

Original Research Article

The persistent challenges and strategies for effective rehabilitation among obstetric fistula patients at Kitovu Mission Hospital, Uganda: a qualitative study

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ABSTRACT

Background: Obstetric fistula poses a great physical, psychosocial and economic burden to girls and women in low and middle-income countries. About 53% of the obstetric fistula patients may live with untreated fistula for more than a year, thus patients require rehabilitation as they await repair and after repair. Little qualitative research exists on rehabilitation particularly on the challenges and effective strategies that inspired this study.

Methods: A cross-sectional qualitative research approach used in-depth interviews and key informant interviews to collect data from 10 obstetric fistula patients who had been registered by the Urogynecology Department, Kitovu Hospital within two years before the time of data collection status and 12 key informants who include hospital staffs engaged in the management of fistula and patients' partners who were involved in caregiving. Data were analyzed thematically using ATLAS.ti 7.5.

Results: The major constraints encountered during rehabilitation were limited resources for practice, inadequate counseling especially among immediate relatives, and inadequate capital for self-sustainability and limited employment opportunities. Key informants also mentioned the issue of limited resources, budget constraints, inadequate supervision and follow up of patients. Only one patient who had not had fistula repair had knowledge of rehabilitation. To address the challenges, the participants suggested the need for rehabilitation despite repair status. They required more knowledge about sustainable livelihood programs and cash grants.

Conclusions: The patients identified socioeconomic, institutional and political challenges to their rehabilitation. They emphasized the need for improved political commitment, adequate budget, and resource allocation and regular support supervision to ensure their effective rehabilitation.

Keywords: Fistula, Kitovu Hospital, Obstetric fistula, Rehabilitation, Social reintegration, Uganda

INTRODUCTION

The obstetric fistula poses a great physical, psychosocial and economic burden to girls and women in low and middle-income countries.¹ Obstetric fistula is a traumatic birth injury currently affecting approximately 2 million

people globally with about 100,000 new cases per annum.² In Uganda, approximately 2 percent of the women of reproductive age are living with untreated fistula, yet with 1900 new cases annually.³ When women experience prolonged obstructed labor, the blood supply to the soft tissues of the vagina and surrounding tissues is

cut-off, which results in tissue necrosis leaving a “hole” that instigates urine and/or fecal incontinence.^{4,5} Alongside the leakage, women get uterine and cervical injuries, develop genital sores, suffer infections, foot drop, nerve damage, and secondary infertility. They are highly stigmatized, have low social standing, are unproductive and unable to participate in social events.^{6,7} Therefore, they are socio-economically incapacitated and the effect extends to family and community.^{4,8}

The treatment of fistula improves the quality of lives of obstetric fistula patients but it is partially effective.² A recent study in Tanzania indicated that about 16 to 32% of the patients continue to experience stress incontinence and psychosocial hurdles. Again, about 53% of them may live with untreated fistula for more than a year hence patients require rehabilitation as they await repair and after repair.⁹

Rehabilitation refers to a set of measures aimed to assist a person with an injury or disability to achieve and maintain optimal level of functioning as they interact with the environment. It reduce the impact of various health conditions and improves functioning generally. It should be person-centered focusing on needs, preferences, and experiences and ought to be initiated as soon as the health condition is recognized. Early initiation of rehabilitation prevents and slows the loss of function. Rehabilitation should generally aim to restore function, or compensate for the loss or maintain the patient's current state. Once this is achieved, the patients can regain strength, communicate freely, move about, have leisure and recreation time, love and take care of themselves, get employed, participate in social groups and have their quality of lives improved. Patients should be able to comfortably stay in their homes and if they have been rejected, they should return home.¹⁰ However, returning to a normal life remains a dream to many obstetric fistula patients.⁵

Few studies document the challenges and strategies for rehabilitation and social reintegration among the obstetric fistula patients more so in Uganda, which inspired this study. The research question was; what challenges are persistent despite rehabilitation efforts and how can rehabilitation of the obstetric fistula patients be more effective? The findings provide information to ensure patients are effectively reintegrated and rehabilitated as well as well could be used in future studies.

