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ABSTRACT Background: Obstetric fistula is not just a medical condition but also a social problem. Successful surgical repair does not mean all is well with the clients as some of them still suffer some form of discrimination and economic deprivation. The study was undertaken to understand the experiences and problems of women who had fistula repair and were back in their communities. **Methodology:** It was a qualitative study carried out in Inyimagu and Amegu communities both in Ikwo Local Government Area of Ebonyi State, South-East Nigeria from June 2016 to June 2017. The collection of data was done through in-depth interviews and focus group discussions using well-designed interview guides. A total of 74 in-depth interviews and 7 focus group discussions were conducted in both communities. The verbal information obtained with voice recorders was transcribed from Ikwo language into English. Themes were built from the stated objectives to facilitate identification of essential issues and patterns as they related to re-integration of the women and insightful deductions. **Results:** Forty-two women who had fistula repair participated in the in-depth interview and focus group discussions. The mean age of the women was 36 ± 11.57 years. The family community members received the women with joy and without discrimination. Many of the women however suffered marital disharmony in the hands of unsupportive partners who were not willing to comply with sexual abstinence following surgery. All the respondents revealed that the women still live in poverty and as such need financial empowerment. The members of the community revealed that there was no cultural belief against the re-integration of these women. However, many of the women though continent, still suffer from shame and stigma of the pre-operative period and have refused to socialize with people. **Conclusion:** In conclusion, after repair of the obstetric fistula, the women are happy to live a normal life again and they are received by family and community members without any cultural barriers to their re-integration. However, many women continue to suffer marital and psychosexual problems, abject poverty and social stigma regardless of their successful surgery.

INTRODUCTION

Obstetric fistula is an international public health problem with serious psychosocial consequences[1]. It is characterized by significant emotional disturbance due to continuous involuntary leakage of urine and/or feces and the resultant discrimination as a result of persistent offensive odour. It is prevalent in resource-poor countries of the world especially in Sub-Saharan African and South Asia.[1] The prevalence of obstetric fistula in Nigeria is 0.4%, ranging from 0.2% South-West to 0.8% in North-Central geo-political zones.[2] There are an estimated 400,000 to 800,000 women currently living with the problem in Nigeria where about 20,000 more women develop new fistula cases yearly. In Nigeria, therefore, accounts for 40% of the global fistula burden[2,3].

Obstetric fistula is in most cases a consequence of injuries from prolonged obstructed labor among extremely indigent women with reduced access to quality maternity care. It is largely a problem of the developing world where there is extreme poverty, ignorance, low level of skilled birth attendants, weak health systems, dwindling health financing, logistics, and infrastructure. Other predisposing factors include early marriage and pregnancy, harmful cultural practices, restriction of women's movement and late presentation to health facility[4,5]. The definitive treatment for obstetric fistula is a surgical repair. This is usually after prolonged periods of rejection, marital disharmony, ostracization, hospitalization and disrupted family life[2-5].

Obstetric fistula is not just a medical condition but also a tremendous social problem. Successful surgical repair does not mean all is well with the women as some of them still suffer some form of discrimination and economic deprivation when they get back to their communities[6-8]. The women will need comprehensive rehabilitation and re-integration to restore self-respect and productivity. Also, there is a dearth of knowledge and feedback from the community on the acceptability, wellbeing and general satisfaction of these women after prolonged social exclusion[9,10]. It is therefore imperative to study the experiences and problems of these women after repair so that we can propose a comprehensive program of re-integration to restore self-respect, acceptance, and productivity.

The findings from this study will form a basis for a larger study across the state and region on the re-integration of women the following surgery to address gaps in knowledge that may be observed. Having gained an in-depth understanding of possible socio-cultural beliefs and other factors that lead to discrimination against these women, the study will also form a basis

for counselling of clients and their partners, training of caregivers, education of community members and advocacy to policymakers to ensure complete re-integration of the women following surgical repair of fistula.

The aim of the study was to study the experiences of women who underwent obstetric fistula repair and were back in the community. Specific objectives were to determine the attitudes of partners, family members and the community towards the women, the level of economic support available to them following repair, and the relationship between the socio-cultural beliefs and the re-integration process.

