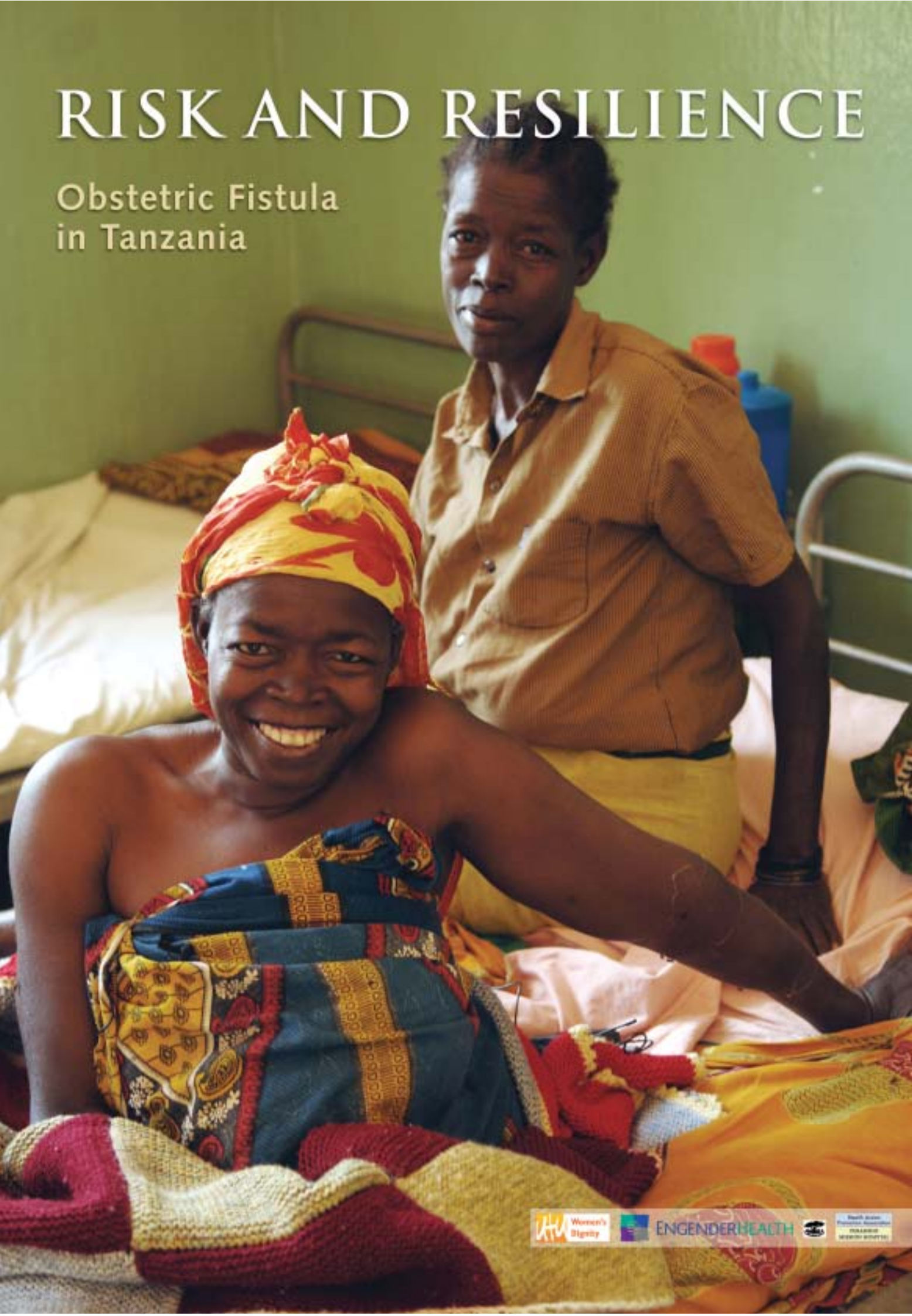


# RISK AND RESILIENCE

Obstetric Fistula  
in Tanzania



# RISK AND RESILIENCE:

## **Obstetric Fistula in Tanzania**

**Women's Dignity Project and EngenderHealth**

In partnership with  
Health Action Promotion Association,  
Kivulini Women's Rights Organization,  
and Peramiho Mission Hospital

**November 2006**

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## ACRONYMS AND ABBREVIATIONS

ANC	antenatal care
CCBRT	Comprehensive Community Based Rehabilitation Tanzania
DHS	Demographic and Health Survey
EmOC	emergency obstetric care
HAPA	Health Action Promotion Association
RCHC	Reproductive and Child Health Coordinator
RVF	recto-vaginal fistula
TBA	traditional birth attendant
TSh	Tanzanian shilling
VVF	vesico-vaginal fistula

## ACKNOWLEDGMENTS

Women's Dignity Project and EngenderHealth would like to thank the women, families, community members, and health care providers who gave generously of their time to make this research study possible.

This study was a collaborative effort of a number of institutions, including Women's Dignity Project and EngenderHealth, together with partners in Tanzania: Bugando Medical Centre; Health Action Promotion Association (HAPA); Kivulini Women's Rights Organization; and Peramiho Mission Hospital. We thank the many staff members of those institutions who helped to develop and implement this study: Maggie Bangser, Catherine Kamugumya, and Atuswege Mwangomale of Women's Dignity Project; Manisha Mehta, Rachel Goldberg, Mary Nell Wegner, and Karen Beattie of EngenderHealth; Yacinta Mkama of Bugando Medical Centre; Mary Zablon and Francis Diu Donko of HAPA; Barnabas Solo and Yusta Ntibashima of Kivulini Women's Rights Organization; and Marietha Mtumbuka and

Barnabas Cipeta of Peramiho Mission Hospital and Muhukuru Wards, respectively. The research team also thanks Reproductive and Child Health Coordinators Appolonia Makubi, Alfreda Kabakama, Margaret Shaka, and Mary Lungwa, as well as the other health officials in the study districts, for the support they extended.

We acknowledge Nicole Barber, Mevi Gray, Malika Gujarati, and John Lindsey of the New School for Social Research, New York, for their able support and assistance with data management and analysis, and the technical input provided by Janet Singer of Women's and Infants' Hospital, Rhode Island.

This report was written by Manisha Mehta and Maggie Bangser. Kirrin Gill, Mary Nell Wegner, and Michael Klitsch assisted in editing the report, and Sarah Markes in the design.



## EXECUTIVE SUMMARY

Fistula provides a critical lens onto the health and social systems that promote - or limit - the capacity of girls and women to achieve well-being. Underlying the medical presentation of fistula are its true determinants: poverty, which constrains families from accessing basic health care services; resource limitations, which undermine the capacity of health care workers to deliver high-quality care; insufficient investment in infrastructure, which makes transport to a health care facility nearly impossible, particularly in times of emergency; insufficient access to information and knowledge about maternal health and pregnancy-related emergencies; inadequate decision-making status for girls and women; and a continuing acceptance of women dying in childbirth or surviving with unspeakable consequences.

Obstetric fistula is a hole (or “false communication”) that forms between the bladder and the vagina (known as a vesico-vaginal fistula, or VVF) or between the rectum and the vagina (a recto-vaginal fistula, or RVF) during prolonged and obstructed labor. The constant pressure of the fetal skull against the soft tissue around the vagina and the bladder and/or rectum cuts off the blood supply to the tissues, causing them to disintegrate (ischemic necrosis). A hole is then left, and urine and/or feces leak continuously and uncontrollably from the vagina. In nearly all cases of obstetric fistula, the baby dies.

Approximately 2 million girls and women are estimated to be living with fistula worldwide, yet fistula remains one of the most neglected issues in women’s health and rights. It devastates lives, causing women, in most cases, to lose their babies and to live with the humiliation of leaking urine and/or feces constantly. Fistula inhibits women’s ability to work or interact with communities, driving them further into poverty and often exacerbating both their economic and their social vulnerability. Fistula also affects families: The financial burden of paying for treatment and transport to hospitals, together with the loss of one income-earner, places significant strains on the families of girls and women living with fistula. Families also suffer stress and worry about the impact of fistula on the girl or woman.

Examining fistula from the perspectives of girls and women living with the condition provides vital evidence on how health care and social systems often fail to meet women’s basic needs. Yet the voices of these girls and women are rarely heard, much less reported. Their experience can shed critically needed light onto policies and interventions to decrease maternal morbidity and mortality, as well as improve the health and well-being of girls and women in poverty.



### Purpose

The purpose of this study was to understand the many dimensions of fistula and its related social vulnerability through the experiences and views of girls and women living with fistula as well as their families and communities and the health workers who care for them. The study also explored participants’ recommendations on locally appropriate solutions to prevent and manage fistula.



## Participants and Methods

Study participants included 61 girls and women living with fistula, family members, community members, and health care providers. The study was conducted in three districts of Tanzania: Singida Rural, Songea Rural, and Ukerewe. Additional interviews were conducted with patients at a partner hospital in Mwanza. Data collection instruments included in-depth interviews, group discussions, problem trees, and freelist and ranking exercises. All girls and women living with fistula who participated in the study were provided with surgical repair of their fistula.

## Key Findings and Recommendations

This study brings to light a range of findings on fistula, based on the experiences of women living with the condition, their families, community members, and local health care providers. The findings dispel some long-held views on fistula and on girls and women living with the condition, and they provide information for building locally appropriate solutions. We conclude that action is urgently needed to ensure that no girl or woman dies in childbirth or is forced to live with the lifelong consequences of obstetric fistula.

### The six major findings and recommendations from the study are:

#### 1. **Fistula affects girls and women of all ages, both at first pregnancy and in later pregnancies.**

Although data from other countries reporting a high caseload of fistula patients note a large number of women with fistula who are young and primigravida, this study did not find similar data. In fact, the median age at which women in the study developed a fistula was 23. Fewer than half of the women were 19 or younger when the fistula occurred. In addition, about half of the women were in their second or higher pregnancy.

*Policies and programs addressing fistula need to expand beyond currently held views that fistula largely affects young girls. Public education and interventions to mitigate the risks of fistula must address the full reproductive life-cycle of girls and women.*

#### 2. **Antenatal care services, while widely available and used, are inconsistent and inadequate.**

A majority of the women in the study attended antenatal care (ANC) services—nearly all of them at least twice—but the services received were inconsistent and inadequate and differed greatly from Ministry of Health guidelines. No hemoglobin tests, urine analysis, or blood grouping were reported to have occurred, and the opportunity to discuss labor and delivery options seems to have been largely missed.

*Providers need adequate training, supplies, and equipment, as well as supportive supervision, to implement high-quality and consistent ANC services.*

#### 3. **The lack of birth preparedness, including basic information on childbirth and taking action around “delays,” increases risk.**

Nearly all of the girls and women in the study who labored at home made at least one move to get appropriate care, and a majority faced multiple delays in reaching a facility with the necessary services. The reason most often cited for the delays was the lack of recognition on the part of the woman or family that a problem was occurring. Other causes were lack of transport, delay by the traditional birth attendant, failure to take action after the family or friend recognized that there was a problem, and delay by a provider at the health care facility.

*Concrete information on birth preparedness that is understood and acted upon is critical for preventing emergencies.*

#### 4. **Lack of access to emergency caesarean section poses a great threat to women’s lives.**

For girls and women in the study, the most commonly cited barriers to facility-based delivery were that they lacked money and that the hospital was too far away. Nearly all of the women who made a move during childbirth eventually got adequate care at the hospital level and not at a peripheral-level facility. The majority of the women incurred some costs for transport to a facility, and a minority reported having to pay some type of fee for the delivery. The second most commonly

reported delay was “delay in transportation.” These barriers are critical reasons why women who need skilled assistance at delivery do not get the care they need; poor women in rural areas are likely to be disproportionately affected by the barriers.

*Girls and women, particularly in rural areas, urgently need access to emergency obstetric care provided by trained health care workers. The financial and logistical barriers to service must be eliminated.*

**5. The cost and inaccessibility of high-quality fistula repair services represent a barrier to care for many girls and women.**

The majority of the women had lived with fistula for two or more years. At the time of the interview, the majority had already sought fistula repair or were seeking treatment. Of those women who sought repair, fewer than half went to only one facility. A similar number went either to multiple places (including traditional healers) or to the same facility multiple times. Among all the women who sought treatment prior to the interview, fewer than half had a successful repair.

Of the women in the study who specified reasons for not getting repair, the primary reason was because they did not have the money to seek treatment. Those women and their families who accessed treatment had sacrificed significant amounts of time and money to do so, including

selling assets to pay for transport and treatment.

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

**6. Even though most women with fistula have support from others, the emotional and economic impacts of fistula are substantial for the woman herself, as well as for her family.**

Although it is widely noted in the literature that girls and women with fistula are emotionally and economically vulnerable, this study adds critical knowledge to understanding the shape these vulnerabilities take. For example, the majority of girls and women said that they felt supported by another friend or family member, but many also reported feeling the need to isolate themselves out of shame. Additionally, girls and women highlighted the enormous economic cost that fistula can have on an individual and on her family, because of the additional resources needed for her care. There is often less income coming into the family because the woman with fistula is forced to leave the paid workforce due to the stigma of the condition.

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

## Conclusion

**A robust policy and set of interventions, backed by high-level commitment, must be implemented to reduce maternal death and disability in Tanzania. The findings of this study, together with the 2004–2005 Tanzania DHS, provide evidence of the barriers girls and women face in accessing quality maternal and reproductive health care services. Urgent action is needed to address these barriers and to save the lives of girls and women in Tanzania.**



## I. INTRODUCTION

Obstetric fistula is one of the most neglected issues in the field of women's health and rights. Despite more than a decade of work on "safe motherhood" internationally, millions of girls and women still die in childbirth or live with maternal morbidities such as fistula. The World Health Organization estimates that approximately two million girls and women live with fistula worldwide and that an additional 50,000–100,000 girls and women are affected each year (Murray & Lopez, 1998). Experts on fistula working in the field report that this is likely to be a serious underestimate of the problem. In Tanzania alone, approximately 2,500–3,000 new cases of fistula are estimated to occur each year (Raassen, 2005).

Obstetric fistula is a hole (or "false communication") that forms between the bladder and the vagina (known as a vesico-vaginal fistula, or VVF) or between the rectum and the vagina (a recto-vaginal fistula, or RVF) as a result of prolonged and obstructed labor. The constant pressure of the fetal skull against the soft tissue around the vagina and the bladder and/or the rectum cuts off the blood supply to these tissues, causing them to disintegrate (ischemic necrosis). A hole is then left, and urine and/or feces leak continuously and uncontrollably from the vagina. In nearly all cases of obstetric fistula, the baby dies.

Although fistula presents as a medical condition, it is rooted in social, cultural, and economic determinants that underlie vulnerability. Fistula largely affects girls and women living in poverty and those living in rural areas. They often lack access to adequate health care services and information, cannot pay for medical treatment, and are poorly educated. Fistula affects young and old alike.

Data also suggest that fistula can be caused in hospital settings themselves, through improper caesarean section and negligence (Nicol, 2005). This raises serious questions about the provision of quality health care within facilities and the need for rigorous attention to improving the skills, working conditions, and attitudes of health care providers.

This study on fistula and social vulnerability was a qualitative and participatory analysis of the multiple dimensions of fistula. An explicit focus of the study was to provide a platform through which girls and women living with fistula, and others, could express their views on the impact of fistula and strategies to prevent and manage it. The intensive and in-depth nature of the study has yielded extensive data on constraints, as well as opportunities, in social and health care systems to prevent and manage fistula and other conditions that impact the well-being of people living in poverty.



## II. STUDY DESIGN AND METHODOLOGY

### A. Study Location

The study was conducted in three districts of Tanzania: Singida Rural, Songea Rural, and Ukerewe, which are located in the central, southern, and northwestern parts of Tanzania, respectively. Additionally, at a later date, interviews were conducted at Bugando Medical Centre in Mwanza, which is also in the northwestern part of the country.

### B. Study Partners

In two of the study locations, a community-based organization with a strong local presence was identified to serve as a research partner. Each organization had the capacity to follow up with participating communities after the conclusion of the study. Additionally, each organization was interested in incorporating lessons learned from the study into their ongoing work in the community.

In Ukerewe, the study partner was Kivulini Women's Rights Organization, which focuses on the prevention of gender-based violence in families and communities. In Singida, the partner was Health Action Promotion Association (HAPA), which facilitates community-based advocacy for access to health care and education and promotes citizen engagement. In Songea, the research team worked with Peramiho Mission Hospital, which provides fistula repair for women. Additionally, the research team worked closely with the District Reproductive and Child Health Coordinators (RCHCs) in all three districts.

Hospitals participating in the study included Bugando Medical Centre in Mwanza and Peramiho Mission Hospital in Songea, both of which provide fistula treatment. In addition, Makiungu Mission Hospital in Singida facilitates referrals for fistula patients to other hospitals and helped identify women for the study.

### C. Study Instruments

Several instruments were used for data collection: in-depth interviews, group discussions, problem trees, and freelisting and ranking exercises. All of

the tools were developed in English and translated into Swahili, the national language in Tanzania, by professional translators. Detailed information about each of the instruments follows below. (Table 1 provides an overview of the purpose of each of instrument.)