METHODS

Study design

A cross-sectional descriptive survey was done qualitatively with in-depth and key informant interviews.

Study setting

This study took place at Kitovu Mission Hospital in Masaka district in the Central region of Uganda. Kitovu Hospital is one of the hospitals with a specialized unit for repair of obstetric fistula patients. It also has a record of repairing the highest number of patients in Uganda on an annual basis.¹¹

Population

The participants were obstetric fistula patients, survivors and key informants composed of hospital staff (the director of the fistula program at the hospital who was also a fistula surgeon, another surgeon, two nurses, a desk officer, and a social worker) and patient partners. The study was conducted during the obstetric fistula annual camps at Kitovu Hospital that were held between January 2019 and September 2019.

Inclusion and exclusion criteria

The participants were identified purposively and through the snowballing technique from the Urogynecology Department at Kitovu Mission Hospital, Masaka, Uganda. Their selection depended on whether they were or had been obstetric fistula patients registered by Kitovu Mission Hospital in the previous two years before the time of data collection, whether they were hospital staff involved in the management of obstetric fistula, and whether they were partners who were caregiving their spouses. Whereas some patient and their spouses were found at the hospital during the camps, others were invited by direct phone calls. Besides, they gave informed written consent and assent to take part in the study

Sample size

A total of 22 participants took part in the study; 10 obstetric fistula patients and survivors and 12 key informants composed of 6 hospital staff and 6 patient partners. To arrive at this number, the interviews went on until there was a saturation of their views.

Instruments

The tools were open-ended interview guides. The question for the obstetric fistula patients was: What challenges do you continue to face despite efforts to socially reintegrate and rehabilitate you? The questions for key informants were: What challenges do obstetric fistula patients continue to face despite efforts to reintegrate and rehabilitate them? How can the rehabilitation of obstetric fistula patients be made more effective? The questions were translated in Luganda and Kiswahili languages which were the most spoken in Uganda. Also, studies indicate that the condition is common among women and girls with a low level of education. Therefore, the interviews were conducted in

the language each participant was most fluent in. Each interview took about 30 minutes.

Ethical consideration

Ethical approval was sought from a local institution: the Makerere University School of Public Health Institutional Review Board under protocol 639 and the National Council of Science and Technology under Institutional Review Board number HS361ES.

Each patient received a sum of 30,000 Ug shillings (~US\$8) each as reimbursements for transportation and off-pocket funds.

Data management and analysis

Both in-depth and key informant interviews were audiotaped, and later the recordings were transcribed and only in-depth interview recording was back-translated to the English language. The transcripts were revised for abstraction and data was entered in ATLAS.ti version 7.5, a qualitative data analysis tool, hence coded, organized and analyzed systematically for common themes. The emergent themes were identified, categorized and discussed amongst the authors. Data was later represented in the results section.

RESULTS

The obstetric fistula patients who participated in the study were 10, these included: 4 participants who had not had fistula repair at all, 2 had had unsuccessful repairs and 4 had had successful repairs. All of them had primary level of education, 6 of them were below the age of thirty years, 3 had separated with the spouses, 3 were single, and 4 were married. Of the 10 participants, 8 had vesicovaginal fistula while 2 had a complex fistula.

The challenges to the rehabilitation of obstetric fistula patients

The obstetric fistula patients and the key informants indicated the challenges the patients continue to face despite efforts to reintegrate them. Results indicate that 5 of the patients who had not had repaired indicated that they had not been rehabilitated thus they had no idea of the persistent challenges. Some patients expressed that their major challenge unemployment. They had inadequate capital to startups and sustain small scale businesses. Others noted that they had received inadequate training during the fistula camps due to limited resources while some patients noted that their major challenge was incontinence. They anticipated that if they received repair everything else would normalize. Their responses were represented in Table 1.

Table 1: The obstetric fistula patients' responses about the persistent challenges to their rehabilitation.

