

*Sharing the Burden:
Ugandan Women Speak
About Obstetric Fistula*

**Women's Dignity Project
and
EngenderHealth**



November 2007

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Ugandan Women Speak About Obstetric Fistula

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Recommended citation: Women's Dignity Project and EngenderHealth, Sharing the Burden: Ugandan Women Speak About Obstetric Fistula, Dar es Salaam, Tanzania, 2007

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Acknowledgments

Women's Dignity Project and EngenderHealth would like to thank the women, families, community members, and healthcare 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 the Women's Dignity Project and EngenderHealth, together with partners in Uganda: the Association for the Reorientation and Rehabilitation of TESO Women for Development (TERREWODE), Good Hope Foundation for Rural Development (GHFRD), and Kitovu 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; Alice Emasu and Janeth Apugo of TERREWODE; Kabanda Obed and Louise Nakabugo of GHFRD; and Annet Nangonzi and Adah Nkolenta Ojur from Kitovu Mission Hospital. The research team would also like to thank the Director of Health Services at Kitovu Mission Hospital, Regis Nansubunga, and the nurse midwives of Kitovu; Dr Fred Kirya at Soroti Hospital; and officials of the Ministry of Health in Uganda for their support and collaboration throughout the study.

We would like to acknowledge Nicole Barber, Mevi Gray, Malika Gujrati, and John Lindsay of The New School for their able support and assistance with data management and analysis; and the technical input provided by Janet Singer of Women and Infants' Hospital.

This report was written by Manisha Mehta, Maggie Bangser, Nicole Barber, John Lindsay, and Malika Gujrati. Dr Henry Kakande and Julie Wiltshire from EngenderHealth's Uganda office reviewed and provided comments on the report. The report was edited by Chris Daly.

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List of Abbreviations

ANC	Antenatal care
GHFRD	Good Hope Foundation for Rural Development
CBO	Community-based organization
NGO	Non-governmental organization
PLA	Participatory, learning, and action
PMTCT	Prevention of mother-to-child transmission (of HIV)
TBA	Traditional birth attendant
TERROWODE	Association for Reorientation and Rehabilitation of Teso Women for Development
UBOS	Uganda Bureau of Statistics
UMOH	Uganda Ministry of Health
UShs	Ugandan shillings ¹
VCT	Voluntary counseling and testing (for HIV)
WDP	Women's Dignity Project
WHO	World Health Organization

¹ All costs are given in Ugandan shillings and US dollars. The average interbank currency exchange rate over the period of data collection from April to July 2005 was 1750 UShs = 1 USD

Executive Summary

Obstetric fistula - a devastating injury sustained by women due to prolonged obstructed childbirth - is a clear marker that health and social systems fail to support women during pregnancy and delivery. In countries where quality obstetric care is available, fistula was all but eradicated half a century ago. However, in developing settings where access to obstetric care is limited, large populations of women still experience fistula. As many as 130,000 new cases are occurring annually worldwide, and up to 3.5 million women may be living with the condition (Wall, 2006). In Uganda alone, an estimated 2.6% of women of reproductive age have experienced obstetric fistula (UBOS, 2007). Based on population data from the most recent census, this equates to a national prevalence of over 142,000 women.

Indeed, the widespread incidence and prevalence of fistula (and maternal deaths and disabilities more broadly) can only be understood in the context of women's acute socio-economic vulnerability in developing countries which denies them access to timely and appropriate health care. Underlying fistula's medical presentation are its true determinants: the powerlessness of women to control their sexual and reproductive lives and to decide on their own healthcare; a lack of education on pregnancy and childbirth; poverty that denies families the means to afford health services; the severe shortage of qualified health workers and adequately equipped facilities; and the lack of transport and roads to reach facilities quickly when maternal emergencies arise.

Purpose of the Current Study

Efforts to prevent fistula, and to promote maternal health overall, can be significantly strengthened by utilizing the testimony of girls and women to develop effective recommendation and interventions. Appropriate policies and interventions rely on solid evidence of the socio-economic and cultural contexts within which mothers die or are left severely disabled without the prospect of treatment or rehabilitation. However, the voices of women are rarely reported, much less utilized to advance and inform national policies and programs for maternal health.

The current study is a qualitative and participatory analysis of obstetric fistula in Uganda. The research was conducted to understand girls and women's vulnerability to fistula through their own views and experiences, as well as the views of family and community members, and local health care providers. The study provided a platform for women to convey the multi-faceted impact of fistula, and a means to capture their recommendations for local solutions to prevent and manage the condition.

Study Methods and Participants

The study was supported by the Women's Dignity Project and EngenderHealth and carried out in four rural districts of Uganda: Kasese, Masaka, Soroti, and Kaberamaido. Research methods included semi-structured in-depth interviews, group discussions, problem trees, and freelist and ranking exercises. All methods were conducted in local languages. Data collection was completed between April and July 2005 by three local partner organizations: the Good Hope Foundation for Rural Development in Kasese, Kitovu Mission Hospital in Masaka, and the Association for Reorientation and Rehabilitation of Teso Women for Development in Soroti/Kaberamaido. The research was approved by the Ugandan Ministry of Health as part of its institutional effort to address fistula.