#### In-Depth Interview on Pregnancy, Labor, and Delivery

The interviews explored women's pregnancy, labor, delivery, and post-delivery experiences related to the pregnancy that caused the fistula. Women were asked about their experiences related to health care during pregnancy, access to resources and social support, antenatal care, and access to health care services. Additionally, women were asked about their recommendations on pregnancy-related information and services for pregnant women.

#### In-Depth Interview on Experience with Fistula

This interview was conducted to understand the personal and social impact of fistula. Women were asked how fistula had affected their lives and those of their family - psychologically, physically, financially, and socially. Additionally, women were asked about the coping mechanisms they used to mitigate the impact of fistula.

#### In-Depth Interview with Family Members on Labor, Delivery, Impacts, and Care-Seeking Behavior

Interviewers used this instrument to understand family members' perspectives on the experiences and care-seeking behavior related to the pregnancy that caused the fistula. Specifically, the interview focused on the actions that the woman and her family and friends took and the woman's access to resources during labor and delivery. The interview also explored the personal, social, economic impact of fistula on the lives of the family members and the coping strategies used to mitigate the impacts of fistula on the family.



**Table 1: Overall Purpose of and Issues Explored in Each Type of Tool**

Tool	Overall purpose and issues explored
In-depth interview on pregnancy labor and delivery (girls and women)	To understand factors related to women's pregnancy, labor, delivery, and post-delivery experiences with the pregnancy that caused the fistula
In-depth interview on experience with fistula (girls and women)	To understand women's experiences of living with fistula, including impact and coping mechanisms
In-depth interview with family members on labor, delivery, impacts, and care-seeking behavior	To understand family members' perspectives on experiences and care-seeking behavior related to the pregnancy that resulted in the fistula, the impact of fistula on the family, and coping strategies used by the family
Group discussions with providers and community members	To understand perspectives on socioeconomic, cultural, and familial factors contributing to fistula
Problem trees with women with fistula, family members, community members, and providers	To understand root causes and beliefs about fistula and coping strategies used to mitigate its impact.
Freelisting and ranking with community members	To understand the three most important contributing factors to maternal health complications during labor and delivery

### **Problem Trees on Obstetric Fistula**

A problem tree is a participatory, learning and action (PLA) visual tool that allows participants to probe for the causes and consequences of a particular issue. Participants draw a “tree” and indicate the issue on the trunk of the tree. The roots of the tree are then the causes of the problem and the branches are the consequences of the problem.

Problem trees were carried out with women with fistula, family members, community members, and providers to understand beliefs about the causes and consequences of fistula. Respondents were asked the local names for fistula and how these were interpreted locally and personally. This exercise also explored the coping strategies used to mitigate its impact.

### **Group Discussions with Providers and Community Members on Factors That Contribute to Fistula**

Group discussions were carried out with providers and community members to understand their perspectives on the socioeconomic, cultural, and familial factors contributing to fistula. In addition, they were asked their recommendations about how fistula could be prevented.

### **Freelisting and Ranking Exercises on Maternal Health Complications**

Freelisting and ranking is a PLA tool where participants brainstorm and list responses to a particular question. Once this has been completed, they then rank their responses in order of priority. In this study, community members identified the factors that contribute to maternal health complications during labor and delivery and then ranked them in order of importance. Additionally, they were asked their opinions about the different maternal health information and service needs of women of reproductive age in their community and their opinion of general health care services in their community.



## D. Study Participants

Study participants included girls and women living with fistula, family members, community members, and health care workers. Details about each of these groups of participants follow below. Study participants were from several different ethnic groups in Tanzania: Bens, Jita, Kara, Kerene, Kuoya, Matango, Ndendeule, Ngoni, Nyaturu, Sukuma, and Zinza.

### Women and Girls with Fistula

In total, 61 girls and women were interviewed regarding their pregnancy, labor, and delivery history and their experiences living with fistula. (See Annex 1 for the total number of participants involved in the different research activities, by district.)

On average, each interview lasted two hours, with one hour focusing on their experiences with pregnancy, labor, and delivery and the second hour focusing on their experiences living with fistula.

Thirty-two women and girls were interviewed at home and 29 at a hospital. Women with fistula were identified and asked to participate in the study in different ways. Our study partners communicated with staff at partner hospitals to ask them if they knew of any women with fistula in their community or at the hospital who might be interested in participating in the study. These included women who presented at the hospital with a fistula or who were seeking care because of fistula-related complications, as well as women who were interested in getting treatment for fistula. Staff at the hospital communicated with these women and asked them to come to the hospital to meet with researchers. Study participants also were recruited among women awaiting fistula treatment at partner hospitals.

Researchers met with the women, explained the research study, and asked for permission to interview them and their families. If the women were interested, they signed an informed consent form to participate in the study. After the interviews were completed, and if the interviewee gave permission, the research team went to the homes of interviewees to talk to family members. In some cases, researchers were unable to go to the communities because they were too far from

the location where they first interviewed the women. For example, some of the women who were interviewed at Peramiho and Bugando hospitals came from communities that were not easily accessible to the researchers.

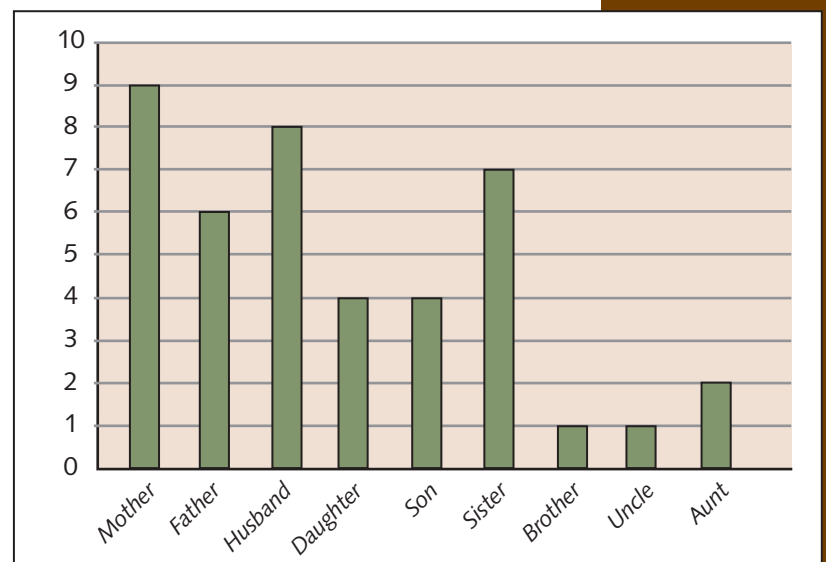
When the study team visited the communities of the women they had interviewed at the hospital, they traveled with the District RCHC. During those visits, they asked community members if they knew other women there who had fistula who might like to participate in the study. Researchers approached these women and asked them if they wanted to participate in the study. If they agreed, the researchers followed the same informed consent and interview procedure as they had used with the women they interviewed at the hospitals.

### Family Members

The researchers traveled to the villages in which families of the girls and women with fistula lived and asked family members to be available for interviews on a selected day. The researchers explained the purpose of the study to the family members and obtained their informed consent to participate in the study.

In total, 42 different family members participated in the study through in-depth interviews and problem-tree exercises. Researchers interviewed any family member present at home, including parents, husbands, sisters, brothers, children, aunts, and uncles (see Figure 1).

Figure 1: Family Members Interviewed





The discussions with family members focused on understanding their perspectives on the pregnancy that resulted in the fistula and the personal, social, and economic impact of fistula on their lives. Family members also were asked about the coping strategies they employed to deal with the impact of the fistula and their recommendations for ways to prevent fistula.

### **Community Members**

Community members living near the homes of girls and women living with fistula were included in the study. Their views helped provide a more complete understanding of the broad community and social factors that affect women's and girls' risk of developing fistula, as well as the experiences of girls and women living with fistula. In total, the study involved 68 community members in group discussions, problem trees, and freelisting and ranking exercises. During these visits, researchers and community members also discussed local plans that could be instituted to help prevent fistula and maternal health problems and to support girls and women living with fistula.

### **Health Care Providers**

Researchers met with clinical officers, maternal and child health aides, public health nurses, and medical attendants in dispensaries and health

centers near the homes of the women participating in the study. In total, 23 providers participated in the study. The researchers visited the health care facilities or other locations, explained the purpose of the research, and made an appointment to conduct the discussions.

Group discussions with health care providers explored their perceptions of the socioeconomic, cultural, and familial factors contributing to fistula, including the experiences that a woman might face during pregnancy, labor, and delivery that could lead to obstetric fistula. Additionally, four problem-tree exercises were conducted to obtain providers' perspectives on what they believe are the causes and impact of fistula.

### **E. Fistula Treatment**

All girls and women living with fistula who participated in the study had their fistula surgically repaired. The organizations conducting the research believed strongly that there was an ethical imperative to offer repair to all study participants and to make every effort to ensure that other women living with fistula who were met through the research had the opportunity to be repaired. Most of these repairs were done at Bugando Medical Centre, Peramiho Mission Hospital, and Kilimanjaro Christian Medical Centre in Moshi.



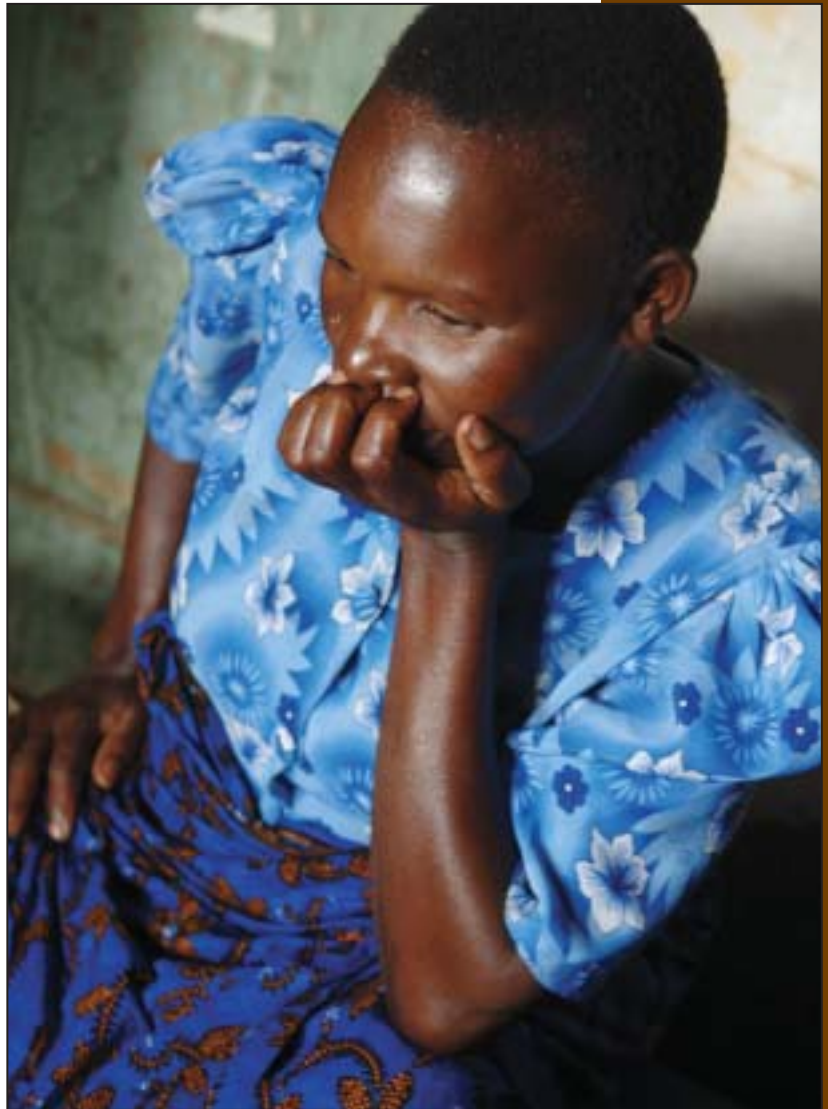
## F. Data Collection

Data collection took place between July 2003 and September 2005 and was undertaken by two researchers from Women's Dignity Project and two staff from each of the local partners: HAPA (for Singida), Kivulini Women's Rights Organization (for Ukerewe), and Bugando Medical Centre and Peramiho Mission Hospital (for Songea).

After obtaining informed consent from each of the participants, a team of two people—a principal interviewer and a note-taker—conducted the interviews and other study methods. The research team made a decision not to tape proceedings of the interviews because they felt that the participants would be more comfortable discussing a stigmatizing condition and voicing criticisms of the health care system if the interviews were not recorded.

Researchers received one week of training from facilitators before going into the field. The training consisted of a detailed orientation to the study objectives and the multiple dimensions of obstetric fistula. Additionally, facilitators reviewed all of the data instruments in detail with the researchers and trained them on how to use the instruments to record information. Following the training, researchers pretested the tools with women with fistula who were at a hospital in Dar-es-Salaam awaiting repair or had already been repaired but were receiving treatment for complications. Changes were made to the tools based on the pretest. A training reference manual was also developed and provided to the researchers to support them after the training was completed.

Interviews were conducted in Kiswahili using the data collection instruments described above. Each instrument had one or more "guiding questions" to start off the discussion and a series of related questions to help interviewers probe issues with the participants related to the original "guiding question." For example, in the in-depth interview focusing on pregnancy, labor, and delivery, the researchers explored how women made the decision about where to deliver by asking the guiding question, "During your pregnancy, did you and your family discuss where you would deliver the baby?" A series of follow-up questions probed issues related to the original question, such as



"Who was involved in the discussions about where to deliver?" "Who made the final decision about where to deliver?" etc.

The note-taker made detailed, handwritten notes on the discussions, including verbatim quotes where possible. Directly after each interview, the researchers reviewed and amended their notes for consistency and accuracy. They also reviewed their notes at the end of the day to confirm they had captured as much information as possible from the interviews. Researchers then transcribed these notes onto recording forms, which were organized according to the "guiding" questions in the data collection instruments.

## G. Approvals for the Study

The study was approved by the National Institute of Medical Research in Tanzania.



### III. ANALYSIS AND REPORTING OF FINDINGS

#### A. Data Analysis

All of the recording forms were translated into English from Swahili, with a second translator double-checking for accuracy. Two Women's Dignity Project researchers checked all recording forms for completeness and quality against the original notes. Any gaps in information or need for clarity were discussed with the local research partners, and corrections were made as a result. Lastly, researchers translated the handwritten notes from the interviews and compared them to the recording forms to verify that all of the information from the handwritten notes had been accurately and comprehensively captured on the recording forms.

A team of four persons from Women's Dignity Project and EngenderHealth developed initial codes based on a preliminary review of the recording forms. The team developed a codebook using an iterative process: At least two individuals independently coded each text segment using Atlas-ti; the team discussed coding discrepancies; the codebook was revised accordingly; and recoding was performed when necessary to ensure consistent application of codes. Atlas-ti was used to generate an initial report of the findings. The final results of the study were shared with all participating communities and study participants during community feedback meetings at each of the three study sites (see below).

This report, written by Women's Dignity Project and EngenderHealth staff, represents the final

analysis of the data collected during the study. Percentages were calculated for each topic based on the number of respondents reporting, and findings are written in this report using the descriptive indicators described in Table 2.

#### B. Community Feedback Meetings

The research teams conducted feedback meetings to share preliminary research findings and to get input from study participants on the accuracy and quality of those findings. In each district, community feedback meetings were held at two sites: communities where more than two women with fistula were interviewed originally, and where focus group discussions with community members and health care providers were conducted. These follow-up visits to the communities also enabled researchers to talk with women after their surgical repair and understand their initial experiences of reintegration into the community.

The research team identified suitable dates for the community meetings in conjunction with the community leaders, who then informed community members about when the meetings would be held. Approximately 100 community members attended each feedback meeting. There was broad consensus during the follow-up meetings that the findings were correct. Participants also endorsed the ideas they had discussed during the original community meetings with researchers.

#### C. District Feedback Meetings

The research teams also held meetings with staff from different departments in the district councils (local authorities), including the District Medical Officer, the District Executive Officer, the Planning Officer, and the Community Development Officer. These meetings were used to share information and to identify strategies for the prevention and management of fistula. The research team shared key preliminary findings and provided an update from the community feedback meetings. These sessions were highly appreciated by council authorities, who had expressed a desire to be informed about the study findings and to support further work on fistula in their locales.



## IV. STUDY LIMITATIONS

### A. Length of Time Living with Fistula

At the time of the interview, some of the respondents had been living with their fistula for several years; therefore, they were reporting on a pregnancy that had occurred years ago. As a result, in a few cases, it was difficult to get detailed information about the antenatal care they received or their labor and delivery experiences during the pregnancy that caused the fistula.

### B. Facility-Based Entry

The majority of the girls and women with fistula in the study were identified at participating hospitals; just under half were identified at the community level. The girls and women who were already at a facility might not be a representative of all those living with fistula; they may represent women with greater proximity to health care facilities, family and social support, and/or economic resources. Thus, the experiences of the most isolated and vulnerable girls and women in the most difficult conditions may be more accurately reflected by the experiences of girls and women whom the researchers met at the community level.

