

3 LIVING WITH OBSTETRIC FISTULA: The Devastating Impacts of the Condition and Ways of Coping



Obstetric fistula is a severe and debilitating injury sustained by women during prolonged obstructed labor. The injury causes a woman to leak urine and/or feces continuously and uncontrollably from her vagina, resulting in constant and humiliating odor and wetness. Left untreated, fistula can lead to frequent and painful rashes, infections, and ulcerations, [1][2]. Traumatic labor can also result in extreme nerve damage to the woman's lower limbs. This can lead to paralysis or a disabling condition known as 'foot drop' in which the toes droop downward impeding the ability of the woman to walk normally [1].

Beyond the serious medical consequences, many girls and women are socially ostracized and ridiculed, or become so ashamed of their condition that they isolate themselves from their communities. Others are abandoned by husbands and families. Moreover, women may be left with few, if any, opportunities to earn a living, and be forced to rely on others to survive. The costs of

seeking treatment can also result in severe economic hardship. Nonetheless, so many girls and women suffering fistula show remarkable determination and resilience, and succeed against overwhelming odds to live with dignity and support themselves and their families [1][3].

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 third in a series of four thematic briefs developed from the study, examines the impacts of the condition on the women with fistula and their families. The brief also explores the methods women adopted to cope with the chronic symptoms of fistula, and the sources of support they had, if any, while living with fistula.

STUDY FINDINGS¹

Years Living with Fistula

There was a significant range in the length of time the girls and women had lived with fistula, spanning from one month to 50 years. The majority of women had lived with fistula for two years or more at the time of the study. A minority of the women had lived with fistula for more than ten years.

The Impact of Fistula on Women's Physical Health

Fewer than half of the women interviewed specifically mentioned health related impacts of fistula. Fewer than half mentioned having sores around their genitals as a result of fistula. Other women reported suffering foot drop, feeling a lack of energy, experiencing weakness, or tiring easily. The majority of women had access to health services after getting fistula. However, a minority indicated that despite access to services, they could not use them because of lack of income. In addition, two women did not use health services because they felt ashamed of their problem and did not want it to be revealed.

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%).

LIMITED CAPACITY TO WORK DUE TO THE HEALTH IMPACT OF FISTULA

In Songea, a 22-year-old young woman explained how, after getting fistula, she was able to continue performing her daily chores such as cooking and laundry, but she did not have the strength to work on the farm. She also did not generate any income from the petty business she used to conduct; she could no longer run the business effectively since sitting for a long period of time was too painful.

Without her trade, she became completely dependent on her husband who had to support the family on his own. She reported that her family's economic situation had been badly affected by her being forced to give up her business.

The Impact on Marital Status

The majority of women were married before they sustained fistula and remained married afterwards. The stability of these marriages appears to run counter to common perceptions of the impact of fistula on women's marital status. In several cases, women's partners continued to stay with them after the fistula despite pressure from others. In one instance, a 54-year-old woman from Singida explained that her husband's brother told her husband to divorce her, but he stayed with her and they had 11 children together. Another husband related that when he married a woman

with fistula, people used to say he was strange and asked him how he could live with a woman who leaked urine. He would say that it was not her fault; it's God's will, because she did not ask for it to happen.

However, fistula negatively affected the marriages of some women. Fewer than half of the women who were married before fistula were divorced as a result of the fistula, and several women reported very traumatic and painful endings to their marriages. One woman described: "My husband said 'I can't live with a woman who rots my mattress with urine.' (*Woman from Songea, age 20*) He left me and threw out all my belongings." Another woman similarly recounted: "Currently, I am divorced after my belongings had been thrown out one morning. I leave everything to God because I am suffering, and I am useless." (*Patient at Bugando, Age 30*) In a third case, a woman's partner left her after she sustained fistula and remarried. Her mother-in-law then said to her, "What are you waiting for when you have this urine problem? Get out of here and go back to your parents." (*Woman from Ukerewe, Age 23*)

A minority of the women that had remained married said that they did not have sexual relationships with their husbands after fistula. In one case, a woman reported that although she and her partner were happy, they did not share the same bed and did not have sex. A few of the women who were single at the time of the fistula had their partners refuse to marry them because of either the fistula or the loss of the baby. Only two women had additional children after sustaining fistula.