EXPERIMENTAL

Study Area

The study was carried out in Ikwo Local Government Area of Ebonyi State, South-East Nigeria. The Federal Military Government created Ebonyi State on October 1, 1996, with Abakaliki as the capital city. The state has 13 Local Government Areas and 77 Development Centers spread across three senatorial zones. The state lies between 7.3ºN and 5.4ºE and has a landmass of approximately 5,932 square kilometers. It has boundaries in the North with Benue State; East with Cross-River, South with Abia State and West with Enugu State. The population of Ebonyi state according to the 2006 Population Census was 2,173,501 persons. The state is made up of two major cultural zones, namely Abakaliki coming from the old Enugu State and Afikpo from the old Abia state. Polygyny is practiced in the two cultural zones of the state, with its reproductive health implications. The state is culturally heterogeneous as reflected in their political life, religion, inheritance pattern and reproductive life.

Ikwo is the largest Local Government Area in Ebonyi state and covers about 500 square kilometers. It is a flat undulating land scrape, some 120-180 meters above sea level. It lies between latitude 45º to 76º North of the Greenwich meridian and between 50º to 40º North of the equator. The local government area shares boundaries with Abakaliki and Izzi local government areas in the north, Cross Rivers State in the east and south, and Ezza South local government area in the west. The local language of the people is Ikwo and Igbo. Farming is their major occupation, the major crops grown to be yam, rice, and cassava.

Study Design

A qualitative study (survey) was done. The study involved qualitative primary studies aimed at reporting perspectives and experiences of rehabilitation and re-integration process after surgical repair of obstetric fistula in these women.

The collection of data was done through in-depth interviews and focus group discussion using well-designed interview guides. The interview guides sought to evaluate the rehabilitation and re-integration process of women who had repaired. It also elicited information from partners and other stakeholders in the community on their personal views on the subject matter in line with the objectives of the study. The focus group discussions gave the respondents the opportunity to express their views on the subject matter. This involved the family members of these women and a detailed discussion schedule was used.

Research assistants who spoke and understood Ikwo, the local language spoken in the study area, anchored all the sessions of the in-depth interviews and focus group discussions. A tape recorder was used to record and store the detailed verbal responses from the in-depth interviews as well as the focus group discussions.

Study duration

The study was carried out from June 2016 to June 2017.

Study population

The study was carried out among women who have had successful repair of obstetric fistula and were back in their communities. It also included their partners, family members, community members and other stakeholders including opinion and religious leaders.

Sampling Methods

Women from Inyimagu and Amegu communities both in Ikwo Local Government Area of Ebonyi State were studied. This Local Government was selected by purposive sampling being the Local Government Area with the highest prevalence of obstetric fistula in Ebonyi State based on data available at the National Obstetric Fistula Centre, Abakaliki. The two communities were selected by convenience sampling.

Data collection

Data were collected using in-depth interviews and focus group discussion. 74 in-depth interviews were conducted in both communities. In Inyimagu. 38 in-depth interviews were conducted. These comprised 15 women who have had surgical repair, 7 partners of such women, 6 religious leaders and 10 community leaders. In Amegu. 36 in-depth interviews were conducted. These comprised 13 women who have had surgical repair, 7 partners of such women, 7 religious leaders and 9 community leaders.

7 focus group discussions were conducted in both communities. There were 4 focus group discussions in Inyimagu and 3 in Amegu. There were 5 to 7 participants in each group. The women who had repair were participants in 2 groups while their family members were participants in 5 groups.

Analysis of Data

Research assistants who understood and spoke both languages fluently transcribed the verbal information obtained with voice recorder from Ikwo language into English. The contents of the responses to both the in-depth interviews and focus group discussions were organized and analyzed in a narrative form. Data analysis employed the phenomenological approach proposed by Creswell to sift out how these women were being re-integrated after fistula repair. Specifically, themes were built from the stated objectives to facilitate identification of essential issues as they related to re-integration as identified by the women and other respondents. The patterns and themes from the responses were examined and compared. Each theme was discussed and necessary illustrations and quotes extracted to support the views expressed.