Patient's response	Case number
"I have not been involved in any rehabilitation activities, so I am not aware of how it has been done".	P 1: Case 1- 1:33
"When I went to Kitovu Hospital for repair, my grandmother and I were counseled because they realized she was rude and mistreating me, this has improved our relationship. However, I do not have adequate capital to startup a business".	P 2: Case 2- 2:33
"No idea. I have not had repair of the fistula, I have severe leakage of urine. I came here in March, I was examined, given tablets and told to return after three months. I have not observed any difference since then".	P 3: Case 3- 3:33
"They have been training patients in the knitting of blankets and sweaters. They also train in tailoring but the training is inadequate due to limited machines. Each patient is trained for five minutes and another one takes over".	P 4: Case 4- 4:33
"I have no clue because I have not been rehabilitated. [Donot you know anyone who has been rehabilitated?]. I am not in touch with people who have had this condition before".	P 5: Case 5- 5:33
"I have not received any rehabilitation or integration services and I am not sure about others".	P 6: Case 6 - 6:33
"I have no idea of how community reintegration has been done, however, my family is supportive".	P 7: Case 7- 7:33
"I have been repaired, counseled, and trained in hairdressing skills. My major challenge remains that of inadequate skills and capital to have my salon. I am undergoing training to master hairdressing".	P 8: Case 8- 8:33
"I have had a repair and counseling. I have no problem now, everything is in the past".	P 9: Case 9- 9:33
"Kitovu hospital repairs patients, many of them are healed which increases their re-acceptability. We are also counseled and assured [of] getting better. Patients who recovered share their experiences also and assure us that it is curable. They train handcraft at the hospital but I have not been able to master because they give a few minutes to each patient [to practice]".	P10: Case 10-10:33

The key informants had relatively similar views with the patients regarding the challenges the patients continue to face despite efforts to rehabilitate them. They also

mentioned issues around employment, stigma, inadequate capital, skills, and secondary infertility. Their responses were represented in Table 2.

Table 2: Key informant's responses on the persistent challenges among obstetric fistula patients.

Key informant's response	Interview identification number
"Patients are encouraged to start an income-generating activity but most of them cannot sustain the projects because of inadequate capital".	P 1: K1- 1:16
"Social exclusion, inadequate capital, the sustainability of their planned projects and incontinence among some patients".	P 2: K2- 2:16
"Stigmatization even after repair, unemployment, inadequate skills, and inadequate capital for an income-generating activity of interest".	P 3: K3- 3:16
"Some of the repairs are unsuccessful; some may continue to be stigmatized, unemployed, failure to mend broken marriages".	P 4: K4- 4:16
They continue to be unemployed because the community still stigmatizes. They also lack adequate capital to kick start and maintain the projects discussed at the clinic".	P 5: K5- 5:16
Some continue to be ostracized by communities, some are against reintegration as they have been through a lot and are deeply wounded, as such, they wish to relocate. Some continue to face unemployment challenge because they are considered cursed and may bring bad omen to people's businesses".	P 6: K6- 6:16
"Unemployment, unsuccessful repairs in some instances, barrenness, and stigmatization".	P 7: K7- 7:16
"No reintegration is done so patients continue to suffer stigmatization and self-hate".	P 8: K8- 8:16
"Financial challenges to implement and sustain the projects started after training".	P 9: K9- 9:16
"Stigmatization, inadequate skills, and capital".	P10: K10- 10:16
"Not everyone in the community is accommodative of her, some show it openly by leaving their seats when she sits close to them like in church but this has not stopped from going though she complains about it. Besides, sometimes diseases attack the chicken and they die. Thus, she starts afresh from scratch".	P11: K11- 11:16
"Patients do not face any challenges related to obstetric fistula as long as they demonstrate they have been successfully repaired. However, they continue to have inadequate skills, capital and unemployment like any other citizens".	P12: K12- 12:16

Strategies for rehabilitation among obstetric fistula patients

The key informants particularly contributed to the strategies for effective rehabilitation. They noted that comprehensive counseling, partner or family involvement

in the management of obstetric fistula, facilitation of repair centers with adequate training materials, follow up of the patients, adequate supervision and coordination of the obstetric fistula programs could ensure effective rehabilitation of the patients. Their responses were represented as in Table 3.