Table 1: Impact of Fistula on Marital Status

Marital Status Pre Fistula	Marital Status Post Fistula	No. of women*
Married	Married	30
	Divorced	13
	Divorced, married after treatment	1
Not married	Not married	9
	Married after treatment	2
	Married, divorced	1



* Status for four women not available

Stigma and Isolation: The Social and Psychological Impacts of Fistula

The Impact on Women with Fistula

The majority of the women with fistula isolated themselves from their communities. They remained in their homes as much as possible, stopped making social visits, and no longer attended public events such as funerals, celebrations, and meetings. Fewer than half of the women specifically mentioned not going to religious gatherings. The women felt a strong sense of shame about their condition and did not want to soil themselves in public or to smell badly. As one woman explained, "I got on well with the community, but did not want to visit them because I was ashamed of the urine." (*Woman from Ukerewe, Age 70*) Another woman expressed a similar sentiment, "At mourning places, I stay isolated, and I also sleep in the corner so that people should not notice." (*Woman from Singida, Age 45*) A third woman explained, "I was also disturbed because I couldn't go anywhere. I just stayed inside and couldn't even go to church." (*Woman from Ukerewe, Age 21*)

Fewer than half of the women mentioned being ridiculed or being segregated by community members. A woman explained "I feel shame. They laugh at me. They turn their lips up, and others leave the moment, I enter to take my tea with them." (*Woman from Singida, Age 54*)

"LIFE IS BAD. WHEN I GO OUT IN THE STREETS, PEOPLE YELL AT ME THAT I WAS DIVORCED BECAUSE OF WETTING AND ROTTING A MATTRESS." (*Woman from Singida, Age 20*)

Stigma also came from loved ones at times. This same young woman was treated badly by her grandmother, who told her, "Get lost, I am fed up. I can't put up with your smell!" (*Woman from Songea, Age 20*)

Fewer than half of the women appeared to be treated well by the community, and did not isolate themselves. One woman reported that community members bring her fuel wood, water and various gifts. They also wished her well in seeking treatment. Another woman reported that her community cares for her and provides her with casual jobs so that she can get money for daily needs. A minority of the women interviewed said that the community did not know about their condition. One woman felt that this was the reason she got along well with her neighbors. Another said that only two of her daughters knew of her fistula, despite the fact that she had lived with the condition for eight years.

Other than shame, women also reported other social and emotional impacts resulting from fistula. Fewer than half of the women reported feeling greater stress in their lives. Additional stress was experienced due to their inability to attend church and/or mosque, and being unable to have a child or to marry again. Two girls were unable to return to school, and two other girls reported the need to eat separately from others.

"THINGS ARE UPSIDE DOWN BECAUSE OF THE URINE PROBLEM AND I DON'T HAVE A SINGLE CHILD. WHAT KIND OF LIFE IS THIS?"

(*Woman from Songea, Age 30*)

The majority of family members interviewed confirmed that women with fistula experienced isolation, mainly as a result of shame, but also due to the fear of harassment/ridicule or physical weakness that compromised a woman's ability to walk. A minority of family members explicitly mentioned the sadness of living with fistula. For example, one set of parents reported that their daughter experienced sadness and loneliness, and another set of parents said that their daughter was always unhappy because she could not walk properly and could not visit relatives or friends because of shame.