Ethical Considerations

The study was carried out after obtaining approval from the University Research Ethics Committee (UREC) of the Ebonyi State University (EBSU), Abakaliki and the Health Research and Ethics Committee of the National Obstetric Fistula Centre, Abakaliki, Ebonyi State. In designing this study, the ethical principles of informed consent, autonomy, beneficence, and non-maleficence were adhered to. All information obtained from the participants kept strictly confidential.

RESULTS

Socio-demographic characteristics women who had repair

42 women who had fistula repair participated in the in-depth interviews and focus group discussions. The mean age of the women was 36 ± 11.57 years. The mean parity of the women was 4±2.27. Thirty-six (85.7%) of the women were married. Seventeen (40.5%) had the primary education while 15 (35.7%) had no education. Their major occupation was farming 33 (78.6%). Mean duration of leakage of urine was 4.7±7.33 years.

Attitudes of the respondents

Many of the community members described the period after fistula repair as a time of celebration and testimony. They all noted that they related well to the women once the repair was successful. One of the community leaders expressed his joy, that as a village chairman for seven years, he had seen five women with the successful repair.

He said: "It was a very big jubilation for us in the community. The family members of the women welcomed them and everybody celebrated the women because formerly we think VVF is like HIV/AIDS that cannot be cured. It was recently through the help of the state government that we know that it could be cured. People went for repair and come back without the associated odour."

After the successful repair, some women encounter challenges from their partners due to the period of sexual abstinence to allow complete healing. Three of the partners agreed that they still live with their wives but they were able to pass through endure only by the special grace of GOD. One partner described VVF as a "joy killer" both pre- and post-operative. This term drove home how their sex life was affected.

He said: "when my wife was leaking, I couldn't have sex, then after the repair, she said no sex for 1 year. She showed me a paper from the hospital to convince me. It is terrible. The relations came to meditate, yet she refused. I became a stranger in my own house. She has not come close to me for over three years so I lost interest. I don't love her again".

Another woman who has been treated, in her response, said:

"The community loves me but my husband hates me. My husband took my land. Even when I rented land to cultivate, he will collect my crops and give to my co-women. I thought that

everything will be fine after the repair, no, it got worse. When I came back from the hospital we were warned not to have sexual intercourse until six months. He wanted to force me to sex within one week of discharge but I refused. I ran to my mother-in-law's house that night. In the morning he told me that I am rejoicing that I am repaired, but that I will have the injury again. Since then, he has been hard on me and my two daughters. He refused to give us shelter, he remarried. Whenever I make money with my sweat, he collects it and gives it to my co-wife. My children and I have been in a bad condition. Since then he chased us away and we are currently living in a neighbor's house*".*

Also, another woman who had repair said:

"My husband rejected me when I had the problem, it was my own family that took me to the hospital, and I returned to my parents. My husband has not come since then and I heard he has married another woman".

Other family members had the good disposition towards these women. They all stated that although, before surgery, they ran away from the women, after repair, and the woman no longer leaked urine, they related with them allowed them to take up their position in the family.

Economic support following fistula repair

The women said after repair, they needed economic support because following surgery, they were told to avoid strenuous jobs for a period.

A woman who had repair explained this:

"Eh yes, any repaired patient needs support. Like my own, I did not finish my tailoring agreement before I got pregnant and the sewing machine the man bought for me that time was taken from me when the problem occurred. I did not continue tailoring again. My elder sister gave me money after I was tired of staying at home. The man who promised to marry me before did not ask how I feel again, neither do the community nor church people asked. My sister was the only one that supported, and the money is not even much. She just gave me ten thousand nairas (N 10, 000.00) only and I'm managing it to do a small business. I pray I get money to go back to my tailoring job*".*

All the women interviewed stated that they did not have any form of support. They further explained that they were all farmers and because they were told not to do hard work again, the government should support them. Another woman expressed her feelings towards the need for economic support.

She said "the problem I face now is how to train my children in school. My husband is not helping issues at all."

One woman explained: "After the surgery, I was counseled not to deliver on my own again. I had the cesarean section in 2013 and 2015. I don't have time to do farm work again (shaking her head), my husband is not providing for me." Another one said "I need money to feed my children. This one (pointing to her child) is six months old, and the other one is two years, there is no money to buy foodstuff."