Table 3: Key informants' responses on the strategies for effective rehabilitation of obstetric fistula patients.

Key informant's response	Interview identification number
"Probably more preparation of patients in terms of counseling, allocation of adequate funds for the program and supervision of activities carried out by health institutions and NGOs that are involved in reintegration and rehabilitation could help".	P 1: K1 - 1:17.
"We need to follow up [patients in the communities], involve partners, community-based organizations, extend skills training sessions, and involve all stakeholders at every stage from planning to effective reintegration, research, talk shows on all kinds of media, supervision by managers, and survivors' active engagement".	P 2: K2 - 2:17.
"Repair of patients, continuous professional development of specialists, increased community-based activities for communities to understand and appreciate the problem and work together with health workers to address it".	P 3: K3 - 3:17.
"Community mobilization and engagement in the Campaign to End Fistula program. The campaign should include not only televisions and radio talk shows but also communities based campaigns because the patients are isolated and are poor, they may get information from the televisions and radios".	P 4: K4- 4:17.

Continued.

Key informant's response	Interview identification number
"There is a need for more community-based organizations to holistically develop the patients and more development partners to facilitate budgets of those organizations. Several organizations start and do a great job but these close within a few years especially when donors withdraw. A sustainability plan and supervision of those projects is desirable".	P 5: K5- 5:17.
"Through community mobilization and sensitization, partner involvement, competence-based training; support community-based projects and enhance supervision of programs and projects engaged in community reintegration and rehabilitation".	P 6: K6- 6:17.
"They should be repaired and counseled together with their family members. Testimonies from those who have recovered from the condition should also be part of the camping program. The camping should be fun, can you imagine we have been here for a week but we have not seen a health worker coming to talk to us".	P 7: K7- 7:17.
"Radio announcement, health education in villages and on televisions".	P 8: K8- 8:17.
"Repair, home visits, start-up capital once their goals and needs have been assessed".	P 9: K9- 9:17.
"More community sensitization about the condition, its cause, centres offering treatment, costs, and benefits".	P10: K10- 10:17.
"She needs more skills in various income-generating activities on how to manage poultry diseases. She also needs more capital to enlarge her business".	P11: K11- 11:17.
"Training should be thorough. It should involve practicum and assessment or else patients go back when they cannot do much from the skills training they have had. Subsidized capital should also be availed to the patients".	P12: K12- 12:17.

DISCUSSION

All the patients that took part in this study had a primary level of education. Several other studies note that obstetric fistula patients generally have a low level of education. For example, Wilson et al study in Tanzania in 2015 noted that the obstetric fistula patients had a low level of education.¹² Besides, they are often adolescents and young adults, primiparous, and peasants but in most cases they are unemployed.^{9,13}

Challenges to the rehabilitation of obstetric fistula patients

The findings of this study indicated that rehabilitation had been common among patients who had had repair of the fistula. Some of them had been counselled, had had training in knitting, tailoring, and hairdressing. Nonetheless, they still suffered social exclusion, stigma which in some instances was self-stigma, inadequate skills as a result of inadequate training, unemployment, inadequate capital to start-up small scale business or even to sustain them, separation, retaliation, stress incontinence, unsuccessful repairs, and barrenness.

The persistence of stigma, and isolation among obstetric fistula patients are indicated by several studies.^{6,9,13,14} They indicate how the leakage of either urine or fecal material disrupts a woman's social status. Women with fistula have low social support, and experience comorbidities which greatly contribute to trauma. These studies explicitly present the psychological symptoms, and the experiences of social support among which the

challenges are highlighted however, they did not explore the challenges along the rehabilitation process.