### C. Limited Research Experience

To ensure that the research findings would be used for programmatic work in the study communities, community-based organizations from each of the study sites were selected as research partners. This had positive outcomes in establishing a rapport with communities and trust with the study participants; in addition, it helped the community-based organizations to better understand how to address maternal health in their communities. However, the researchers' relative lack of research experience was a limiting factor. For example, in some instances, the data did not capture nuances around some of the issues or provided only partial summaries of the participants' perspectives on certain issues.

**Table 2: Descriptive Indicators**

Descriptor	Associated percentage
All	100%
Nearly all	80–90%
The majority	More than 50%
About half	Around 50%
Fewer than half	Around 25–45%
The minority	10–25%
A few	Less than 10%

### D. Interviews Not Taped

The research team decided not to tape the discussions with participants, because it was felt that participants would be more comfortable discussing a stigmatizing condition and voicing criticisms of the health care system without being recorded. As a result, in certain situations, the researchers were not able to record all of the participants' experiences verbatim.

### E. Detailed Questions on Labor Times

The research team did not ask exact times when the women went into labor, the exact steps in the labor process, etc., because it would have been difficult for women to recall this information precisely. In addition, it was not possible to measure the onset of labor directly or utilize a standardized definition for when labor began across all study participants. Therefore, all data on the labor and delivery times reflect the women's reporting of their own experiences.



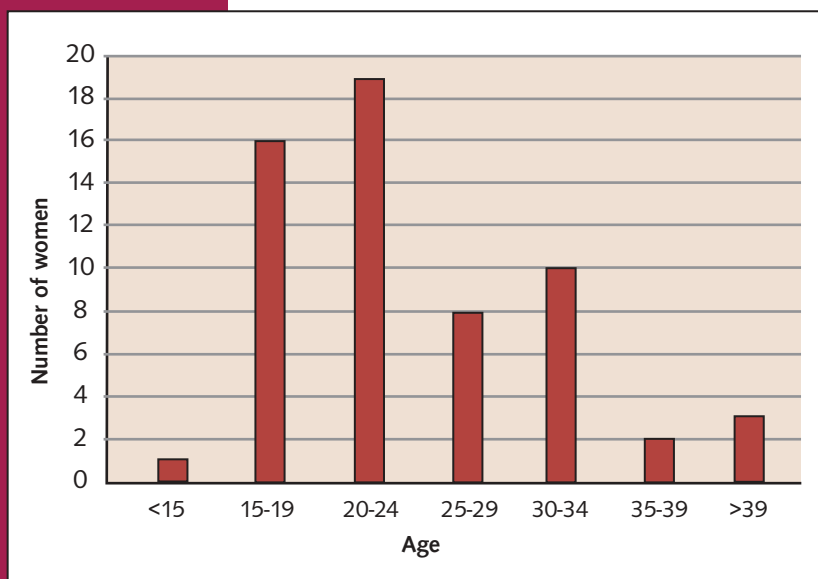
## V. FINDINGS OF THE STUDY

### A. Demographic Information

#### Age

The mean age of the girls and women at the time of the study was 32. The youngest participant was 17, and the oldest was 78.

Figure 2: Age at Fistula



#### Age at Fistula

The mean age of women at the time they sustained their fistula was 23; the youngest was 12 and the oldest was 46. More than half of the women were 20 or older at the time the fistula developed. The breakdown of the age at fistula of participants is shown in Figure 2. These findings are noteworthy, given the common perception that fistula occurs primarily at a young age.<sup>1</sup>

#### Gravidity

About half of the 42 women who responded to this question were on their second or higher pregnancy at the time they developed a fistula; the remaining women were on their first pregnancy.<sup>2</sup> This finding, like age at which the woman got the fistula, highlights the fact that fistula does not only affect young girls on their first pregnancy, as is often assumed.

### B. Pregnancy History

The information summarized in this section is based on women's experiences during the pregnancy that caused their fistula.

#### Antenatal Care

Nearly all of the women in the study had gone for antenatal care (ANC) at least twice. Of the women who mentioned how they made the decision to go for ANC, fewer than half said they had decided by themselves to go. For these women, their decision to attend ANC was largely because they had seen other women go or because their friends encouraged them to go. Of the remaining women, fewer than half went for ANC because a family member - parents, husbands, in-laws - had decided that they should go, while a few mentioned deciding jointly with their husbands to go for ANC. In one situation, a woman indicated that she only decided to attend ANC when she was seven months pregnant. She reported that her mother-in-law told her that pregnancy is not a disease; therefore, there was no need for her to attend clinics. Her father-in-law then intervened and told her that she "should attend clinic because it is important to have regular check-ups." (*Woman age 23, Ukerewe*)

For the women who did not go for ANC, it was mostly because the distance to services was too large. One woman from Ukerewe explained that she never attended ANC because it was far, and when she was pregnant with all of her previous children, she never went to the clinic. Another reason given for not going to the clinic was not having the decision-making power to do so. One young girl, for example, indicated that, because she was 15, she had no power to determine whether to go to the clinic.

Despite the fact that nearly all of the women with fistula had received some ANC, study data indicate that ANC services were inconsistent, were inadequate, and differed greatly from the guidelines issued by the Ministry of Health.

1 Data gathered separately from Bugando Medical Centre in Mwanza and CCBRT Hospital in Dar es Salaam confirm the findings of the study, with each site reporting a mean age of 23 among their fistula patients overall (Mach & Nicol, 2004).  
2 Information regarding gravidity was not available for 19 women.

Moreover, the services received varied greatly by individual. During ANC, about half of the women were weighed; fewer than half had their height measured or were given some type of medicine; and a minority had their height measured. Two women reported that they were given medication for malaria. No hemoglobin tests, urine analysis, or blood grouping were reported. The story of a patient at Bugando illustrates a typical ANC experience: She reported that during her first and second visits, her abdomen was examined, she was given an inoculation, and her height was measured. During her fourth and fifth visits, her abdomen was examined and her height was measured, but she received no other type of care.<sup>3</sup>

None of the women participating in the study had a discussion related to pregnancy or labor and/or delivery during ANC visits, except that in a few cases, the woman was simply told to deliver in a facility. In one case, a woman was advised to deliver at a hospital because of her age; in another case, a woman was told during routine health education sessions to deliver at a hospital. One woman said that she attended ANC clinics regularly. They often took her weight and blood pressure. When she realized that she was past her delivery date, she asked the health care provider what was causing this delay, because she was one month overdue. When the health care provider could not explain why, the woman decided that she would deliver at home.

ANC services are an important opportunity for women to receive pregnancy, labor, and delivery-related information and counseling from providers. It also provides an opportunity for health care workers to diagnose serious problems that women may face during labor, such as pre-eclampsia. The findings suggest that for the study participants, ANC was a significant “missed opportunity” to deliver such information and services.

According to guidelines issued by the Ministry of Health in Tanzania,<sup>4</sup> women should have at least four focused ANC visits during their pregnancy. A woman’s first visit should be at 16 weeks, the second visit should be at 20–28 weeks and the third and fourth visits should be between 28 weeks and when the woman delivers. (Table 3 provides information about what should be done at each of the four visits.)

### Health Status, Food, and Work Load during Pregnancy

The majority of the women with fistula reported no serious problems during pregnancy. Those who did report problems mentioned experiencing weakness, general malaise, and body pains. A few women reported more serious health problems, such as malaria, syphilis (contracted from the husband), and pus in the genital area. Almost all said that they had adequate food during pregnancy, and no woman mentioned eating more

**Table 3: Services to Be Provided at Each Antenatal Care Visit**

a If not done at the first visit.  
b This would be the second dose and should be four weeks after the first dose.

	Visit 1	Visit 2	Visit 3	Visit 4
Take history of the health of the woman.	X			
Do physical examination, checking the woman from head to toe.	X	X	X	X
Check the woman's hemoglobin and provide iron supplements.	X	X	X	X
Check the woman's blood group.	X			
Screen the woman for syphilis.	X			
Screen for HIV/offer voluntary counseling and testing for HIV.	X	X	X	X
Give tetanus toxoid vaccine.	X	X <sup>a</sup>	X <sup>b</sup>	
Check woman's blood pressure and urine.	X	X	X	X
Counsel the woman and provide health education.	X	X	X	x
Ensure the woman has an individualized birth plan.	X	X	X	X
Listen for the fetal heartbeat and check position and presentation of the baby.		X	X	X
Provide a dose of anti-malaria medicine.		X	X	
Inform the woman about pregnancy, labor, and delivery danger signs.		X	X	X

3 Patients interviewed at Bugando Medical Centre came from many locations in Tanzania seeking fistula repair. Their comments and quotations reflect experiences before their admission to Bugando.

4 Orientation package for service providers, Ministry of Health, (RCH/NMCP) JHPIEGO, October 2004.



than usual. Since the study did not explore the quality or quantity of food intake, it is difficult to determine whether it was sufficient for the women during pregnancy. Nearly all of the women said that throughout the entire pregnancy they did all of their usual chores, which generally included farming, washing, cooking, walking long distances to fetch water, and collecting firewood.



### Knowledge of Pregnancy and Labor

All of the women who mentioned knowing anything about pregnancy and labor had this knowledge because of past experience with it. A few women in Songea mentioned having received this knowledge from rites of passage. As one woman said, "my in-laws explained (it) to me during initiation rites." (*Woman from Songea, age 60*) A few women also mentioned having this knowledge because of friends or relatives: "I didn't know much about pregnancy because I was too young, but my sister-in-law explained to me what labor is like." (*Woman from Ukerewe, age 48*) Another woman said: "I didn't know I was pregnant until a friend of mine commented: you look so beautiful and your skin is so smooth, you might be pregnant. You need to go for a check up at the hospital to be sure." (*Woman from Songea, age 20*)

### Use of Traditional Medicine

The majority of women had taken traditional medicine at some point in the pregnancy process; however, only a minority had taken it during labor as a way to stimulate labor. Reasons women reported for taking traditional medicine during pregnancy included ensuring that the baby was in the right position, facilitating a smooth pregnancy or detachment of the placenta after delivery, stopping vomiting, and curing other diseases and infections related to the pregnancy. A few women mentioned taking traditional medicine during labor to stop labor pains. One woman reported: "I used traditional herbs to speed up the dilation because this was my first pregnancy." (*Woman from Songea, age 22*)

### Family Planning

Nearly all of the women who spoke about family planning had never used a family planning method.<sup>5</sup> Fewer than half of these women said that they had not used family planning because they did not know about family planning methods. A similar number said they had not used family planning because the pregnancy that resulted in the fistula was their first pregnancy, so they did not need to use family planning. A few women indicated that they did not use family planning because of side effects. One woman reported that she does not use family planning methods because she believes that use of family planning will result in abnormal children in the future, will cause her to menstruate twice a month, and will reduce her sexual pleasure.

## C. Birth Preparation

### Delivery Place

The majority of the women interviewed indicated that they were planning to deliver at a health care facility of some type, although the specific type of facility (e.g., hospital, health center, or dispensary)<sup>6</sup> was not always clearly defined by respondents. As

5 There was no information related to family planning in 16 of the interviews.

6 Dispensaries and virtually all health centers in Tanzania lack the capacity to provide caesarean section.

one woman indicated, "I and my family decided that I should give birth at the hospital. My mother made the decision for me to give birth at the hospital." (*Woman from Ukerewe, age 28*)

Of the women planning to deliver at a facility, the majority started at a lower-level health care facility, or began at home with a traditional birth attendant (TBA), or went to the hospital too late after trying to deliver at home. A few of these women had been told to deliver at a more specialized site during ANC. About half of the women planning to deliver at a facility had set aside some funds for costs related to labor, delivery, post-delivery and/or transport - but still did not go immediately to the hospital when labor started. Some women mentioned specific constraints that prevented them from going to the hospital, such as not having enough money, lacking access to transportation, or having insufficient knowledge and information about labor.

Fewer than half of the women planned to deliver at home. Among those who did plan to deliver at home, a few reported doing so because they had already had successful deliveries at home or because the health care facility was too far away from their home. A minority had not discussed where they would deliver prior to going into labor, although one woman had wanted to deliver at the hospital but had not discussed her plans with any of her family members. One woman reported that her family did not discuss where she would deliver, but she was certain it would be at home because she had always delivered at home.

About half of the women indicated that they faced constraints when planning for facility-based delivery. The most common factors were a lack of money and the hospital's being too far away. One woman said that her husband was not home for two months prior to the birth and did not leave enough support (money). She went on to explain that "money determines where one gives birth, because if you go to the hospital before going into labor, it means you have to stay with someone or rent a place to stay close to the hospital, and that costs money." (*Patient at Bugando, age 28*) Other reported constraints included lack of funds for

transport, lack of access to transportation facilities, and inadequate information about the importance of facility-based delivery.

### **Who Made the Decision on Where to Deliver?**

Of the women who indicated how they made a decision about where to deliver, the majority did so in conjunction with their husband or their family. Fewer than half of the women were not involved in the decision about where to deliver because it was made by a family member and/or husband.

### **Plans Made for Transport**

A minority of all the women with fistula had set aside funds for transport. Reasons for not doing so included that they were planning to deliver at home; that the health center was close by; that it was against their customs to put aside money for delivery; or that they did not have sufficient funds. One woman from Ukerewe reported that she did not make any special arrangements for transport to go the health center because she knew she would deliver at home. In another case from Songea, a woman explained that she did not make preparations for transport to the health center because, according to her customs, it is improper to make preparations before delivery because this could result in a stillbirth.

### **Setting Aside Money**

Fewer than half of the women with fistula had set aside funds for some aspect of labor, delivery, post-delivery and/or transport. Three women mentioned saving money for emergencies, while one specifically mentioned keeping money aside for gloves. The amount that women or their families had saved ranged from a low of Tanzanian Shillings (TSh) 3,500 (US\$3.50) to a high of TSh 50,000 (US\$50).<sup>7</sup> Reasons for not setting aside money included expecting to deliver at home and simply having no money. One woman indicated that she had set aside TSh 2,000 (US\$2.00) for delivery fees, TSh 1,500 (US\$1.50) for gloves, and TSh 1,500 (US\$1.50) to buy baby clothes. In contrast, another woman reported that her family did not prepare anything because they were too poor.

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<sup>7</sup> Throughout this report, costs are given in Tanzanian shillings and U.S. dollars at the approximate exchange rate at the time of the study: TSh 1,000=\$1.

## Preparation for the Baby

The majority of the women did not prepare for the baby in any way. One of the common reasons expressed was that preparing for a baby was against their customs and that they wanted to wait until the baby was born because they did not know if the baby would be born alive. According to one woman, it is taboo in her ethnic group to make preparations before the baby is born. A minority of the women prepared for the baby in some way, either by buying clothes for the baby, buying powder, and/or buying bleach to wash the baby's clothes.

## D. Labor, Delivery, and Referral Trajectory

### Onset of Labor

Nearly all of the women started labor at home; of these, the majority went into labor in the evening or at night, when it was more difficult to access assistance. A few started labor while outside the home, either while doing chores, while at church, or while visiting relatives. A few also started labor when they were in transit to the hospital or when they were already at the hospital.

### Delivery Trajectory

Nearly all of the women who began their labor at home had to make at least one move. Their move was based on seeing that there was a delay or problem that needed appropriate care. Only seven women delivered where they started labor - five at home<sup>8</sup> and two at the hospital. Table 4 shows the number of moves made by women from the initiation of labor until the delivery of the baby.

Of the women who had to make a move to receive appropriate care, about half made only one move; of these women, nearly all went from their home to a hospital where they received the necessary help.

Fewer than half of the women had to make at least two moves from the place where labor began to where they completed delivery. Among these women, nearly all had to go to a hospital before receiving appropriate care. (See Annex 2 for further details on where the women sought care after initiation of labor.)

Of the women who started their labor at home, fewer than half were assisted by a TBA, while the rest were generally assisted by family or friends. In two cases, women were assisted by community-based providers (a pharmacy assistant and a nurse) who were not TBAs. Of those women who were assisted by a TBA, nearly all had to seek care elsewhere after experiencing labor and delivery problems.

### Reasons for Moving

The most common reason for making the first move was because the woman or her family realized that substantial time had passed in labor without progress. The second most common reason was because the TBA realized she could not help.<sup>9</sup>

### Who Made the Decision to Move?

The majority of women were helped by others to make the decision to move to another place for labor or delivery. Only five women with fistula made the decision to move during labor totally by themselves. Once a woman was in labor, family and friends were the primary decision makers. Of these, the husband was the most frequent decision maker, followed by the woman's parents. In-laws and neighbors/friends also played a role in making the decision to move the woman to another place for delivery. In one case, the woman experienced difficulty in getting to the hospital because of a family member; as she explained: "I was delayed in getting to the hospital because my mother-in-law wanted me to deliver at home." (*Patient at Bugando, age 17*)

**Table 4: Number of Moves Made by Women from Initiation of Labour to Final Delivery**

No. of moves	No. of women
0	7
1	30
2	19
3	4
>3	1

8 Four of these women received help from TBAs.

9 More detailed information related to the delivery process is offered in the next section.

After family and friends, the most frequent decision makers about when and where to move the women during labor were health care providers and TBAs. This typically occurred when they realized that they could not help the women themselves, or, in the case of formal health care workers, when the facility where they worked was not equipped to assist the women. One woman in Songea who arrived at a health center was asked, "Why did you come here? We told you to deliver at Peramiho." (*Woman from Songea, age 39*) Nonetheless, they examined her and asked her to push. In the evening, they realized she could not give birth and told her to look for transport and go to Peramiho. In Ukerewe, a woman reported that the TBA came and examined her and told her that she had to go the hospital because she could not deliver safely anywhere else.