Another woman pleaded that the government should employ them since they were asked to avoid tedious jobs.

One woman, however, expressed her joy and satisfaction. She said:

"Before GOD and man, I am not expecting any other thing from the government. That I am repaired is a great honor to me. My prayer is that GOD will bless the hospital management, but if they want to do anything GOD will bless them."

The community leaders also agreed that the women needed financial support because since they developed fistula, nobody got close to them, they were always indoors, hence impoverished. They needed financial support from their husbands, community, and government. So many of them were widows, they affirmed.

One of the community leaders stated, "the only economic support available is that if the person has a farmland, she needs to farm, and does not have the means, she can inform the villagers and they will go and assist her with the farm work."

In the views of the religious leaders, the women should be supported to acquire land and seeds. One of them said that the church supports them with clothes and bush clearing for farming. Another religious leader affirmed that:

"The women need financial support to take care of themselves because the only support we give at the church level is after testimony, we do make provision for young boys to go and

farm for them, and the sisters to weed and renders other forms of domestic assistance to such a person if needed".

In the focus group discussions with the family members, the respondents agreed that the women need financial support because they are told to not engage in strenuous exercises after repair.

One of the family members said:

"I have given my mother some money to start up a groundnut business but none of our family members are supporting her except me".

Another one said: "Some family members assist in doing farm work for them but cannot give them money.

Another family member said:

"Some of these women are not even helped at all after they come back from the hospital".

In all these narratives, all the respondents agreed that the women needed financial support from the government to alleviate their suffering since they are told not to engage in strenuous activities after repair, farming being their major occupation.

Relationship between the socio-cultural beliefs and re-integration

The respondents were asked if there was any cultural belief forbidding them from associating with others and performing their roles in the community.

In the words of the women who survived fistula, the general response was:

"There is no culture forbidding us."

One survivor added another dimension. In her words:

"There is none, but in the society today, there is no way a thing like this, people will not interpret it to be something else. The culture, however, does not forbid us from anything."

The partners that were interviewed also affirmed that there is no negative tradition against the women.

One of the partners said: "None of our traditions discriminates against the affected women or those who had repaired."

Another one said: "They are not being deprived of anything".

One of the family members stressed that:

"The culture has nothing against them. When they return they feel as before. There is no traditional right to perform when they return from the hospital, they are being properly welcomed."

The response of the community leaders was not different.

One of them said: "We do not see them different as having done any violation in the community." Another one said: "There is no cultural prohibition except that the person is not supposed to engage in strenuous activities."

One of the village heads said:

"No there is none, unlike, for instance, this leprosy thing, a leprosy survivor will never be allowed to take 'Ozo' (chieftaincy) title but not so with VVF."

Another village head said: "There is no single culture in Ikwo against them."

However, on the field, the researchers were informed by community leaders that many of the women were hiding and were reluctant to come out to be seen and interviewed having previously suffered obstetric fistula.

DISCUSSION

Obstetric fistula is a tremendous medico-social problem. Because of its multifaceted nature, approach to management is multidimensional. The social and psychological effects of the fistula experience are beyond what surgery alone could remedy.[11] Following surgery, it is imperative to re-integrate women who had been previously ostracized because successful surgery is only the first step into the long-awaited new life. The survey yielded useful perspectives from these women, their partners, family members, religious and community leaders on the experiences back in the community.

The reaction of the women after successful treatment is expectedly that of bliss, excitement, and relief. For them, the absence of urine is simply unbelievable. The women have an avid desire to reunite with their families and communities. The family members, religious and community leaders also receive these women with joy and celebration. The women enjoyed the reception of their families and members of the community. An exploratory study of women who had fistula repair in Kenya highlighted family and community support as important factors in the re-integration of the women following surgery.[12]