The Impact on Families

The majority of the women indicated that their family members suffered from stress and worry as a consequence of the fistula. A few family members reported being worried that the woman would be unable to get married, to finish school, or to fend for herself. They felt badly about the treatment of the women by the community, and felt powerless to help them. One woman explained that her family, especially her mother, had been crying constantly because she felt that her daughter's life was over as a result of the fistula. She reported that her mother felt that the fistula was a big punishment since people failed to enter her room due to the smell of urine. Her mother also worried that no man would marry her daughter so she would live a lonely life.

A few family members also mentioned being ridiculed because of their relative's fistula. One woman was accused of having gonorrhea because of the way she walked with fistula. Her children also were harassed by community members, who said to them, "How can you eat with your mother?" (*Woman from Singida, Age 29*). This same woman also said that her husband was subjected to ridicule, and community members thought he was stupid, since they did not understand how he could live with a woman with fistula. Several other women also mentioned that their husbands had been ridiculed or pressured to divorce them, sometimes by close relatives. In one extreme case, a woman had to relocate the family due to insults from co-wives after getting the fistula.

Some women also felt they were not able to provide for their children in the manner they wished. One woman reported that her family was affected psychologically because she was at the hospital rather than at home, and the children asked for her everyday. She mentioned that her family experienced problems because she was not there to provide support or food for her children, or even take care of them when they were sick. In another case, a woman's children were looked after by a neighbor because the woman was at the hospital seeking care for the fistula.

THE CARE AND WORRIES OF LOVING PARENTS

The parents of one young woman with fistula spend most of the time at the hospital seeking treatment for her, but there is no relief. They have been forced to sell their crops for her care, especially for the debt they incurred for the treatment. The father's income has been used for the daughter instead of paying school fees for the other children. One child has had to postpone school for lack of money for fees. The family has not been able to cultivate their farm because of the time they spend caring for the daughter.

They are worried about her because they believe that she cannot get married since men will not take someone smelling of urine. Also, they think that after having had fistula, she will not be able to have children anymore

Their daughter gets pains frequently and sores because of the urine leaking. She cannot work, attend church and she feels ashamed so she does not mix with her friends. As parents, they feel very bad because their daughter dropped out of school when she got pregnant and then got fistula. They also feel ashamed in their community because they are considered to have "lost" by trying to educate a female.

Economic Impacts of Fistula

The Impact on Women

Nearly all of the women with fistula said that the condition affected their ability to work. Of these women, the majority could not work at all, while fewer than half could work, but not as hard as they did before the fistula. A few of the women reported that they could not work, but had to in order to meet their basic needs. Reasons cited by the women for not being able to work, or working less than before, included suffering poor health or feeling pain due to the fistula and/or needing to clean themselves constantly and change clothes.

In a few cases, women reported being unable to work as consequence of stigma. Overall, women experienced a reduction in their sources of independent income, which increased their dependence on others.

“...WE CANNOT OFFER YOU A JOB, YOU SMELL LIKE URINE.”

(*Woman from Songea, Age 20*)

The Impact on Families

Families of women with fistula faced higher expenses in the daily management of the woman's condition, such as costs for extra clothes and soap, and in efforts to seek treatment to repair the fistula. Treatment expenses incurred by families included surgical repair and related expenses such as transport and lodging costs for the person accompanying the woman to the hospital, and food and other necessities while at the hospital, as well as payments to traditional healers. One woman said that “income has decreased because only my husband is working. There are times when we don't have food. Washing daily is costly, you must buy the soap. This money could be used for other things.” (*Woman from Singida, Age 29*)

In addition to these direct expenses of care and treatment, families were also affected by the loss of the woman's contribution to work in the home, on the farm, or in earning income from other employment. One woman described her situation, “My family has suffered economically because I could no longer engage in any income generating activities.” (*Woman from Ukerewe, Age 48*) Another woman explained, “I cannot work because of the sores around my private parts ... my mother has no one to support the work in the farm. We harvest little.” (*Woman from Ukerewe, Age 28*) In a third situation, a woman related that “after I got fistula, my husband struggled and in the end became sick himself.” (*Patient at Bugando, Age 32*)

Families also had to forgo income when family members accompanied the woman to seek treatment. Moreover, in a few cases, children had to start working to help with their

INCREASING INSECURITY

In Ukerewe, a 23-year-old woman explained that before fistula, she engaged in petty trade and made 3,000 Tanzanian shillings (Tsh) profit every week (approximately USD\$3.00). Since she sustained fistula and paralysis of her legs, she has been unable to work. As a result, sometimes she was unable to meet the basic needs of herself and her baby.