### Transport and Delivery Costs

The majority of the women interviewed incurred some costs for transport to a health care facility during labor and delivery. Transportation costs ranged from TSh 200 (US\$0.20) to TSh 70,000 (\$70). One woman interviewed at Bugando mentioned that no expenses were incurred because they used her neighbor's bicycle, which was loaned to them free of charge. She further elaborated that they had to use a bicycle because there is no road and no transport system.

A minority of the women reported having had to pay some type of fee for the delivery. The lowest fee paid was TSh 1,755 (\$1.75) and the highest was TSh 62,000 (\$62), which was at a private hospital where the woman had to undergo a caesarean section.

## E. Outcome, Care, and Roles during Labor and Delivery

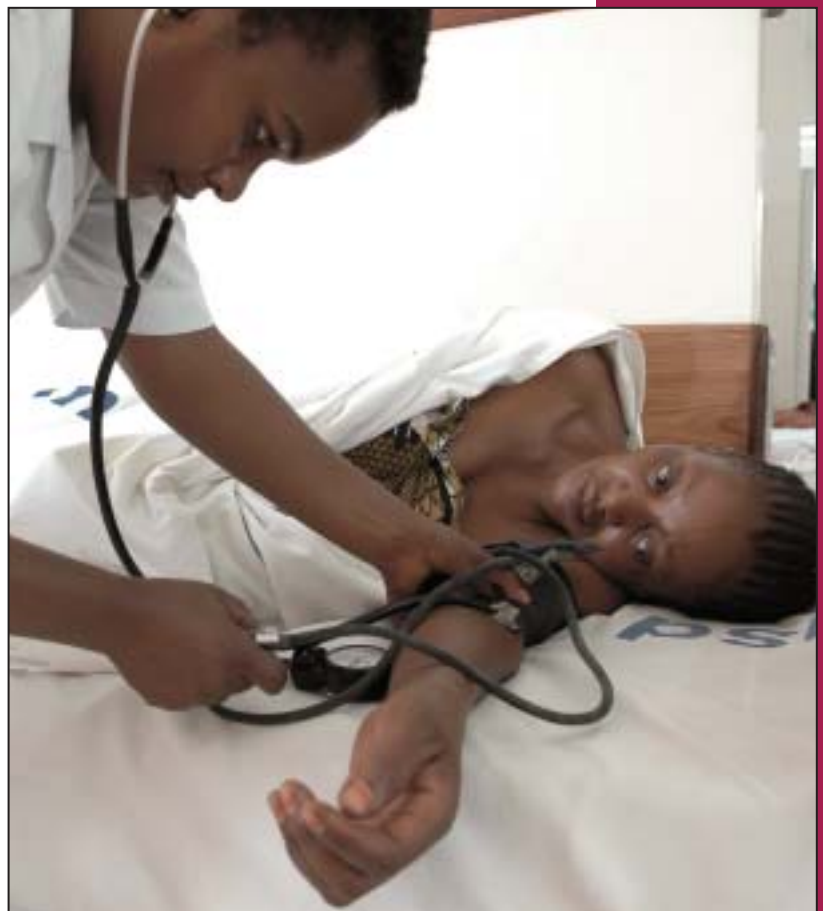
### Outcome and Mode of Delivery

Nearly all of the women with fistula had a stillbirth. Fewer than half of the women delivered vaginally, and a similar number delivered by caesarean section. A minority of the women had a vacuum delivery. One woman stated, "We decided to do a caesarean section after realizing that I could not deliver normally." (*Woman from Songea,*

*age 20*) Another woman at Bugando described, "I realized that there was a problem after I was examined and told that I would deliver by operation." (*Patient at Bugando, age 17*)

### Urination during Labor

A majority of the women in study reported they could not pass urine during labor, passed only small amounts, or urinated only once during labor. A minority of the women found it difficult to remember whether they passed urine or not.



It is important that a woman's bladder not overfill during labor, because bladder distention can prevent the fetal head from descending. Additionally, if the fetal head presses against a full bladder for an extended period of time, this can lead to tissue breakdown and ultimately to fistula. Though we do not have a comparison group of women who did not develop fistula, it seems unlikely that the high percentage of women in our sample who had difficulty urinating is a normal finding. It suggests that being unable to urinate contributes to the development of fistula.



## Health Care Providers' Roles during Labor and Delivery

In general, the type of care given by the health care provider depended on the level of facility that the woman reached. Fewer than half of the women interviewed who sought help at a dispensary or health center mentioned that the providers examined and referred them to another facility. This occurred after the health care provider realized that they could not help the women because the site was not equipped to deal with emergencies. At the tertiary sites, the majority of the women said that the providers' main role was to help deliver the baby through either caesarean section or instrumented delivery.

In a couple of instances, women mentioned having negative experiences with providers. In one case, the woman said: "Nurses were asking for soda before they would give us service. At one point, they told a patient they wouldn't dress her wound unless she gave them a soda." (*Woman from Ukerewe, age 29*)

## Role of Family and Friends during Labor and Delivery

All of the women received support of some kind from their family or friends during labor and delivery, and in most cases, the role these people played in the lives of the women was very positive.

The most frequent type of support given was accompanying the woman to a facility or helping in some way during labor and delivery. One woman's mother-in-law, for example, helped her by providing medicine and preparing food for her during labor and delivery. In another case, the woman said that "my father and relatives provided the assistance that enabled me to get to the hospital. The assistance they gave me was very useful." (*Woman from Ukerewe, age 28*) Another woman explained, "My uncle paid the delivery fees." (*Woman from Ukerewe, age 21*)

Friends and family also played an important role in arranging for transport, in making decisions about getting treatment, and in getting help from others. In some cases, friends and family provided funds or food, as the following woman stated: "The assistance I received included food and clothes.

My brother gave me TSh 6,000 (US\$6), and I used this money to buy sugar and fuel wood." (*Woman from Songea, age 29*)

However, a few women had negative experiences with family and friends. In one case, a woman spoke about the treatment she received from relatives when she needed to go to a facility during labor. She reported that when they went, she could not walk, so her relatives slapped and kicked her, and her mother-in-law pinched her so she would walk faster. In another case, a woman said that she did not inform her family that she was supposed to deliver at the district hospital because she was afraid that her father would have shouted at her.

## Role of the TBA during Delivery

**"THE TBA CARE WAS BAD BECAUSE SHE FORCED [ME] TO DELIVER AT HER PLACE WHILE SHE DIDN'T HAVE THE SKILLS. SHE DIDN'T WEAR GLOVES; SHE USED HER BARE HANDS."**

(*Patient at Bugando, age 21*)

Fewer than half of the women were attended by TBAs at some point in the labor process. Nearly all of these women reported that the TBAs examined them by using their hands to see if the cervix had dilated and then tried to help them to deliver. One woman said: "The TBA care was bad because she forced [me] to deliver at her place while she didn't have the skills. She didn't wear gloves; she used her bare hands." (*Patient at Bugando, age 21*)

In fewer than half of the cases attended by TBAs, the woman also reported that the TBAs gave them traditional medicine to ease labor pains or to stimulate the labor process. In several cases, when they realized they could not help them deliver, the

TBAs referred the women to a health care facility, but this was often after several hours of labor.

### Opinion of Care

**THE NURSE AT A FACILITY TOLD ME, “IF YOU DON’T PAY TSH 15,000 (US \$15), YOU WILL NEVER GET A BLOOD TRANSFUSION. IF YOU HAVE TO DIE, BETTER DIE”.**

*(Patient at Bugando, age 24)*

The women with fistula had varying opinions regarding the care they received during labor and delivery. These depended largely on the type of facility at which they delivered. Nearly all of the women with fistula were satisfied with the care they received at their final place of delivery. Some of the reasons were because the providers saved the woman’s life and/or the baby’s life, or because they were able to identify the problem the woman was experiencing. Another woman reported that the nurses’ aides and nurses took good care of her during the weeks she was in the hospital, checking on her on a regular basis. Another woman from Singida indicated that she was comfortable with the services from the doctors who administered the surgery to her, as they managed to save her life and the life of her baby. One woman told interviewers about a positive experience at a peripheral facility: “Health services at the health center are good. They even discovered I had a problem and told me to go a bigger hospital.” *(Woman from Songea, age 18)*

Fewer than half of the women were not satisfied with the care they received for various reasons. Some women were dissatisfied because they were not treated well. One woman who went to a hospital during her pregnancy was told she would need a blood transfusion. The nurse told her “If

you don’t pay TSh 15,000 (US\$15), you will never get a blood transfusion. If you have to die, better die.” *(Patient at Bugando, age 24)* Another woman shared that “the nurses were there and provided the needed care. Some of the attendants spoke kindly, but some used abusive language.” *(Patient at Bugando, age 28)*

“The nurses were there and provided the needed care. Some of the attendants spoke kindly, but some used abusive language.” *(Patient at Bugando, age 28)*

One woman reported that inadequate care and the high charges at the private hospitals contributed to the loss of her baby. She explained bitterly that she called the nurses during labor, but they did not care. When she called the nurses, they would say, “You keep calling. Do you call us so that we can carry you on our backs? Don’t disturb us, and you go.” *(Patient at Bugando, age 24)* A woman said that she did not get good service because a wound developed after a few days. She explained that “the nurses showed arrogance to my mother, claiming that she was not cleaning the wound properly, and that this was the reason which caused the wound to smell badly and develop into pus early.” *(Woman from Songea, age 18)*





## F. Delays

**“I WAS DELAYED IN  
GETTING TO THE HOSPITAL  
BECAUSE MY MOTHER-IN-  
LAW WANTED ME TO  
DELIVER AT HOME.”**

*(Patient at Bugando, age 17)*

### DELAY IN RECOGNITION OF A PROBLEM

In Singida, a 39-year-old woman started labor at midnight. Her husband went to the dispensary to get an attendant. The attendant examined her and told her husband that she was not ready to deliver. The attendant then went to sleep after telling her husband to call the TBA living nearby. When the TBA arrived, she examined the woman and told her that she was ready to deliver. The woman's labor pains lessened, and the TBA gave her traditional medicine to accelerate the labor. By morning, she still had not delivered. The TBA then realized there was a problem and that she could not deliver at home.

Her husband and relatives decided to take her to a dispensary. They managed to find a wagon pulled by an ox. At the dispensary, she was examined and told that they could not help her. She had to go to the regional hospital in Singida. Her husband then had to hire a car to take her to the hospital. When she arrived at the hospital, the doctors decided that she needed a caesarean section. However, there was no power at the hospital, so she was sent to a mission hospital, where she finally received a caesarean section about 24 hours after the onset of labor. She was unconscious, and the baby had died by the time the caesarean section was completed.

### Problems Leading to Delays

A majority of the women interviewed faced multiple delays<sup>10</sup> in reaching a facility with the necessary services to enable them to deliver safely. Only eight women with fistula did not face any type of delay. Table 5 shows the number of delays experienced by the respondents.

For the majority of the women, either the woman or her family or friends delayed in identifying a problem that needed to be addressed by a skilled provider. In all cases, this was because the woman began her delivery at home, with only family members or friends present.

**Table 5: Number of Delays Experienced by Women with Fistula**

No. of delays	No. of women
0	8
1	9
2	24
3	13
4	3
5	3
6	0
7	1

The majority of the women mentioned that they knew they were having delivery problems because they had been in labor for a long time without any success. One woman said: "I realized that there was a problem after spending the whole night with no progress." (*Woman from Singida, age 35*) Another woman's words indicate a similar story: "I blame myself because at (my local facility) they told me to go to (the district) hospital because my pregnancy was problematic, but I ignored the advice. I didn't think I had a problem. When the baby began to go up instead of down, that is when I realized there was a problem." (*Woman from Ukerewe, age 39*)

**“I REALIZED THAT THERE  
WAS A PROBLEM AFTER  
SPENDING THE WHOLE  
NIGHT WITH NO  
PROGRESS.”**

*(Woman from Singida, age 35)*

<sup>10</sup> Information on delays was derived from the detailed information given by the women of their care seeking behavior during labor and delivery.

<sup>11</sup> Estimates of the length of labor are based on what the women reported.

The length of labor reported by women varied from 10 hours to four days.<sup>11</sup> Other signs of delivery problems mentioned by the women included bleeding, stopping of labor pain, and partial emergence of the baby.

#### FOUR DAYS IN LABOR

In Ukerewe, a 23-year-old woman spent four days in labor before reaching a hospital where she could get care. She went into labor at midnight. Her husband went to get her mother-in-law, who examined her and told her to be brave because she was experiencing labor pains. The woman wanted to be taken to the dispensary, but her mother-in-law said no and told her she was just scared. Her husband and mother-in-law stayed with her but did little to help. After the woman had spent two days in labor, her mother-in-law called the TBA, who examined her and recommended that she go to the hospital. Her family decided to take her to the dispensary in the village first, before going to the hospital.

To get to the village dispensary, the woman walked for two hours with her husband and in-laws. On the way, they hit her with a stick, and her mother-in-law pinched her to make her walk faster. At the dispensary, they informed her that she would have to go to the district hospital, but she had to stay overnight because it was already dark. The next day, they walked to a health center, because her mother-in-law refused to go to the district hospital.

At the health center, the providers shouted at them for not going to the district hospital and gave them a referral letter to go there. They finally went to the district hospital by boat and vehicle. The woman was rushed to the labor room, but she was already unconscious. The baby died and the woman had developed a fistula.

One woman reported that her husband decided to take her to a private hospital after she had been in labor for four days at home. In another case, a woman's father decided to take her to the hospital after she had been in labor for three days. (See Table 6 for information about the type of delays reported by the women.)

**Table 6: Types of Delay Experienced by Women with Fistula**

Type of delay	No. of women
D1a: Lack of recognition of problem by woman or friend/family	31
D1b: Delay by TBAs in identifying problem and/or taking action	18
D2: Delay in seeking care <sup>12</sup>	16
D3: Delay in transportation	30
D4a: Delay at site due to lack of supplies, equipment, etc.	6
<b>Type of site</b>	
Regional hospital	2
District hospital	1
Dispensary	1
Hospital	1
Health center	1
D4b: Delay by provider at the site	15
<b>Type of site</b>	
Dispensary	5
• Failure to recognize a problem	3
• Failure to recognize a problem and inattentiveness to patients' needs	2
District hospital	
• Failure to recognize a problem	5
Health center	4
• Failure to recognize a problem	4
Hospital	1
• Failure to recognize a problem and inattentiveness to patients' needs	1

The majority of the women also faced a delay because a TBA or a facility-based provider<sup>13</sup> did not recognize the problem or provide service to her in a timely manner. One woman arrived at the hospital and the doctor told her: "I can't perform the operation, I am leaving." She finally left the hospital on morning of the third day and went to

12 This includes all delays related to not taking immediate action to seek care after a problem has been identified.

13 These were primarily at the dispensary or district level. Five of the cases occurred at the district hospital level or at the dispensary, and four occurred at the health center level.

another hospital in order to get help. (*Patient at Bugando, age 19*) One woman who waited for two days at a hospital prior to receiving a caesarean section described a situation where "some of the patients gave the doctors money in order to get fast attention," (*Woman from Songea, age 20*) during which time her labor pains stopped. In another case, a woman said that the TBA "agreed that we could go to hospital after realizing that the baby was dead." (*Patient at Bugando, age 21*)

### Different Choice Made

Nearly all of the women who responded to the question "Would you have done anything differently?"<sup>14</sup> said that they would have gone to the hospital earlier. A minority of the women in the study said that they would have followed the advice they received during ANC about delivering at a particular site. Other responses included setting aside money to go to the hospital and receiving help earlier.

delivery. Of these, almost all spoke of getting to the hospital earlier, either before or right after the beginning of labor.

It was clear from some statements of family members that they felt a sense of guilt for not having done more to prevent the problem. For example, one husband said that his wife sustained her fistula because he made a mistake calling the pharmacy attendant and the TBA, rather than going directly to the hospital. Had he known there was a problem, he would have taken her to the hospital and, therefore, likely prevented the fistula. He also explained that he faced other constraints. He had wanted her to be transferred to a hospital and stay there until she delivered because she had been sick during her pregnancy. However, he had no money for the hospital charges and no one else at home to take care of the family. Therefore, it had not been possible.