Studies also indicate that some obstetric fistula patients rely so much on avoidance and resignation as coping strategies especially when the fistula has not been repaired which continually confine them. Women try as much as possible to keep such information to themselves and avoid public places.¹⁴ Also when they have had a repair, they live with an intense fear of the reoccurrence of fistula. Thus, they avoid risky behaviours including sexual intercourse and childbirth subsequently resulting in marital conflicts.^{15,16} Accordingly, they fear penetrative intercourse due to a narrowed vagina.¹⁶ Their opportunities for earning a living are also minimal.^{8,17,18} Such challenges are not unique to Sub-Saharan countries but also in South Asia. A study in Bangladesh by UNFPA in 2015 noted that women with obstetric fistula in this area are stigmatized, abandoned and unemployed.¹⁹

Nonetheless, women with a high level of social support may endure distress and are more likely to engage in social activities.^{12,17} Again, a study by Heller et al, in Niger and Ethiopia noted that a large number of women with obstetric fistula received social support and kept in their relationships.²⁰ This means that the trend could be changing or it could be the efforts of stakeholders in those geographical regions. Some countries in Sub-Saharan Africa though, still have inadequate infrastructure, and outreach programs targeting obstetric fistula patients.¹⁷ As you will notice, these studies discuss lived experiences and not the persistent challenges encountered during the rehabilitation process.

Strategies for the rehabilitation of obstetric fistula patients.

The repair of the fistula, adequate counseling of the patients and their immediate families, mobilization of community members, and partners, sensitizing them and engaging them in various activities about obstetric fistula were mentioned by almost all of the key informants. Other effective strategies mentioned were: allocation of adequate funds to institutions that are involved in the management of obstetric fistula, adequate supervision by coordinating bodies, follow-up of patients, research, continuous professional development of carers and specialists, and issuance of capital to start-up income-generating activities and designing a project sustainability plan whose implementation should be emphasized.

A previous study by Kabayambi et al provides strategies that the patients have often resorted to which include: strict personal hygiene, avoiding public places and gatherings, ignoring uninvited comments and leading prayerful lives.¹⁴ Although this study was done in Uganda, it discussed the challenges and coping strategies generally among obstetric fistula patients attending a fistula clinic more so in a different setting and not particularly the challenges encountered in the process of rehabilitation which left a gap for this very study.

Khisa et al noted that the very first step to normalcy among obstetric fistula patients is seeking medical care during which the fistula is repaired.²¹ The patients often feel relieved once the fistula has been repaired.^{2,15} However, repair without rehabilitation is considered partially effective.¹⁹ Therefore the strategies for effective rehabilitation are: having well-equipped rehabilitation centers in place: rehabilitation centers, for example, those in Bangladesh have been noted to have contributed to complete healing of the obstetric fistula patients, and also equipped them with supportive skills. Other strategies include family-based interventions such as post-repair counseling, and home visits, women empowerment which includes: training them in vocational skills and connecting them to income-generating or job opportunities, engaging patients and survivors in outreach activities, and appraisal of rehabilitation efforts.^{8,15} The issues around sexual dysfunction and dyspareunia should be incorporated in rehabilitation programs.¹⁶ A study by Wilson et al in Tanzania pointed out the need for use of a cognitive behaviour framework in the rehabilitation process. The cognitive behaviour framework addresses depressive symptoms, stigma, promotes social skills and emphasizes social support.¹² Nonetheless, these studies highlight lived experiences among the patients and provide strategies to overcome the negative experience. However, these strategies could also be incorporated in the rehabilitation programs in Uganda, particularly at Kitovu Hospital to make them more effective.

CONCLUSION

The challenges encountered in the rehabilitation process could be categorized as socio-economic, institutional and political. Rehabilitation strategies could be extended to the immediate family members of patients and to the patients awaiting repair since they may take longer to be repaired due to inadequate resources at the obstetric fistula specialized clinics. These strategies are more feasible with improved political commitment, adequate budget, and resource allocation and regular support supervision.

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