However, the experience of the women with their partners is on the contrary. Because of the period of sexual abstinence prescribed for these women at discharge to allow good healing of the vaginal tissues, they experienced family disputes, psychosexual problems, marital disharmony, gender violence and separation resulting in another life of misery. In a study done in Malawi, following repair of the fistula, despite the improved quality of life and the warm reception by the community, some women narrated that marital disharmony with unsupportive partners became one of their greatest problems. Many women had to come to terms with the reality of polygamous relationships and their new role as a second wife, which was the decision of their husbands. This was because of sexual dissatisfaction during the period of healing with associated problems such as pain during intercourse, reduced vaginal capacity after repair and the fear that sexual intercourse could cause fistula recurrence. Some women feared they would never be able to marry following repair due to reduced vaginal size from surgery and the need to delay marriage so vaginal tissues could heal.[13]

All the respondents interviewed agreed that the women needed financial support to alleviate their hardship. Having a means of livelihood is very important in the re-integration of these women. Considering the fact they have suffered a lot of pain from poverty, shame, and neglect before surgery in the past, discharging them into the community to continue to live in poverty is starting another vicious, which may result in another fistula. The Kenyan study identified provision of income generating activities, skill acquisition training, and governmental support as services that would significantly enhance the re-integration of this women.[12]

All the respondents stated that there is no cultural belief that forbids association with these women. According to the respondents, socio-cultural beliefs do not to interfere with the process of integration of these women. They are allowed to mingle with others as well as play their roles in the community.

The observation that many of the women were hiding and were reluctant to come out to be seen or interviewed, having previously suffered fistula, appeared contrary to the verbal responses from the community. This refusal to socialize is a significant finding that requires further investigation. It is possible some of them still suffer some degree of stigma even after treatment. The Kenyan study reported that social stigma following corrective surgery had negative impact on the re-integration of the women into the community.[12] In a Tanzanian study of women's expectation after fistula repair, some of the women interviewed said they would never want to have close friends again because their friends did not support them at the time they needed them most.[14] It may also be because some women find it difficult to get over the shame and stigma of fistula due to depressive illness. Such women may refuse to mingle with others in the community even when people are open and willing to receive them. This calls for psychiatric evaluation for women who remain withdrawn after successful repair. A study of the experiences of 51 Ethiopian women showed that although the majority of the women experienced joy and relief after repair, some continued to experience mental anguish and stigma. One of the women studied said she did not feel equal to other women in the community because those who knew her history still discriminated against her.[15]

Our study reveals that although successful surgery restores joy and hope to women with obstetric fistula, it takes care of only a small proportion of the myriads of problems these women experience. Many of them continue to languish in extreme poverty, marital conflicts and stigma. A systematic review of 10 qualitative studies of rehabilitation experiences of women who had undergone obstetric fistula repair in sub-Saharan Africa showed that negative experiences were reported in almost all the studies. Long-term emotional, economic and physical consequences were the most commonly reported negative aspects of rehabilitation. Many of the women reported that being an economic burden to their families was traumatizing to them. The inability to talk about their fistula experience, from shame or stigma, was reported in three studies, while isolated experiences included lack of social service support, difficulty with partners and lack of information about recovery after fistula repair and misconceptions about fistula among communities.[16]

The limitation of this study included the fact that the researchers needed the services of research assistants who spoke Ikwo to overcome the problem of language barrier. Because the responses were transcribed and translated by these assistants, some responses appeared altered and difficult to understand. In addition, because of the stigma experienced even after

treatment, some of the women did not come out to be interviewed. This might have limited the experiences shared on the field.

CONCLUSION

In conclusion, after successful repair of an obstetric fistula, the women are excited to live a normal life again and reunite with their families and communities. Family and community members are also happy to receive them without discrimination. They, however, have disputes with their spouses who are not willing to comply with the prolonged period of sexual abstinence. They also continue to live in poverty, as there are no plans to ameliorate their financial hardship post repair. In addition, some of them still live with stigma even after the successful surgery.

POLICY RECOMMENDATIONS

The partners of the women will need to be educated that these women are normal after a successful repair and that a period of sexual abstinence is necessary for full recuperation. There should be a policy of engaging them after successful surgery for proper re-orientation and re-integration.

There should be a programme of economic rehabilitation for women the following repair. This could be done by incorporating empowerment and skill acquisition into fistula care programmes.

There is also need for psychologic and psychiatric evaluation for women after repair to ensure full integration on getting to the community and to help them in getting over the shame and stigma experienced since the development of the fistula.

CONFLICT OF INTEREST

None declared.

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