**“MONEY DETERMINES WHERE ONE GIVES BIRTH, BECAUSE IF YOU GO TO THE HOSPITAL BEFORE GOING INTO LABOR, IT MEANS YOU HAVE TO STAY WITH SOMEONE OR RENT A PLACE TO STAY CLOSE TO THE HOSPITAL, AND THAT COSTS MONEY.”**

(*Patient at Bugando, age 28*)

One set of parents said that they longed to reach the hospital in time so they could save the life of the baby. Another mother said that there had been negligence on the part of her husband, who had refused to send their daughter to the hospital early (though the husband did not directly admit this). In another case, the father realized the danger of

### DELAY IN TRANSPORT - A DEADLY BARRIER TO WOMEN'S HEALTH

Most of the women who reported on delays in reaching a skilled provider or an appropriate facility said that the delay was caused by a lack of transport. One woman from Ukerewe explained that she had no money to hire a vehicle, so they transported her on a bed placed on two bicycles. Another woman reported that she had been taken to the hospital on an office chair placed on a bicycle. A woman from Songea reported that she took a district vehicle, which was owned and operated by the district government. The vehicle dropped her off at the bus stop because it could not go further, since the driver had other things to take care of. She remained at the bus stop for six hours, since all of the buses were full. Finally, a truck stopped there, but before it reached the mission hospital, it broke down. The woman and her attendants had to spend the night where the truck broke down. They finally found transport in the morning and reached the hospital in the afternoon.

### Reactions Regarding Delays

Of the family members interviewed, five explicitly mentioned that they thought something could have been done differently during labor and

<sup>14</sup> Nineteen women responded to this question.

fistula, and when his other daughter got pregnant, he told her husband to send her to the mission hospital before labor started.

Another set of parents blamed the medical attendants<sup>15</sup> at the local dispensary, who had examined their daughter earlier, since these attendants could have identified and prevented the problem.

### G. Perceptions of Causes of Fistula

Women, their families, and community members had different views about the causes of fistula, as described in the following sections.

**“IF I HAD GONE TO THE  
HOSPITAL ON TIME, I  
WOULD NOT HAVE  
FISTULA.”**

*(Woman from Ukerewe, age 28)*

#### Women’s Explanation of Fistula

According to findings from the in-depth interviews, the majority of girls and women with fistula believed their condition was caused by factors

related to the delivery process itself. Fewer than half of the women reported fistula to be caused by a delivery delay. One woman stated, “If I had gone to the hospital on time, I would not have fistula.” (*Woman from Ukerewe, age 28*). Similarly, another woman said, “I think I stayed in labor pain for a long time and that caused the bladder to break.” (*Patient at Bugando, age 24*) In addition, fewer than half of the women attributed the fistula to hospital procedures or to the provider. One woman said, “I think they caused it because they used instruments.” (*Woman from Singida, age 18*) Another woman reported that her fistula problem started after the doctors and nurses pulled out the baby with delivery instruments.

Fewer than half of the women perceived bewitchment to be a cause of fistula. A woman from Singida believed that she was bewitched because she used to deliver on her own, without the help of TBAs. She believed that the community members and TBAs hated her because she denied the TBAs the gifts and other privileges they get for helping women deliver. A few women believed that their fistula was the result of people inserting their fingers into the vagina during labor. Some of the other reasons given by women as causes of the fistula included: the baby was too big; the woman was scared to push during labor; it was God’s will; and it was bad luck.

The group discussions and problem trees among women with fistula confirmed these findings, though less emphasis was given to problems during delivery itself and more to delays in getting emergency care. Not delivering at health care facilities, living far from the hospital, not having the means to go to the hospital, and being hesitant to go to the hospital because of traditional beliefs were all listed as precursors to getting fistula. Also mentioned were being bewitched, using traditional

**Table 7: Women’s Perceptions of Causes of Fistula**

Causes	No. of women <sup>16</sup>
Delivery-related procedures	32
Use of instruments during delivery	9
Provider’s fault	8
Woman afraid of pushing	6
Insertion of hands in the vagina by provider/family and friends during labor	5
Operation (caesarean section)	4
Delivery delay	27
Delayed/prolonged delivery	14
Delay in reaching the hospital	12
Delay in getting a caesarean section	1
Bewitched	16

<sup>15</sup> Attendants at the local dispensary are generally untrained providers.

<sup>16</sup> Some women provided multiple responses.

medicines to speed up labor, “being short,” being malnourished, marrying early, and having initiated sex at an early age.

### Family Explanations of Fistula

Interviewees most frequently cited bewitchment as the cause of fistula. They often described bewitchment as the result of jealousy of either the woman or her family. About half of the respondents selected this cause. The husband of one woman reported that his wife was bewitched by his relatives because they did not want him to live with her at his own house; they wanted him to live at her house. As a result, they punished her by giving her the fistula.

Community members mentioned being too young as a cause of fistula in all of the focus groups or problem-tree exercises conducted. One respondent in a focus group discussion explained that the likelihood of fistula was higher among young girls because their bodies are not fully developed. The second most frequently cited theme for the cause of fistula was a delay in delivery.

Other causes mentioned less frequently were non-hospital delivery, lack of money, too many children, residence far from health centers or facilities, lack of transport, witchcraft, early marriage, and home delivery because the woman was trying to be “brave” and deliver at home. Community members associated early marriage with poverty and lack of schooling for girls. Two women also mentioned providers’ use of fingers as a cause of fistula, saying,

**“I HATE IT WHEN EVERYBODY INSERTS THEIR FINGERS INTO ME. THEY DON’T EVEN WEAR GLOVES! THEY END UP BREAKING YOU!”**

*(Ukerewe, participant in community discussion)*

### Providers’ Knowledge about Fistula

In the group discussions, most providers mentioned that fistula is a problem in their community, but they claimed that it does not affect many women. The providers also reported that they had not experienced it when helping women deliver. In Ukerewe, providers reported that only one woman consulted the health center with the problem, and that she was informed where to seek assistance. As in most communities, providers in Singida reported that the fistula problem exists in the community but is not common. They explained that there is one girl in a neighboring village with fistula. Only providers in Songea indicated that fistula is a big problem in their community, because they had come across two women with it in a short period of time.

**Table 8: Family Members’ Perceptions of Causes of Fistula**

Causes	No. of people
Bewitchment	8
Use of instruments during delivery/provider mistake	6
Delivery delay	5
God’s will	4
Failure to deliver at a hospital/being too young/lack of care by provider	3

In in-depth interviews, fewer than half of the family of women with fistula believed hospital procedures and delay in going to the hospital were significant contributors to fistula. The belief that it was God’s will, failure to deliver at a hospital, lack of care by provider, and young age were considered by a minority as causes of fistula.

### Community Members’ Explanations of Fistula

In all four group discussions, community members said they were familiar with fistula and knew of women in their communities with the condition.

**Table 9: Community Members’ Perceptions of Causes of Fistula**

Causes	No. of people
Too young	6
Delivery delay	5
Failure to deliver at hospital/lack of money/too many children	4



**Table 10: Providers' Knowledge about and Perceptions of Causes of Fistula**

Causes	No. of providers
Failure to deliver at the hospital	6
Too young	5
Lack of money	5
Delivery delay	4

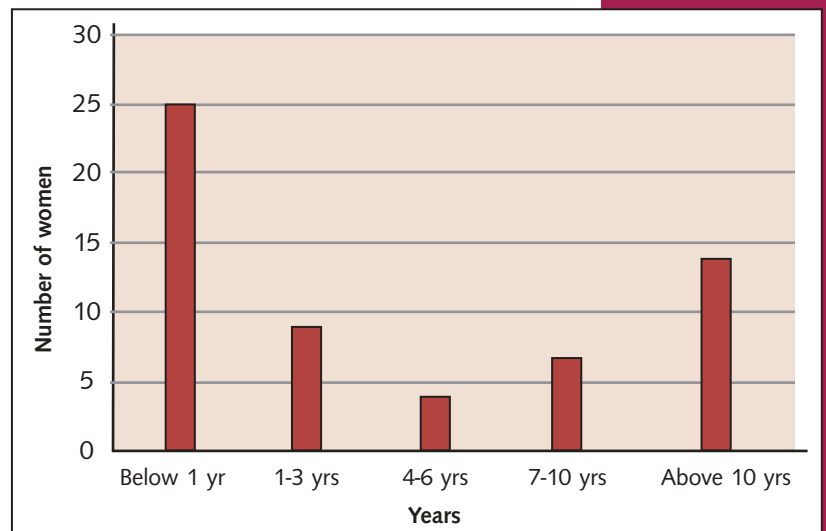
In group discussions and problem-tree discussions, providers mentioned multiple causes of fistula. Many of the causes had to do with contextual factors in the lives of the women that contribute to fistula, while others had to do with health-related issues. The most common factor cited by providers was the woman's experiencing a delivery delay and/or not delivering at the hospital due to the unavailability of transport, her inability to afford transport, her living far from a health center, or her lack of autonomy in making the decision to go to a facility. As providers in Songea pointed out, only two buses pass through a village: The first leaves the village in the morning, and the second returns in the evening. So, effectively, only one bus goes to the place where the hospital is located, and generally it is always full. Therefore, in case of an emergency, it can be difficult to provide assistance to patients who need to go to the hospital. In another focus group discussion, providers pointed out that women have no voice in the family and that even when a woman is sick, she cannot decide to go to the hospital or clinic without the permission of her husband or father.



In one of the group discussions, providers mentioned that a lack of political will can cause fistula. They explained that there are by-laws in (parts of) Tanzania providing that families who allow women to deliver at home must pay a fine. However, these laws are not enforced. Providers also cited other contextual factors that contribute to fistula, particularly young age of the woman. Other factors, such as lack of income, poor nutrition, and lack of education on reproductive health, were less commonly mentioned.

## H. Impact of Fistula on Girls and Women

**Figure 3: Years Living with Fistula**



### Years Living with Fistula

There was a large range in the length of time the girls and women had lived with fistula, spanning from one month to 50 years. The majority of the women had lived with fistula for two years or more at the time of the interview. The largest single group had lived with fistula for less than one year. A minority of the women had lived with fistula for more than 10 years.

For some women, the length of time before seeking treatment was because they did not know treatment was available. Others knew treatment was available but could not afford to get to the hospitals that provide repair. A few women mentioned not receiving repair because they were in poor health after delivery.

17 Information on this issue was not available for six of the women interviewed.



## Number of Children

The majority of women who responded to this question did not have children after developing the fistula.<sup>17</sup> Two women had had children after developing a fistula: One had 11 after her fistula (and before having the fistula repaired; the other woman had a fistula, was repaired, had two children, and then sustained another fistula.

## Marital Status

The majority of women with fistula were married before they sustained their fistula and stayed married after developing the problem (Table 11).<sup>18</sup> This contravenes many widely held assumptions about the impact of fistula on women's marital status.

*Bugando, age 30*) In another case, a woman's partner left her and got remarried after she sustained a fistula. Her mother-in-law 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 who had remained married said that they did not have sexual relations 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.

Of the women who were single when they sustained a fistula, a few reported that their partners refused to marry them because of either the fistula or the loss of the baby. In two cases, the woman's partner abandoned her after the pregnancy but before she sustained a fistula. Two women were not married before they sustained the fistula but got married to their partners after treatment. In only one case did a woman get married after fistula but then was forced to get divorced because of a difficult mother-in-law.

**Table 11: Impact on Marital Status**

Pre-fistula marital status	Post-fistula marital status	No. of women
Married	Married	30
Married	Divorced	13
Not married	Not married	9
Not married	Married after treatment	2
Married	Divorced, married after treatment	1
Not married	Married, divorced	1

A minority of the married women got divorced as a result of the fistula. This was a painful experience for them. In one case, a woman said, "My husband said, 'I can't live with a woman who rots my mattress with urine.' He left me and threw out all my belongings." (*Woman from Songea, age 20*) Another woman similarly recalled, "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*

One 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. However, he would say that it was not her fault; it's God's will, because she did not ask for it to happen.

## Economic Impact

Nearly all of the women with fistula said that fistula 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 woman reported that they could not work, but had to in order to meet their basic needs. Some of the reasons for not being able to work or for working less than before had to do with the health effects of fistula (e.g., feeling pain or in poor health), the constant

## CONTINUING SUPPORT OF HUSBANDS

In several cases, women's partners stayed with them after the fistula, despite pressure from others not to do so. 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. She emphasized that when people visited them and saw them together, they sometimes mistook them for lovers rather than for husband and wife.

<sup>18</sup> Status was unavailable for four women.

need to clean themselves and change clothes, and, in a few cases, stigma. As one woman explained, "At one point, I went to search for an odd job at someone's home. She insulted me, saying that we cannot offer you a job, you smell like urine." (*Woman from Songea, age 20*)

#### NARROWING OPTIONS

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.

Overall, this led to a reduction in their sources of independent income. It also increased their dependence on others. However, fewer than half of the women indicated that they did not have control over their income because of the fistula.

#### Stigma and Isolation

The majority of the women with fistula isolated themselves from other community members, remaining in their homes as much as possible and forgoing public activities such as funerals, celebrations, meetings, and social visits. This isolation was caused by a strong sense of shame about their condition and by a strong desire not to soil themselves in front of anyone or to smell badly. As one woman explained, "I got on well with the community, but I 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*)

**"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*)

Fewer than half of the women mentioned being ridiculed or being segregated by community members. One 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*) Another woman said, "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. The same woman was also being 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*) A minority of the women mentioned being treated well by some community members but being ridiculed by others.

Fewer than half of the women appeared to be treated well by the community and did not isolate themselves. One woman reported that members

**"MY HUSBAND SAID 'I CAN'T LIVE WITH A WOMAN WHO ROTS MY MATTRESS WITH URINE.' HE LEFT ME AND THREW OUT ALL MY BELONGINGS."**

(*Woman from Songea, age 20*)

of her community bring her fuel wood, water, and various gifts, and that they also wished her well so that she would get treatment and come back home safely. Another woman reported that her relationship with community members is good: They care for her and provide her with casual jobs so she can get money for daily needs.

Fewer than half of the women specifically mentioned not going to religious gatherings. As one 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*) One woman from Singida attended religious gatherings, but she said, "I go to church with friends and they know, but I have to leave before mass ends." (*Woman from Singida, age 54*)

**"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*)

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. One woman said that the only people that knew of her fistula were two of her children (daughters), despite the fact that she had lived with fistula for eight years.

Other than shame, women also reported other social and emotional impacts resulting from fistula. Fewer than half of the women reported a negative impact on their stress level due to "living with worries." Additional stress came from spiritual repercussions (due to their inability to attend church and/or mosque) and the inability to have a child or to marry again. Two girls mentioned their inability to return to school, and two reported the need to eat separately from others. A woman explained: "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*)

## **Views of Family and Community Members**

Family members described how they perceived fistula's impact. The majority mentioned that women experienced isolation, mainly as a result of shame (fear of leaking in front of people or of smelling), of fear of harassment/ridicule, or of weakness due to their compromised ability to walk. A few family members also indicated that fistula had an impact on the spiritual lives of the women because of their inability to attend church and/or mosque. 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 mentioned that their daughter was always unhappy because she could not walk properly and could not visit relatives or friends because of shame.

Community members were also asked their perception of the impact of fistula on girls and women living with the condition. They mentioned loneliness, shame, and isolation after fistula, as well as the fact that in some cases, women with fistula are discriminated against by their family and friends. Health care providers also mentioned isolation, shame, and loneliness as a result of fistula.

## **Health Impact**

Fewer than half of the women interviewed specifically mentioned health-related impacts of fistula. Of these, around half mentioned that their health had changed or that they felt sick or had pain. Fewer than half mentioned having sores around their genitals as a result of fistula. Other responses mentioned included foot drop,<sup>19</sup> feeling a lack of energy, experiencing weakness, or tiring easily. The majority of women had access to health care services after sustaining a fistula. A minority, however, indicated that they had access to services but could not use them because of lack of income. Two mentioned not using health care services because of shame or because then their problem would be revealed.

<sup>19</sup> "Foot drop" is a weakness of the muscles that are involved in flexing the ankle and toes, which may be caused by the pressure of the baby's head on the nerves of a woman's legs during labor. As a result, the toes droop downward and impede the normal walking motion.

## I. Impact on Family

**“IT IS HARD ON MY FAMILY, BECAUSE MY BROTHER IS FORCED TO LOOK AFTER ME, AND HE HAS TO LOOK FOR MONEY TO TREAT MY PROBLEM.”**

*(Woman from Ukerewe, age 28)*

### Economic Impact on Family

Money for treatment, clothes, and soap were the most frequently mentioned expenses incurred by the families of women with fistula. Treatment included fistula repair and related expenses (such as transport costs for the person accompanying the woman to the hospital, food and other expenses at the hospital, and lodging for the person accompanying the woman), as well as treatment from traditional healers. One woman said that her family was affected “because (the) mother-in-law was forced to sell one cow so that I could get treatment.” (*Patient at Bugando, age 17*) Another woman expressed the difficulty her family faced by telling us, “It is hard on my family, because my brother is forced to look after me, and he has to look for money to treat my problem.” (*Woman from Ukerewe, age 28*) In another situation, a woman’s mother suffered because she lost her job, since she was trying to look for treatment for her daughter.