She also became an economic burden to her family. Her father was always looking for money to pay for her treatment by the traditional healer and her other expenses, such as the food she needed while staying at the traditional healer. The money used for her treatment and expenses was supposed to have been shared by all the family. Her mother also was not able to do farm work because she had to accompany her daughter to the traditional healer. With these fewer resources and greater expenses, the risk of food insecurity increased in the family.

mother's care. One woman said that her children had to bear the burden of her fistula. She reported that her children had to perform activities that were beyond their ability because they were still young.

Coping with Fistula

Nearly all of women sought to cope with the hardships of fistula by washing their clothes regularly and taking baths frequently. Other coping mechanisms to manage the odor and leaking included changing clothes frequently, using perfumes and lotions, and wearing padding.

“I PAD (PUT CLOTH BETWEEN MY LEGS) WELL TO CONTROL THE SMELL OF URINE WHICH CONTINUES TO LEAK.”

(*Woman from Songea, Age 18*)

A minority of women mentioned that they coped by seeking treatment. Others coping mechanisms cited by respondents included: isolating themselves by staying home, keeping their fistula a secret, working, being supported by the family, praying and reading the bible, and perseverance/self determination.

“I CAN TAKE CARE OF MYSELF. I GROW MY OWN FOOD, RUN A FISH BUSINESS AND FETCH WATER, FUEL WOOD, AND, AT SOME TIMES, LOOK AFTER MY HEALTH.”

(Woman from Ukerewe, Age 39)

The Impact of Water Scarcity

In places with water scarcity – a common problem throughout much of Tanzania – women with fistula and their families faced the added difficulty of determining what to do with the little water they collected. They needed to weigh the benefits of women using the water for bathing and cleaning their clothes, versus cooking, drinking, and other family needs. One woman described the situation poignantly:

“IMAGINE YOU HAVE FISTULA. YOU HAVE TO WALK 6 HOURS TO GET ONE BUCKET OF WATER. NOW, YOU HAVE TO DECIDE HOW YOU ARE GOING TO USE THE WATER - FOR WASHING, DRINKING, BATHING, COOKING, OR FOR YOURSELF.”

(Woman from Singida, Age 39)

Another woman with fistula explained: “Water ...we get it from very far away and, if the children don't go to fetch the water, it can be a problem since I can't go myself because of the sores on my private parts.” *(Woman from Singida, Age 29)*

Sources of Support for Women with Fistula

All of the women mentioned being supported by at least one person – if not by family members, then by people in the community or an employer. None of the women were totally isolated and unsupported. This finding may be partly due to the method of recruitment for the study; the whereabouts of the more isolated women might not have been known by others and thus the circumstances of these women were not reported in the current research. Nonetheless, all of the women mentioned some type of support.

The type of support most often cited by women was assistance seeking treatment from a traditional healer or at a facility. Other key types of support were money, food, emotional support, and help with work and chores.

