4 Mending Lives and Recovering Livelihoods:
Repair of Obstetric Fistula and Reintegration

In most cases, obstetric fistula can be repaired with surgery by a specially trained doctor for as little as $300 in local 'developing country' settings. However, services are often difficult for girls and women to access due to the distances to facilities providing fistula care, the scarcity of trained doctors, and the prohibitive costs of transport and treatment [1]. Many girls and women with fistula are also unaware of the availability of repair since information on services is often scarce. For those who do receive a successful fistula repair, life can improve remarkably. With restored health and dignity, women are able to return to work and to renew family and community relationships. Reintegration programs, based on a thorough understanding of what women with fistula themselves say they need, may help support their new lives.

This policy brief is based on the study, Risk and Resilience: Obstetric Fistula in Tanzania, by the Women's Dignity Project and EngenderHealth, in collaboration with Health Action Promotion Association, Kivulini Women's Rights Organization, and Peramiho Mission Hospital. The study included 61 Tanzanian women with obstetric fistula, members of their families and communities, and local health care providers. This brief, the last in a series of four thematic briefs developed from the study, explores the women's experiences in seeking fistula treatment, and describes the changes in their lives following fistula repair.

STUDY FINDINGS[1]

Time living with fistula

The majority of the women had lived with fistula for two years or more at the time of the study. Some women were not aware that treatment was available. Others did know treatment was available, but could not afford to get to the hospitals providing repair.

One woman expressed her desire to receive treatment, but she was unable to find services: "I really wanted to get treatment for the urine problem but I didn't know where to go. I even went to the district hospital but was not treated. I wasted my fare and I was tired" (*Woman from Songea, age 20*).

Seeking fistula repair

The majority of the women interviewed had sought fistula repair or were seeking fistula repair at the time of the interview. These women and their families had sacrificed a significant amount of time and money to seek this treatment. Fewer than half had sought help in multiple places, including traditional healers, or attended the same facility on multiple occasions seeking repair. Of the women who had sought

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The following descriptive indicators with associated percentages of respondents (in brackets) are used to report findings: Nearly All (80-90% of respondents); The Majority (more than 50%); About Half (around 50%); Fewer than Half (25-45%); A Minority (10-25%); and A Few (less than 10%).

fistula repair prior to the study, fewer than half had a successful repair following surgery.

One woman said that her "mother-in-law was forced to sell a cow so that I could get treatment" (*Patient at Bugando, age 17*), and another woman's mother lost her job because she was trying to look for treatment for her daughter. In a third case, a woman recalled her inability to receive successful treatment. In 1990, she underwent surgery to repair her fistula and stayed at a hospital for 21 days, but the treatment was not successful. She underwent a second operation but again it was not successful.

Costly Attempts to Seek Treatment Without Success

In 2002, the family of one woman sold all of their chickens to get the money for transport to a health facility and for repair of her fistula. But when they arrived at the facility, she didn't get treatment. They were told to return in January 2003. When they returned, she again received no treatment and they were told to come back in May 2003. They could not return in May 2003 because they had no money. (*Woman from Songea, age 26*)

The most common reason cited for not getting a repair was lack of money to pay for treatment. One participant from Singida recounted: "I went to the regional hospital but they said they couldn't do it. They told me to go to Bugando. They said I should look for money. My father has no money, and I just stayed there feeling bad." (*Woman fom Singida, age 22*) Another patient who accessed services at Bugando said that, "At our place, treatment is a problem. We have to spend a lot of money to travel in order to get treatment." (*Patient at Bugando, age 24*)

Fewer than half of the women reported using traditional medicine for treatment of the fistula. In some cases, use of traditional medicine had negative economic impacts on the families of women. One woman related: "My family experienced difficulties trying to get me treatment. They took me to traditional healers. They spent a lot of money yet the leaking did not stop." (*Woman from Ukerewe, age 28*)

Life after fistula repair

"Now, I can do anything. I can even run."

(*Woman from Songea, age 60*)

Life improved dramatically for the majority of women in the study following successful fistula repairs. They resumed normal lives, able to interact freely with their families, friends and communities, attend meetings and church services, and take active roles in economic activities.