A woman with fistula commented: “My family is also affected because instead of doing some productive activity at home, they have to plan and visit me at Bugando.” Another woman with fistula explained 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*)

Some families were also in debt from being assessed fees for delivery at the hospital and from borrowing money for transport to the hospital

when the woman was in labor. In one case, a husband needed to sell his land to pay back the money he had borrowed to hire a cart and vehicle to take his wife to the hospital when she was in labor. At the time of the interview, he was working without salary as a guard in the village office to pay back what he had borrowed. In addition, he needed to buy water, because previously his wife had walked for six hours to fetch a bucket of water, but currently she was no longer capable of it. Additionally, he had to support three children in the family.

In addition to the expenses related specifically to fistula, families were also affected because there was one less person working in the home or on the farm or bringing in income from other sources. The remaining family members, therefore, had to do the work that the woman previously did or forgo the income that she previously contributed. One woman described her situation in this way: “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*) A woman stated, “After I got fistula, my husband struggled and in the end became sick himself.” (*Patient at Bugando, age 32*) One

### INCREASING INSECURITY

In Ukerewe, a 23-year-old woman explained that before fistula, she was engaged in petty trade and made TSh 3,000 profit every week (approximately US\$3). Since she sustained a fistula and developed paralysis of her legs, she has been unable to work. As a result, sometimes she is 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 of the family. Her mother also was not able to do farm work because she had to accompany her daughter to the traditional healer. With fewer resources and greater expenses, the risk of food insecurity in the family increased.



woman reported that her children had to bear the burden of her fistula, performing activities that were beyond their ability because they were still young. In another situation, a woman mentioned that her husband was very upset because he had to do all of the jobs at home himself, with little help from her or the children.

**“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 a few cases, women mentioned that their children had to start working to help with the care of their mother. In one case, a woman with fistula described how “my children decided to help their father with some money so that I could be cured.” *(Patient at Bugando, age 40)* In another case, a woman said “I got assistance from my children, and my son remits money to me to buy food, sugar, etc.” *(Woman from Ukerewe, age 60)* In a third case, the woman’s older child had to sell vegetables and sardines so that his mother could get fare to go to the hospital for treatment.

### **Non-economic Impact on Family**

The majority of the women indicated that their family members suffered from stress and worry about their having fistula. They explained that their families felt “sad” or “bad.” A few family members reported being worried about the woman’s being able to get married, to finish school, or to fend for herself. The women with fistula echoed this, saying that their relatives felt badly watching them

suffering. They felt badly about the treatment they received from the community. They felt powerless to help them and wished they could help them more. They also worried about their futures. 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.

### **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.

Her mother also worried that no man would marry her daughter, so she would live a lonely life. Another woman said: “My children felt bad about my situation, but they are too young. My relatives too felt badly when I had fistula.” *(Woman from Ukerewe, age 48)*

ONE WOMAN WAS  
ACCUSED OF HAVING  
GONORRHEA BECAUSE OF  
THE WAY SHE WALKED  
WHILE LIVING WITH  
FISTULA. HER CHILDREN  
WERE ALSO HARASSED BY  
COMMUNITY MEMBERS,  
WHO SAID TO THEM,  
“HOW CAN YOU EAT WITH  
YOUR MOTHER?”

*(Woman from Singida, age 29)*

#### A MOTHER AND DAUGHTER

A daughter describes that her mother has fistula and often becomes sick. Due to illness, her mother sometimes fails to go out and visit people. She cannot work or farm for a long time, since she has to go home and rest and wash her clothes. As a result, the daughter faces a lot of hardship. Sometimes she is forced to abandon her jobs to fetch water for her mother. Her mother needs the water in order to make pots to sell so they have money to live on. She said that in most cases, other girls laugh at her and say her mother has a venereal disease.

A few family members mentioned having been ridiculed because of their relative's fistula. For example, one daughter reported that other girls in her community laughed at her and told her that her mother had a venereal disease. A few of the women with fistula said that their children were subjected to problems in the community because of the fistula. All of these women said their children experienced “back biting.” One woman was accused of having gonorrhoea 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 their relatives (e.g., the husbands' siblings or mothers).

Other impacts on the family included women not being able to provide for their children in the way they would have liked to do. In one extreme case, a woman had to relocate the family due to insults from co-wives after sustaining the fistula. In another case, the children had to keep their mother's fistula a secret from their husbands and other siblings because their mother had told only them. 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 every day. She mentioned that her family experienced problems because she was not there to provide support or food for her children, or even to take care of them when they were sick. In another case, a neighbor looked after a woman's children because she was at the hospital seeking care for the fistula.

#### J. Coping with Fistula

“I TRIED TO TAKE BATHS  
REGULARLY AND WASH  
CLOTHES FREQUENTLY;  
SOME PEOPLE DON'T  
KNOW I HAVE A URINE  
PROBLEM BECAUSE I DON'T  
SMELL BAD.”

*(Woman from Songea, age 20)*

Women living with fistula said they dealt with the hardships of fistula through various coping mechanisms. Nearly all of them said that they

washed their clothes regularly and took baths frequently. A woman said, "I tried to take baths regularly and wash clothes frequently; some people don't know I have a urine problem, because I don't smell bad." (*Woman from Songea, age 20*) Other mechanisms to manage the odor and leaking were to change clothes frequently, use perfumes and lotions, and wear padding. Another woman said "I pad (put cloth between my legs) well to control the smell of urine that continues to leak." (*Woman from Songea, age 18*)

**"I PAD (PUT CLOTH BETWEEN MY LEGS) WELL TO CONTROL THE SMELL OF URINE THAT CONTINUES TO LEAK."**

(*Woman from Songea, age 18*)



Family members' perceptions of the coping mechanisms used by the women were very similar. The strategies they cited were washing clothes regularly and bathing often. A few also said that women with fistula remained at home. In the group discussion, family members mentioned women's seeking treatment, adhering to the advice of health care providers, and "not giving up."

**Impact of Water Scarcity**

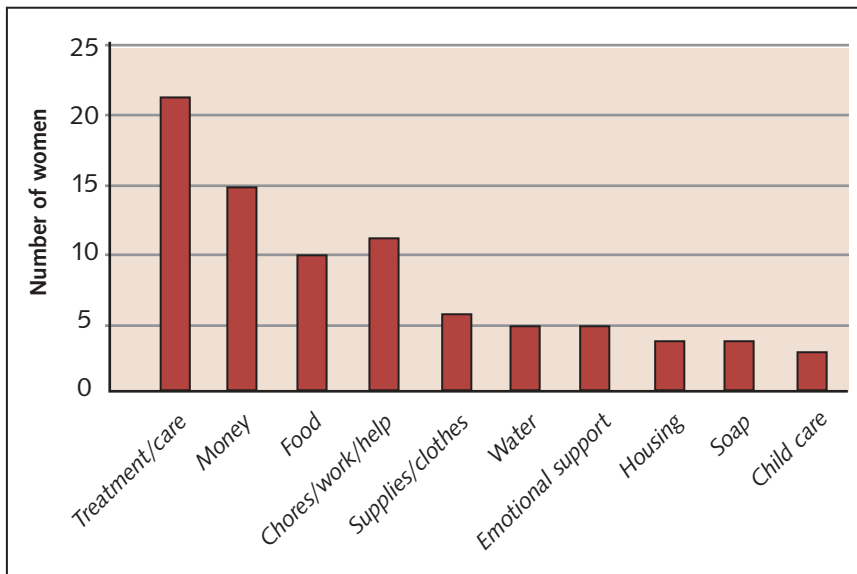
In places with water scarcity, which is a common problem throughout much of Tanzania, women with fistula and their families mentioned the difficulty of determining what to do with the little water they collected. They needed to weigh the benefits of women's using the water for bathing themselves and cleaning their clothes, versus cooking, drinking, and other family needs. One woman described the situation poignantly, saying: "Imagine you have fistula. You have to walk six hours to get one bucket of water. Now, you have to decide how you are going to use the water—for washing, drinking, bathing, and 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*)

A minority of women mentioned that they coped by seeking treatment. A woman who sustained two fistulas reported that her main coping strategy after repair of one hole was to keep clean, as well as to go for treatment to repair the second fistula. A minority of women mentioned isolating themselves by staying home and/or keeping their fistula a secret. Other coping mechanisms included: work, support by the family, prayer and Bible reading, and perseverance/self determination. A woman reported, "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*)

**K. Support**

All of the women mentioned being supported by at least one person—if not a member of their family, then a person in the community or an employer. None of the women were totally isolated and unsupported.

**Figure 4: Type of Support Given**



the form of assistance in seeking treatment, followed by financial support, emotional support, and help with chores or with work. 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

This finding may be partly a function of the method of recruitment for the study, however. Other people might not know the whereabouts of the more isolated women, and thus the experiences of such women may be underreported in the findings. Nonetheless, the fact that all women mentioned some type of support indicates that these women are not completely isolated.

The most frequently mentioned type of support given to women was for seeking treatment from a traditional healer or at a facility. Other key types of support were money, food, and help with work and chores.

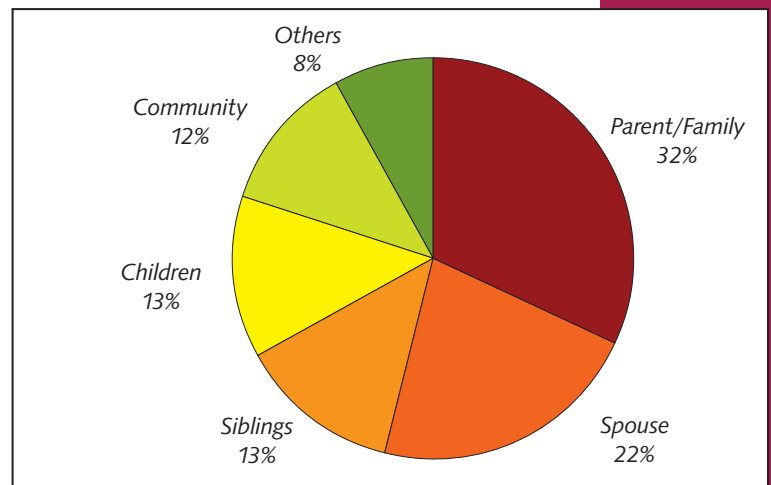
**“THEY FEEL BAD BECAUSE I AM THE ONLY DAUGHTER. MY FATHER FEELS VERY BAD, AND MY BROTHERS TOO; THEY BRING ME FOOD SUCH AS MEAT, FISH AND VEGETABLES.”**

(Woman from Songea, age 24)

By far the most frequent sources of support mentioned by the girls and women were parents and family members. They most often gave help in

Bugando Medical Centre for the treatment, although he had no income, but God helped him." (Woman from Ukerewe, age 31) Another woman shared her story: "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 5: Sources of Support for Women**



Of the married women who stayed married after fistula (n=30), the majority mentioned receiving support from their spouse. As with the parents, the support from husbands was most frequently for seeking treatment, followed by financial support and help with chores and work. One woman was delighted that her husband helped her with her domestic chores. Another woman recalls, "I rely on my husband for everything, even basic needs." (Woman from Songea, age 22)



Unfortunately, not all women had positive experiences with their spouses. One woman reported: "Because of this [fistula], the man who made me pregnant got scared and refused to marry me." (*Woman from Ukerewe, age 29*)

Other sources of social support included siblings and children and, to a lesser extent, grandparents and in-laws. A woman described the support she received from her grandmother: "I thank my grandma. She was very supportive and provided food and other basic needs for me." (*Woman from Ukerewe, age 29*)

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. A minority mentioned negative family relationships. Two family relationships were damaged because some family members thought that other family members had bewitched the girl with the fistula. In another case, a girl was rejected by her grandmother (her primary caregiver) and by her brother because she got pregnant at a young age—the fistula only added to their negative feelings. In another case, a young woman was treated badly by her relatives because of her smell, but she was treated well by her husband. The remaining women said that their relationships with at least their immediate natal families were good.

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 (seemingly, 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.

Echoing the words of the women, relatives also most frequently cited family as sources of support for women with fistula. They mentioned visits to the hospital, food, help with chores like cooking and washing, help with treatment, money, and emotional support. Family members also mentioned that women's groups helped the families with food and farming while their daughters were in the hospital.

## L. Fistula Repair

### Use of Traditional Medicine for Fistula

Fewer than half of the women reported using traditional medicine for treatment of the fistula. In some cases, using traditional medicine had a negative economic impact on the family. As one woman shared, "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*)

### Seeking Fistula Repair

The majority of the women interviewed had sought fistula repair or were seeking fistula repair at the time of the interview.<sup>20,21</sup> These women and their families had sacrificed a significant amount of time and money to attempt to get them this treatment. Of the women who had sought fistula repair prior to the interview, fewer than half had a successful repair.

#### FALSE STARTS

**In 2002, they sold all of their chickens to get the money for the repair of the fistula and the transport to the facility. But when they arrived at the facility, they did not get treatment. They were told to return in January 2003. When they returned, they again received no treatment and 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*)**

20 All of the women interviewed at Bugando Medical Centre were at the site for fistula repair, so they were not included in this calculation.

21 Five women did not respond to this question.

One woman expressed her desire to receive treatment but was unable to find services. She stated: "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*)

Of the women who sought fistula repair, fewer than half went to only one facility. In addition, fewer than half went either to multiple places, including traditional healers, or to the same facility multiple times seeking repair. Of these women, about half had a successful repair, while the rest had failed repairs. One woman recalled her inability to receive successful treatment: In 1990, she underwent repair for fistula, staying at a hospital for 21 days. The repair was not successful. She underwent a second repair, but again it was not successful. She returned home, and the problem was not solved.

About half of the women specified reasons for not getting repair. The primary reason was because they did not have the money to seek treatment, as this woman's story illustrates: "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 from Singida, age 22*) One woman recalled, "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*)

### Time Living with Fistula

The majority of the women had lived with fistula for two or more years. For some, this was because they lacked knowledge about the availability of treatment. Others knew treatment was available but could not afford to get to the hospitals that provide repair. A few women mentioned not receiving repair because they were in poor health after delivery. One woman, for example, recalled that, after delivery, the doctor told her to go to a particular hospital for treatment. When she arrived, she was told that she did not have enough blood. They then sent her back home so she could eat well and increase her hemoglobin count.

### M. 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 after their fistula repair. All but two girls and women had a successful fistula repair and were able to return to their normal lives, interact freely with family, friends, and community, and take an active role in economic activities.

#### A NEW BEGINNING

One woman discussed how, after getting treatment in 2002, her 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*)

The women who were re-interviewed after their successful repair spoke of numerous positive changes in their life.<sup>22</sup> Almost all mentioned that their relationship with the community had improved. They reported no longer being isolated and being able to visit other community members and friends and go to church. Many explained that the "community treats [them] like normal." A 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. Another woman said, "Now, I can do anything, I can even run." (*Woman from Songea, age 60*). A woman poignantly said, "I didn't know that one day, I will be like other women, because the problem was big." (*Woman from Ukerewe, age 48*)

22 The women interviewed at Bugando Medical Centre were only interviewed while awaiting repairs.

The majority of the women who had successful repair also mentioned now being able to support themselves and their families financially. One specifically mentioned being able to engage in petty trade. Almost all mentioned being able to perform domestic chores - such as fetching wood and water, farming and cooking - after repair. A woman said, "I perform my chores without difficulty." (*Woman from Ukerewe, age 21*)

Many women highlighted the emotional impact of the repair on their lives. Many called the cure of their fistula "a miracle." Half of the women specifically mentioned feeling better about themselves after repair. They explained to the researchers that they could now attend meetings and go for prayers; before repair, it was not easy for them to do so.

However, one woman did mention that she still faces stigma after repair, because people do not believe that she has been 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 kind of statement discourages her from telling others about the repair.



found working in their farms, illustrating how they have overcome the stigma and isolation they faced when they had fistula.

### **Treatment by Family and Friends after Unsuccessful Repair Attempts**

Two women commented on the treatment they received by family and friends after their first repair was unsuccessful. Two spoke of an escalation of community mistreatment: One reported that community members were even more spiteful toward her after the treatment failed; they laughed at her and said she was wasting her time. Another woman reported that some of the community members laughed at her and called her names, particularly after treatment failed. They also told her she would never get a cure and was condemned to this for life.

One of the women spoke of her family's disappointment with the unsuccessful repair, since they had sacrificed a lot to get her the repair: She said that they were very sorry about her situation, since she received medical treatment and yet continued leaking urine. She said her husband was restless because he continued asking where the treatment can be found.

### **A FAMILY'S PATIENCE AND SUPPORT**

After being treated in October 2002, one woman told how she can farm, visit relatives, and even go for prayers, as do other believers. In the year of the study, she planned to cultivate a lot, because she was not facing obstacles. The community is amazed when she tells them that she is cured. Family members are very happy, including her children and her husband. She has good relations with community members and she lives without any worries. Her problem of leaking urine has ended, and she can visit local brew clubs to drink alcohol with other people. Many people are amazed that her husband and children were very patient and assisted her to be treated. (*Woman from Songea, age 60*)

During the follow-up visits with communities, most of the women with fistula were not at home when the research teams arrived. They were attending funerals or wedding ceremonies, and a few were

## VI. RECOMMENDATIONS OF STUDY PARTICIPANTS

Study participants offered a number of recommendations on the prevention and management of fistula.