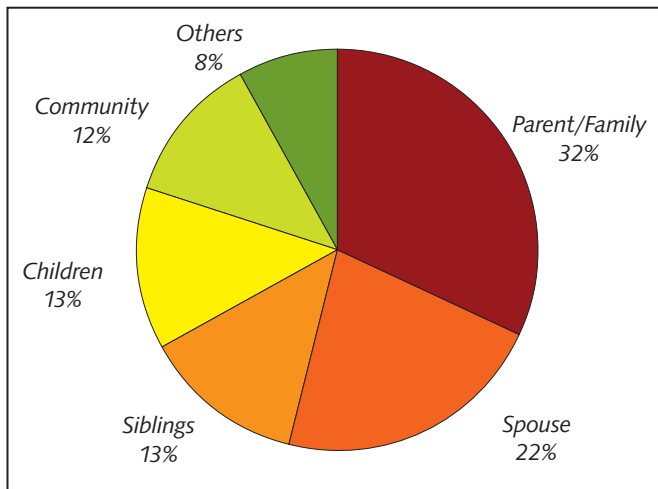
By far the most frequent sources of support mentioned by the girls and women were parents and family members. One woman said, “My brother loves me very much. He provided for everything, gave me encouragement and moral support” *(Woman from Ukerewe, Age 70)*.

Another woman explained, “My father helped me to go to Bugando Medical Centre for the treatment although he had no income, but God helped him.” *(Woman from Ukerewe, Age 31)*

“THEY FEEL BAD BECAUSE I AM THE ONLY DAUGHTER. MY FATHER FEELS VERY BAD AND MY BROTHERS TOO; THEY BRING ME FOOD SUCH AS MEAT, FISH, AND VEGETABLES.”

(Woman from Songea, Age 24)

Figure 1: Sources of Support for Women



Of the women who stayed married after fistula (n=30), the majority mentioned receiving support from their spouse. One woman was delighted that her husband helped her with her domestic chores. Another woman said, "I rely on my husband for everything, even basic needs." (*Woman from Songea, Age 22*)

The high levels of support given to the girls and women runs counter to common profiles of those living with fistula. In this

study, nearly all of the girls and women maintained good relationships with family. However, a minority mentioned problematic family relationships. Two family relationships were damaged because some family members thought other family members had bewitched the girl with fistula. In another case, a girl was rejected by her grandmother (her primary caregiver) and her brother because she got pregnant at a young age—the fistula only added to their negative feelings.

A minority of women mentioned support provided by community members. The most frequent type of support was emotional, often in the form of visits, followed by food, help with domestic chores, and financial support. Women's community groups (apparently groups whose members included mothers of the girls/women with fistula) were specifically mentioned by a few women as sources of support with food and with buying soap. Finally, the church was mentioned by a few women as a source of support in terms of both money and food. One patient at Bugando reported that she receives assistance from the community in the form of fetching water, collecting firewood and even bringing her green vegetables.

CONCLUSION

Even though most women with fistula received support from others, the emotional and economic impacts of fistula were substantial for women and their families. The majority of the women reported that they isolated themselves from their community—a critically important finding. The women felt a strong sense of shame about their condition and did not want to soil themselves in public or to smell badly. A majority of the women also indicated that their families suffered stress and worry, as a consequence of the fistula.

Moreover, women and their families suffered economically as a result of the fistula. Nearly all of the women said that

fistula affected their ability to work. Of these women, the majority could not work at all. As a result, their families were affected by the loss of the woman's contribution to work in the home, on the farm, or in earning income from other employment. In addition, families faced higher expenses in the daily management of the woman's condition, such as costs for extra clothes and soap, and in efforts to seek treatment to repair the fistula. Many families made great sacrifices to help girls and women get fistula repairs, including family members forgoing work and income to accompany the women to seek treatment.

RECOMMENDATIONS

Reduce the barriers to accessing quality fistula repair services, and conduct public education and advocacy efforts to reduce the stigma associated with fistula.

High-quality fistula repair services must be available and accessible to women at no cost or at highly subsidized cost in order to minimize the social and economic impact of fistula on women and their families. At the same time, public education and advocacy efforts which give positive illustrations of support from family, friends, and communities can be used to break the stigma around fistula. The findings from the current study show that families, including husbands, can and do support women with fistula.



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