Almost all the women mentioned that their relationship with the community had improved. They no longer felt isolated. They felt able to visit community members and friend. Many explained that now the "community treats [them] like normal". One woman said, "I can stay with people and eat with no problem" (*Woman from Ukerewe, age 29*). Similarly, another woman reported that the community now viewed her as a human being, and she could share meals with others. A third woman poignantly expressed her recovery: "I didn't know that one day, I will be like other women because the problem was big" (*Woman from Ukerewe, age 48*)

Many women highlighted the emotional impact of repair on their lives, referring to the cure of their fistula as 'a miracle'. Half of the women specifically mentioned feeling better about themselves after repair. The majority of the women had also

A New Beginning

After getting treatment in 2002, one woman's life changed for the better. She was able to get married and perform chores as normal. She works in the 'shamba' (farm) and does things she could not do before her repair. She is able to fend for herself now that she does not have the fistula. Her family also is happy since she had treatment. Even the community treats her as a normal human being, unlike in the past. She now can go out and visit community members and go to church without facing any problems.
(*Woman from Ukerewe, age 22***)**

recovered the ability to support themselves and their families financially after repair, and almost all were able to perform domestic chores, such as fetching wood and water, farming and cooking. One woman specifically mentioned engaging in petty trade.

During follow-up visits with communities, most of the women from the study were not at home when the research teams arrived. They were attending funerals, wedding ceremonies, and a few were found working in their farms, illustrating how they have overcome the stigma and isolation they faced with fistula.

However, one participant related that she still faced stigma after repair because people did not believe she was healed. She said that people looked at the place where she slept and asked each other why she no longer wet the mat. The woman said that some people ridiculed her by likening a bladder to a gourd and saying, "A cloth can be mended but not a gourd. If you mend a gourd and put in water, the water will come out" (*Woman from Singida, age 54*). She admitted that this reaction discouraged her from telling others about her repair.

Treatment by family and friends after unsuccessful fistula repair

Unfortunately, surgical repair for two women were unsuccessful, and both women spoke of an escalation of community mistreatment. One woman reported that community members were even more spiteful towards her after the treatment failed. They laughed at her and said she was wasting her time. The other woman reported that some community members laughed at her and called her names, particularly after the failure of treatment. They also taunted her saying that she will never get a cure and is condemned to fistula for life.
One of the women spoke of her family's disappointment since they had sacrificed a lot to get her the repair. She said that they were very sorry for her; that she received medical treatment, yet continues to leak urine. She said her husband is restless because he continues to ask where treatment can be found.

CONCLUSION

The cost and inaccessibility of high quality fistula repair services are significant barriers to care for many women. The majority of the women in the study had sought fistula repair or were seeking fistula repair at the time of the interview. They and their families had sacrificed significant amounts of time and money, including selling assets to pay for transport and treatment. Still, fewer than half had a successful repair.
Following successful repair, most of the women were able to resume full and productive lives, able to interact freely with their families, friends and communities, perform domestic chores, and support themselves and their families financially. Many women also highlighted the emotional impact of repair on their lives, referring to their return to health as 'a miracle'.

RECOMMENDATIONS

High quality fistula repair services must be made available and accessible to women, and at highly- subsidized or no cost.

Information on where and when fistula repair services are available needs to be widely disseminated. Information channels that reach rural areas need to be prioritized, for example radio broadcast and informational outreach through faith-based institutions such as churches and mosques.

Beyond information, women must be actively supported to access fistula treatment. Given the severe economic impact of fistula on women and their families, it is imperative that fistula repairs be provided at minimal or no cost. Ideally, support should cover the costs of transport and treatment. Fistula programs have an ethical obligation to develop mechanisms of such support, so that advocacy on fistula does not raise women's expectations for treatment when treatment is beyond the reach of those living with the condition.

Advocacy, support, and reintegration efforts should be instituted to reduce the emotional and economic impacts of fistula.

To date, only limited information is available on women's experiences with reintegration. Further research is needed in this area so interventions are based on a thorough understanding of what women with fistula themselves need to help them begin life anew after repair. Reintegration efforts should also be mindful of the potentially differing needs of women who have had fistula for different periods of time, as it is possible that stigma, isolation and emotional trauma deepen the longer that a woman lives with fistula.

Bibliography

[1] Bangser, M. Tanzania Fistula Survey 2001. Women's Dignity Project. Dar es Salaam: 2001.

[2] United Nations Population Fund. Renew: The Campaign to End Fistula.http://www.endfistula.org/surgical_repair.htm

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