### A. Recommendations Regarding Prevention of Fistula

#### Hospital-Based Attendance and Support at the Time of Delivery

Delivering at a hospital was the most often cited recommendation to prevent fistula given by girls and women themselves. This recommendation was frequently echoed by family, community members, and health care providers. Women and health care workers also strongly recommended that family, friends, and community members provide support during delivery.

As one woman explained, "It is important to go to deliver at the hospital, because if it happens that you get the problem, you will be assisted." (*Patient at Bugando, age 25*) A woman from Songea reported that she would not have had this problem (fistula) had she given birth at the hospital.

Even with intentions to assist women to deliver in hospitals, people face obstacles in accessing such care. As the husband of a woman with fistula described, he had wanted his wife to stay at a hospital until she delivered, but he had no money for the hospital costs, and no one at home to care for the family. The combination of these two impoverishing factors created a barrier to accessing hospital care at the time of delivery.

#### Saving Money for Transport and Delivery

Community members and health care providers mentioned the need to save money for transportation and delivery costs. These two challenges are confirmed by findings of the 2004–2005 DHS, which found that money and transport are the leading barriers for women seeking health care (NBS & ORC Macro, 2005).

#### Quality of Care

All four groups of study participants recommended improving the quality of services during labor and

delivery. As one patient from Bugando stated, "At our dispensary, there are no nurses to examine us, there is no treatment for pregnant mothers, and no medicine. We have to buy the medicine. Unfortunately, I have lost the baby because of lack of health services." (*Patient at Bugando, age 24*)

Tanzania faces an acute shortage of health care workers. In addition, people often cite the scarcity of drugs and medicines at health care facilities as serious problems. While Tanzania has a relatively good distribution of primary health care facilities, the quality of care provided within those structures needs significant improvement to reduce maternal deaths and other conditions impacting the poor.



#### Community Education and Avoidance of Delays

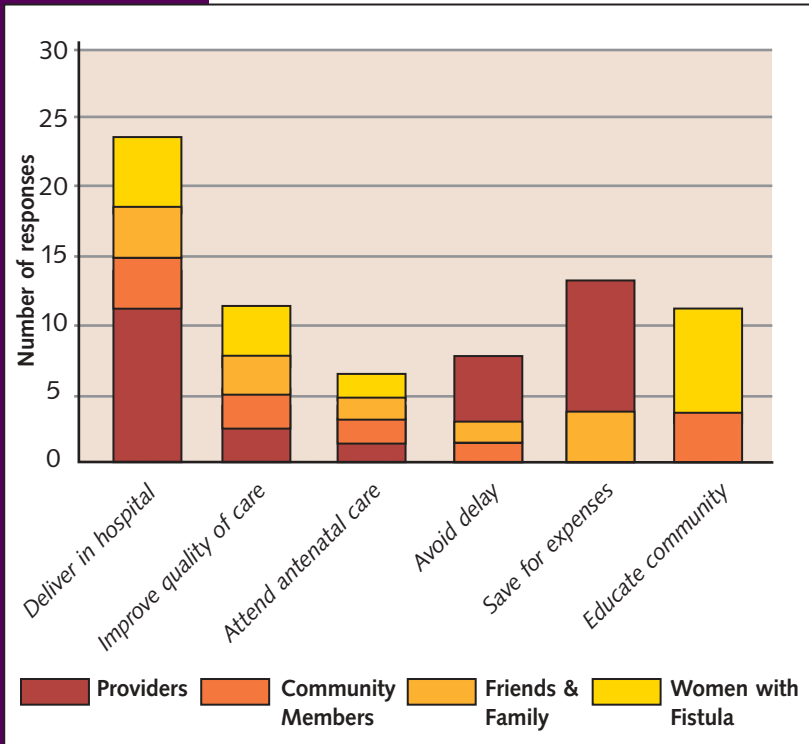
Family, and particularly health care providers, recommended educating the community on the importance of antenatal care, maternal complications, pregnancy care, and delivery in hospitals. Health care providers in particular recommended that people avoid delays in referring girls and women for care during labor and delivery .

#### Summary

The figure overleaf presents the recommendations given by different groups of respondents regarding prevention of fistula. More details about the responses are provided in Annex 3.



**Figure 6: Recommendations on the Prevention of Fistula**



**B. Recommendations on Management of Fistula**

**Seek Treatment and Provide Support**

Seeking treatment and the provision of support from family members and others were the most often cited recommendations by girls and women. The support of people for girls and women living with fistula was also recommended by health care providers.

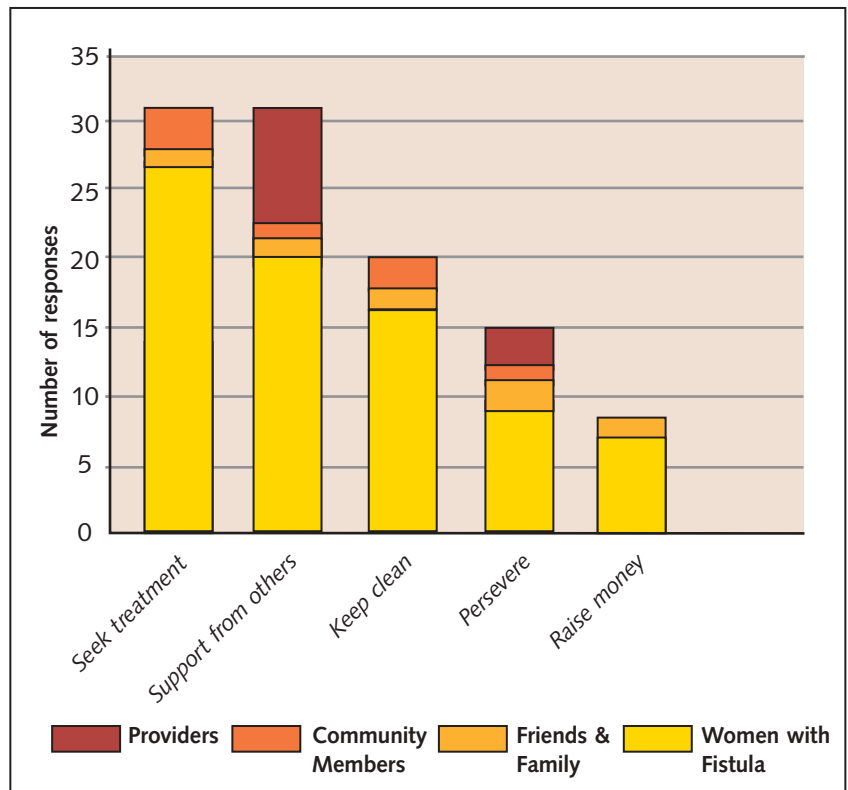
**Other Recommendations**

The women and girls also strongly recommended to keep clean, “persevere,” and try to generate income for daily living and the costs of treatment.

**Summary**

The figure below presents the recommendations given by different groups of respondents regarding post-fistula care. More details about the responses are provided in Annex 3.

**Figure 7: Recommendations on Post-fistula Care**



## VII. FINDINGS AND RECOMMENDATIONS

Fistula provides a critical lens onto the health care and social systems that can promote - or limit - the capacity of girls and women to achieve well-being. Underlying the medical presentation of fistula are its true determinants: poverty, which constrains families from accessing basic health services; resource limitations, which undermine the capacity of workers to deliver high-quality health care; insufficient investment in infrastructure, which makes transport to a health care facility nearly impossible, particularly in an emergency; insufficient access to information and knowledge about maternal health and pregnancy-related emergencies; inadequate education and decision-making status for girls and women; and a continuing acceptance of women's dying in childbirth or surviving with unspeakable consequences.

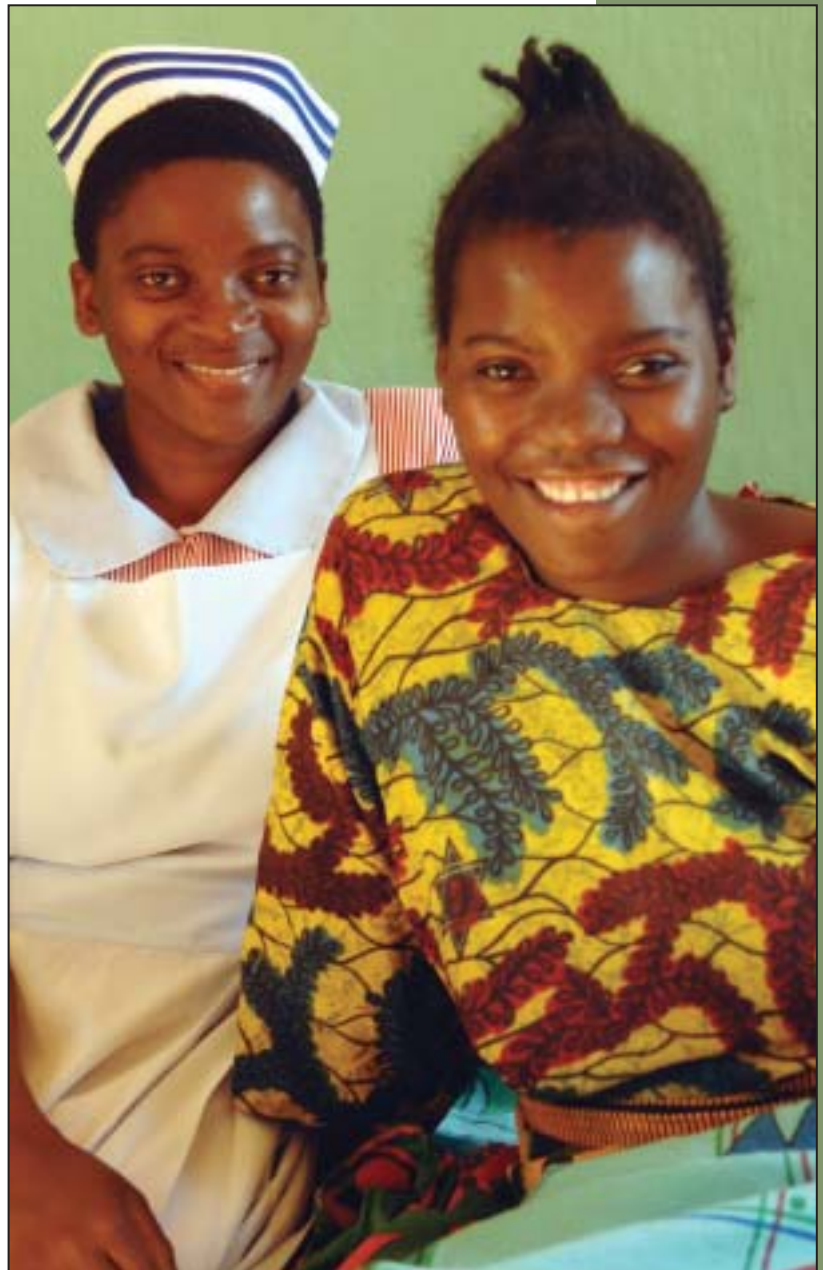
This study brings to light a range of findings on fistula and social vulnerability. The findings are based on the experiences and perspectives of 61 girls and women living with fistula, their families, community members, and local health care providers. The study dispels some long-held views about those who live with fistula and provides evidence for building locally appropriate solutions to address fistula, and maternal mortality and morbidity overall. Finally, the study establishes a call to policymakers, health care workers, donors, and communities to take action on women's health and women's lives.

Following are six major findings of the study, with corresponding recommendations:

**Finding 1: Fistula affects girls and women of all ages, both at first pregnancy and in later pregnancies.**

The median age at which girls and women in the study sustained a fistula was 23. Fewer than half were 19 or younger. In addition, about half were in their second or higher pregnancy. These findings challenge the general portrayal of fistula as a condition affecting largely adolescent girls in their first pregnancy. The reason for this may be differences in age at sexual debut: In countries in which girls get married and/or become pregnant

at relatively younger ages (e.g., 15 and below), it is likely that a higher proportion of fistula patients are young and primigravida.



**Recommendation 1: Policies and programs addressing fistula need to expand beyond currently held views that fistula largely affects young girls. Public education and interventions to mitigate the risks of fistula must address the full reproductive life cycle of girls and women.**

Conventional wisdom holds that very young girls and those having their first delivery are most at

risk for fistula. The data gathered in this study, however, show that women of all ages are at risk, including those who have had “normal” deliveries previously. For this reason, community education efforts must inform people that all women are potentially at risk for obstetric fistula. Information is essential regarding the danger signs during delivery, as well as the importance of having a plan to get rapid access to a facility that can perform caesarean section. Key stakeholders in communities, as well as health care workers at peripheral facilities who can facilitate referrals, should also receive this potentially life-saving information (see Recommendation 3 below).

Girls and women noted that they were rarely the single decision makers in seeking care during delivery; often, other members of the family made the decision about whether, when, and where the girl or woman should seek help. As such, educational messages need to consider women’s and girls’ typical level of autonomy (or dependency). Educational efforts need to reach others who may be in a decision-making role, such as husbands, in-laws, and community and peripheral health care providers.

**Finding 2: Antenatal care services, while widely available and used, are inconsistent and inadequate.**

A majority of the women in the study attended ANC services—nearly all of them at least twice—but the services received were inconsistent, inadequate, and differed greatly from Ministry of Health guidelines. No hemoglobin tests, urine analysis, or blood grouping were reported. Women did report having an abdominal examination and having their weight and height measured, and some were given tablets.

These ANC visits are important “missed opportunities” to provide women with information and services, including on pregnancy, labor, and delivery. All of the women in the study who mentioned any knowledge about pregnancy and labor had this knowledge because of past labor and delivery experiences. None of the women participating in the study had a discussion related to pregnancy or labor and/or delivery during ANC visits, except that in a few cases, the woman was simply told to deliver in a facility.

**Recommendation 2: Providers need adequate training, supplies, and equipment, as well as supportive supervision, to implement high-quality and consistent ANC services.**

Evidence-based and clear information on ANC, labor, delivery, and postpartum care are critical for the adequate training of health care providers. Health care workers also require specific training in appropriate, effective, and respectful communication with a variety of clients. This includes nondiscriminatory communication to vulnerable populations such as poor, disabled, and other marginalized girls and women.





If providers are able to conduct ANC sessions well to educate clients, then clients will emerge with information that will be useful to them if an emergency arises during delivery. If critical supplies and equipment are available and if supervision given to health care workers is adequate, then ANC can be a more promising avenue for averting maternal death and disability.

**Finding 3: The lack of birth preparedness, including basic information on childbirth and taking action around “delays,” increases risk.**

The majority of women in the study planned to deliver at health care facilities, although in the end the majority started labor at home. Most women were assisted by family or friends, with fewer than half assisted by a TBA.

Nearly all of the women in the study who labored at home made at least one move to get appropriate care, and a majority faced multiple delays in reaching a facility with the necessary services. The reason most often cited for the delays was the lack of recognition on the part of the woman or family that a problem was occurring. Other causes were lack of transport, delay by the TBA, no action taken after the problem was recognized by the family or friend, and delay by a provider at the health care facility.

The decision to make a move was most often made by the women’s families and secondarily by the TBA, when she realized she could not assist adequately. However, fewer than half of the women with fistula had set aside money for some aspect of labor, delivery, post-delivery and/or transport, so that when problems emerged, the necessary preparation was lacking.

When asked if they would have done anything differently, nearly all of the women who responded said that they would have gone to the hospital earlier.

**Recommendation 3: Concrete information on birth preparedness that is understood and acted upon is critical to assisting in time of emergency.**

Health care providers, women, and their families need comprehensive information on birth preparedness to help in times of emergencies. This

includes information on childbirth, the “danger signs” that indicate obstetric complications, the imperative to take quick action when signs and symptoms of obstetric complications occur, and the importance of adequate planning (e.g., resources and emergency transport plans) for such potential problems. TBAs and health care workers at peripheral facilities (presumably lower-level cadres) must also have this basic knowledge, so that quick and proper referrals can be made to facilities with qualified medical personnel and adequate supplies and equipment to manage the complication.

**Finding 4: Lack of access to emergency caesarean section poses a great threat to women’s lives.**

For girls and women in the study, the most commonly cited barriers to facility-based delivery were lack of money and the distance to a hospital. Nearly all of the women who made a move during childbirth eventually got adequate care at the hospital level. The majority of the women incurred some costs for transport to a facility, and a minority reported having to pay some type of fee for the delivery. The second most commonly reported delay was “delay in transportation.” These barriers are critical reasons why women who need skilled assistance at delivery are not getting the care they need, and poor women in rural areas are likely to be disproportionately affected by these barriers.

**Recommendation 4: Girls and women, particularly in rural areas, urgently need access to emergency obstetric care provided by trained health care workers. The financial and logistical barriers to services must be eliminated.**

The incidence of fistula and maternal mortality could be reduced by expanding the availability of caesarean sections and by ensuring that high-quality services are affordable and accessible. Key factors include instituting transportation schemes to help women get to an appropriate facility promptly; monitoring for compliance the government statement that services for pregnant women are free and that “delivery kits” are available at health care facilities for all expectant mothers (Kigoda, 2006); training health care workers to perform caesarean sections; and providing consistently the supplies and equipment needed for emergency obstetric care (EmOC) services.



The 2004–2005 Tanzania DHS notes that Tanzanian women have insufficient access to essential maternal health services such as caesarean section. “Getting money for treatment” was the single biggest obstacle encountered by women seeking health care, cited by 40% of respondents. Thirty-seven percent of women cited distance to the health care facility as a big problem, and the same proportion cited having to take transport as a problem. There were striking differences in reporting between rich women and poor women and between urban women and rural women. More than half of the poorest quintile cited distance to a facility and the need to take transport as big problems, compared with fewer than 20% of urban women and of those from the richest quintile (NBS & ORC Macro, 2005).

Great strides in reducing maternal mortality and morbidity, including fistula, could be made by instituting EmOC services in remote, underserved areas of the country. Scaling up successful pilot EmOC interventions will require the hiring, training, and equitably deploying of qualified health care workers. It will also require providing required drugs, supplies, and equipment. Yet currently, Tanzania faces an acute shortage of health care workers (particularly for higher cadres), and the shortage is expected to get worse unless there is a radical change in the training and hiring of health care personnel (Smithson, 2006). In addition, people often cite the scarcity of drugs and medicines at health care facilities as serious problems (Mamdani & Bangser, 2004; REPOA, 2003).

**Finding 5: The cost and inaccessibility of high-quality fistula repair services represent a barrier to care for many girls and women.**

The majority of the women in the study had lived with fistula for two or more years. At the time of the interview, the majority had already sought fistula repair or were seeking treatment. Of those women who specified reasons for not getting a repair, the primary reason was that they did not have the money to seek treatment.

The women and families who accessed care prior to the interview had sacrificed a significant amount of time and money, including selling assets to pay for transport and treatment. Nevertheless, fewer than half of these women had a successful repair. In their search for a repair, fewer than half of the women

went to only one facility. A similar number went either to multiple places (including traditional healers) or to the same facility multiple times seeking repair.

**Recommendation 5: The realities of the economic impact of fistula on women's lives make it an imperative to provide fistula repairs at no cost or at minimal cost.**

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

Beyond information, however, women must be supported to actually access fistula treatment. The realities of the economic impact of fistula on women's lives make the provision of fistula repairs at no cost or at minimal cost an imperative. This includes, ideally, funds for transport to the facility, the costs of treatment, and the cost of transport home. 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 fistula. Sources of financial support might include, for example, allocations from district health budgets, donor funding as part of a national fistula program or special project, and in-kind and financial support from faith-based institutions and nongovernmental organizations.

**Finding 6: Even though most women with fistula had support from others, the emotional and economic impacts of fistula are substantial for the woman herself and for her family.**

All of the women in the study mentioned being supported by at least one person when they sustained their fistula, and none were totally isolated and unsupported. Fewer than one-third of the women who were married when they sustained fistula were divorced as a result of the fistula. Parents, husbands, and other family members played a critically supportive role, and some women also had support from community members. These

findings are in sharp contrast to research from other countries such as Ethiopia, and the generally held view that women living with fistula are typically abandoned and isolated by others.

Nevertheless, the majority of the women reported that they isolated themselves from their community—a critically important finding. This isolation was caused by a strong sense of shame about their condition and by the desire not to soil themselves in front of anyone or to smell badly. A majority of the women suffered stress and worry, including about the impact of the fistula on their families.

Both 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. Fewer than half could work, but they could not work as hard as they did before the fistula. A few of the woman reported that physically they could not work, but that they had to in order to meet their basic needs.

Families were affected by the fistula because as a result one less person was working either in the home or on the farm or was bringing in income from other sources. As a result, remaining family members had to do the work that the woman was previously doing or forgo the income that the woman previously contributed. Some families were also in debt from the fees for delivery at the hospital and from borrowing money for transport to the hospital when the woman was in labor. Many families made great sacrifices to help girls and women get fistula repairs.

**Recommendation 6: Advocacy, support, and reintegration efforts should be instituted to reduce the emotional and economic impacts of fistula.**

Women interviewed after a successful repair talked about having better relationships with their



community and no longer feeling isolated. They were able to support themselves and their families financially. Many called their return to health “a miracle.”

The findings of the study suggest that positive illustrations of support from family, friends, and communities can be used in public education and advocacy efforts to break the stigma around fistula. The illustrations can also show that families - including husbands - can, and do, support women with fistula.

Reintegration programs can strengthen opportunities for successful reentry after repair. However, to date, information on women’s experiences with reintegration is extremely limited. Further research is needed in this area, so that interventions can be based on a thorough understanding of what women with fistula say that they 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 a long time and those living with fistula for shorter periods, as it is possible that stigma and isolation deepen with time.

## VIII. CONCLUSIONS

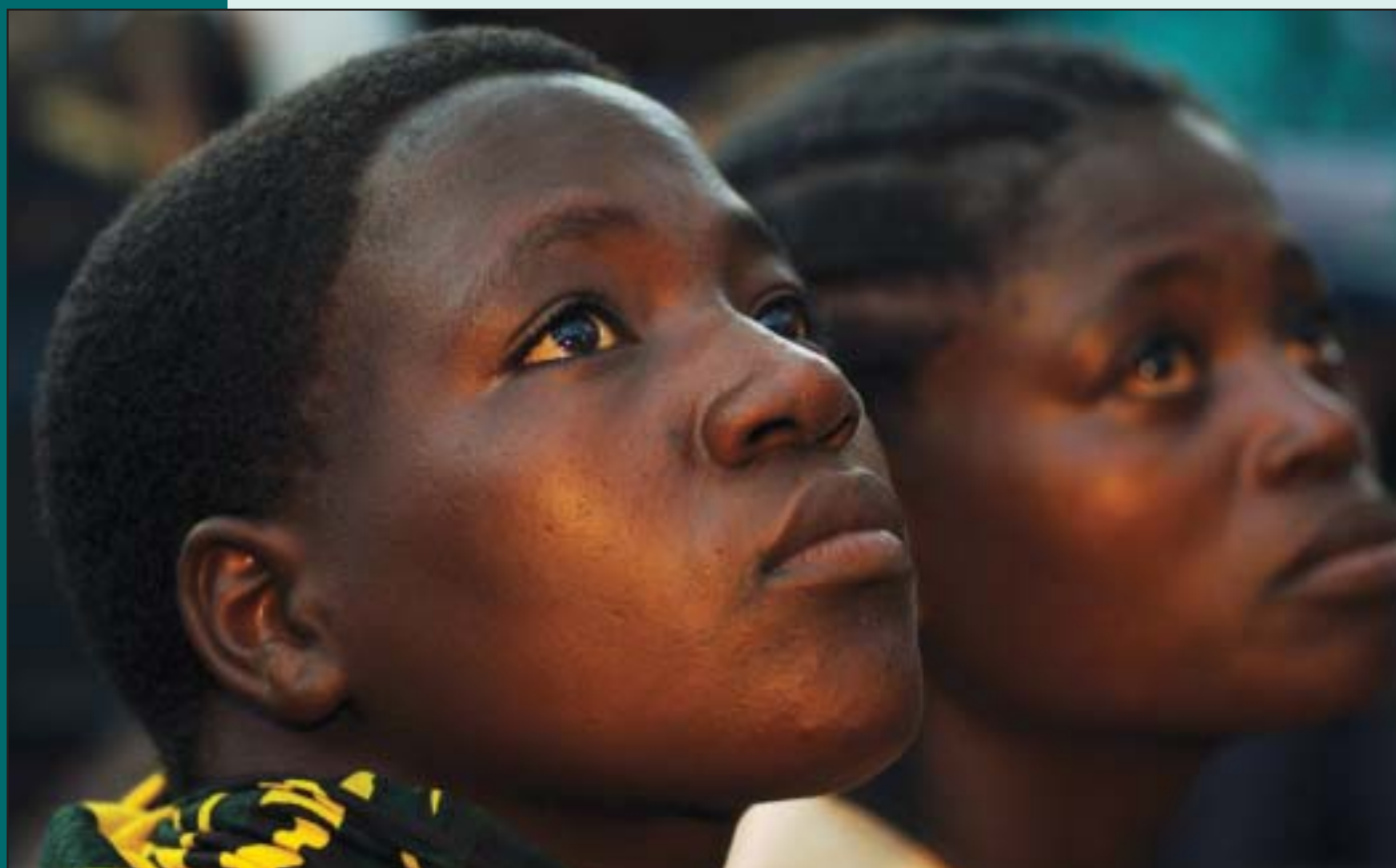
**A robust policy and set of interventions, backed by high-level commitment, must be implemented to reduce maternal death and disability in Tanzania.**

The findings of this study, together with the 2004–2005 Tanzania DHS, provide evidence of the barriers girls and women face in accessing quality maternal and reproductive health care services. Urgent action is needed to address these barriers and to save the lives of girls and women in Tanzania.

Like many countries, Tanzania has had a safe motherhood program in place for decades, yet has made little progress in saving women's lives. The maternal mortality ratio has not declined in the past decade; EmOC (including caesarean section) is virtually unavailable to women at the health-center level; qualified health care workers who could prevent and manage obstetric complications are in extremely short supply; training and supportive supervision of health personnel is highly inadequate; and drugs, supplies, and equipment are severely lacking.

Tanzania needs to care about the fact that women are dying and disabled in childbirth - and to do something about it. Highly promising projects in Kigoma, Rukwa, and other regions of Tanzania, together with those in other developing countries, can point the way toward saving women's lives. Tested and successful interventions include, but are not limited to: basic infrastructure improvements for labor and delivery; staff training and supportive supervision; sustained use of standards and protocols; quality improvement measures such as criterion-based audits and case reviews; consistent provision of obstetric supplies and equipment; and the existence of functioning referral mechanisms, including transport to a facility where emergency obstetric care is available (Mbaruku & Bergstrom, 1995; Kayongo et al., 2006; Santos et al., 2006).

**WE KNOW WHAT TO DO. WHAT IS LACKING IS THE POLITICAL COMMITMENT, THE EFFECTIVE ALLOCATION OF RESOURCES, AND THE DEPLOYMENT OF SKILLED PERSONNEL TO MAKE A DIFFERENCE IN WOMEN'S LIVES.**





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## Annex 1: Total Number of Participants Involved in the Different Research Activities, by District

Type of group	Singida	Songea	Ukerewe	Bugando Medical Centre <sup>23,24</sup>
Interviews with women with fistula: <i>Pregnancy, labor, and delivery</i>	11	12	15	23
Interviews with women with fistula: <i>Experience with fistula</i>	11	12	15	23
Problem tree with women with fistula		4	3	12
Interviews with family members	7	9	12	
Problem trees with family members <sup>26</sup>			14 <sup>27</sup>	
Discussions with health care providers	Clinical Officer (1) Assistant Clinical Officer (1) MCH Aides (2) Dental Assistant (1) Nurse Midwives (1) Medical Assistant (2)	Clinical Officer (1) Nurse Midwife (1) Medical Attendant (2)	Assistant Clinical Officer (1) Public Health Nurse (1) Medical Attendant (3)	
Problem trees with health care providers <sup>28</sup>	Clinical Officer (2) Assistant Clinical Officer (2) MCH Aide (2) Dental Assistant (1) Medical Attendant (7) Nurse Midwife (1) Public Health Nurse (1) Medical Assistants (5)			
Discussions with community members <sup>29</sup>	27	16		
Problem trees with community members			4	
Free listing and ranking with community members <sup>30</sup>	9		12	

23 A subgroup of women interviewed for the study was fistula patients at Bugando Medical Centre. These women were from many different communities throughout the country; it was not possible for the researchers to follow the women back to their communities for additional interviews.

24 Interviews with women at Bugando Medical Centre included patients from a wide catchment area. Therefore, the interviews were done only at the facility, and it was not possible for the researchers to go to communities to interview family and community members, and providers.

25 Researchers were not able to conduct problem-tree exercises in Singida because the sessions ran late in the day and there was not sufficient time to continue another activity.

26 Problem trees, focus groups, and free listing and ranking exercises are group activities. Since the researchers were not able to collect groups in all of the locations, these methods were not done at every site.

27 Problem trees were conducted only in Ukerewe, because

only there did the researchers have sufficient time with community members to carry out the activities. At the other sites, after the few first activities were completed, participants either had to go home or to the market, and therefore the researchers could not carry out all of the group activities.

28 Problem tree exercises were relatively easy to conduct at the health facility in Singida because there are many providers working there. At other facilities with very few staff, the researchers could conduct only group discussions.

29 Researchers were not able to conduct group discussions with community members in Singida because it was market day and it was not possible to bring together a group of community members.

30 Researchers were not able to conduct the free listing and ranking exercises with community members in Songea because sessions continued into the evening and people could not stay longer.

## Annex 2: Details on Women's Movements, from Initiation of Labor to Final Delivery

	No. of women
<b>Women Not Making Any Moves</b>	
Delivered at home	1
Delivered at hospital	2
Started labor at home, helped by TBA, delivered at home	4
<b>Women Making One Move</b>	
Started labor at home, then went to hospital, delivered at hospital	17
Started labor at home with TBA, went to hospital, delivered at hospital	6
Started labor at church/home, went to health center, delivered at health center	2
Started labor in transit to health center, delivered at health center	2
Started labor at home with TBA, delivered in transit to health center	1
Started labor at home, went to TBA, delivered with TBA	1
Started labor at home with TBA #1, went to TBA #2, delivered with TBA #2	1
<b>Women Making Two Moves</b>	
Started labor at home, went to health center, then went to hospital, delivered at hospital	7
Started labor at home, went to hospital #1, then went to hospital #2, delivered at hospital #2	3
Started labor at home, went to dispensary, then went to hospital, delivered at hospital	3
Started labor at home with TBA, went to dispensary, then went to hospital, delivered at hospital	3
Started labor in the bush, went home, then went to dispensary, delivered at dispensary	1
Started labor at home, went to pharmacy assistant, then went to hospital, delivered at hospital	1
Started labor at home with TBA, went to dispensary, then went to health center, delivered at health center	1
Started labor at home with TBA, went to health center, then went to hospital, delivered at hospital	1
<b>Women Making Three Moves</b>	
Started labor at home, went to TBA #1, then went to TBA #2, then went to hospital, delivered at hospital	1
Started labor at home with TBA, went to dispensary, then went to health center, then went to hospital, delivered at hospital	1
Started labor at home with TBA, went to dispensary, then went to hospital #1, then went to hospital #2, delivered at hospital #2	1
Started labor at home, went to hospital #1, then went to hospital #2, then went to hospital #3, delivered at hospital #3	1
<b>Women Making More Than Three Moves</b>	
Started labor at home, went to dispensary, then went home, then went to dispensary, then went home, then went to dispensary, then went home, then went to dispensary, then went to hospital, delivered at hospital	1

### Annex 3: Recommendations on the Prevention and Management of Fistula

Type of recommendations	Frequency of responses			
	Women with fistula	Family members	Community members	Providers
<b>Prevention of fistula</b>				
Deliver in hospital	12	3	3	6
Improve quality of care	2	3	3	4
Attend antenatal care	1	2	2	2
Stay close to health service	1	0		0
Receive information on pregnancy, labor, and delivery	0	0	3	0
Avoid delay	0	1	2	5
Have woman and husband make ANC decision jointly	0	0	0	1
Do not delivery at home/with TBA	0	1	1	3
Save money for transportation and delivery costs	0	0	4	9
Educate community on importance of ANC, maternal complications, pregnancy care, delivery in hospitals, and managing fistula	0	4	0	8
Have community build a hospital	0	1	1	0
Have government provide better quality health care facilities	0	1	0	0
Do not give birth or marry at a young age	0	0	3	0
Have an ambulance available	0	0	0	1
Educate community members to take women in labor to the hospital	0	0	0	3
Do not give birth at a mature age	0	0	0	1
Do not have frequent births	0	0	0	1
<b>Post-fistula</b>				
Seek treatment for fistula	27	1	0	3
Receive support from family, friends, and community	20	1	1	9
Keep clean	16	1	0	3
Persevere	9	2	1	3
Raise money for living/treatment	7	0	0	1
Have friends and family help with chores/work	1	0	0	0
Do not isolate oneself	0	0	0	2
Look for money for treatment	0	1	0	0
No recommendations	11	0	0	3
<b>Labor and Delivery</b>				
Receive support from family, friends and community	20	1	1	9



*Risk and Resilience: Obstetric Fistula in Tanzania* examines the many dimensions of obstetric fistula and its related social vulnerability through the experiences and views of girls and women living with fistula, members of their families and communities, and local health care providers. The results of the study provide vital evidence on how health and social systems often fail to meet women's basic needs.

Obstetric fistula is a devastating childbirth injury that happens almost exclusively in 'developing' countries, and to girls and women living in poverty.

It is their experiences – the survivors of 'near miss' maternal deaths – that can shed critically needed light onto policies and interventions to decrease maternal morbidity and mortality, and improve the health and well-being of girls and women in poverty.

This study brings into the public domain the voices of girls and women living with fistula, voices that are rarely heard, much less reported. The study was conducted in Tanzania by the Women's Dignity Project and EngenderHealth, in collaboration with Health Action Promotion Association, Kivilini Women's Rights Organization, and Peramiho Mission Hospital.