Overall, the study involved 82 girls and women living with fistula, 63 family members, 120 community members, 21 health workers, and 54 traditional birth attendants. All of the women who participated in the study had their fistulas surgically repaired.

Key Findings and Recommendations

The study brings to light the social, cultural, economic, and medical complexities of obstetric fistula, and provides vital evidence on the need for broad-based and sustained action to address maternal morbidity and mortality in Uganda. The data reflects not only the tragic continuum of maternal mortality and severe morbidity, but also the punishing inequities faced by women. By courageously sharing their stories, participants send a clear and unmistakable message to government leaders and policy makers, donors, health workers, and communities that investments in maternal health care are urgently needed to protect the lives and well-being of women in poverty.

The five major findings drawn from the research are listed below with accompanying recommendations:

Finding 1: Fistula is not only a problem for adolescent girls but for women of all ages.

Slightly less than half of the women whose ages were recorded by the study were 20 years or older when they sustained fistula, and fewer than half of respondents were on their second or higher pregnancy. This finding reflects that fistula from obstructed labor can strike any pregnant woman regardless of age or gravidity including those who have had ‘normal’ deliveries before. While it remains vital to recognize and educate communities on the potentially serious health effects of early childbearing and the severe impact of fistula on adolescent girls, these findings expand on the widely held assumption that fistula predominantly affects very young women on their first pregnancy.

Recommendation: Public education and programs to prevent fistula must, therefore, target all women of reproductive age. In particular, maternal health services should provide accurate and timely counseling to women—as well as key decision makers, such as husbands, mothers-in-law and parents— on the danger signs of pregnancy and delivery, and encourage women and their families to have a birth plan in place as well as provisions for handling emergencies.

Health workers, in turn, need to be supported through training and supervision to provide this essential counseling. In cases of clients with fistula, the women and their families must also be given comprehensive information on the medical nature and cause of their condition to dispel any misconceptions about the condition and to enable them to access prompt and appropriate treatment.

TBAs also need to be informed about how fistula occurs and how it can be prevented and treated, since there were many misconceptions about fistula. Additionally, TBAs need to be informed about when and where to refer women in case of prolonged obstructed labor and other emergencies.

Finding 2: Neither antenatal or delivery care meet standards of professional service delivery.

The type and quality of antenatal care services that the women reported receiving were inconsistent and inadequate, and differed greatly from Ministry of Health guidelines (UMOH, 2006). Fewer than half received any type of immunization services, and no hemoglobin tests, urine analysis, syphilis screening, or voluntary counseling and testing for HIV were reported. Only a minority of women reported that the health worker listened for the fetal heartbeat. Moreover, no counseling on risk factors and warning signs and symptoms during pregnancy were reported, and only three women were told anything related to delivery.

With respect to delivery care, nearly all of the women were satisfied with the care they received at their final place of delivery, because the facility had saved their life and/or their baby's life or because staff identified the problem they were experiencing. However, about half of women reported that they were not treated well or were not treated in a timely manner. In addition, nearly all of the women believed that the cause of fistula were providers' mistakes or hospital procedures, and family members cited these reasons most often as well.

Recommendation: Training for health workers on clinical skills, as well as on client-provider interaction, is critical to ensure high quality, professional ANC and delivery services. In addition, more, qualified health workers need to be recruited and essential drugs, supplies, equipment and infrastructure made available to improve the extremely difficult working conditions for staff and enable providers to offer quality care.

ANC services are a significant opportunity to provide women with education and counseling on pregnancy, labor, and delivery. The danger signs of pregnancy and labor and the importance of skilled delivery assistance should be emphasized as timely recognition and treatment of complications is critical for preventing both fistula and maternal crises overall. Crucially, women should be strongly encouraged to deliver in a health facility so they can receive emergency care promptly if needed.

Supportive supervision should also be instituted to monitor service delivery standards and to ensure that abusive health workers are held accountable for mistreatment of clients. The study is not able to confirm independently the reports of negligence leading to fistula, or abuse of patients at any point in the service delivery cycle. However, the negative experiences of women regarding the care they received and the belief among many participants that the fistula was caused by providers requires a thorough investigation into the quality of maternity services.

Finding 3: Girls and women face multiple barriers in accessing adequate care during delivery, including life-saving caesarean section.

About half of the women in the study described constraints they faced when planning for facility-based delivery. The top three limitations were lack of money, high transportation costs, and high hospital costs. Indeed, the majority of the women planning to deliver at a facility had set aside some funds to cover expenses, but still did not go when labor started. In addition, two-thirds of the women faced multiple delays in reaching a facility with the necessary services to enable them to deliver safely. Inability to access transport was the most frequently cited delay.

Recommendation: Concrete strategies must be introduced to reduce the barriers to safe delivery, and to expand access to skilled intrapartum care², including caesarean section. Training health workers to provide skilled maternal care, increasing the availability of basic emergency obstetric care at Level III Health Centers, and the strategic strengthening of Level IV Health Centers as well as hospitals to provide comprehensive emergency obstetric care—starting with facilities in the most under-served areas of the country—would dramatically reduce maternal mortality and

² Management and care during labor and delivery

morbidity in Uganda.³ Improving referral systems at all levels and establishing emergency transport systems to ensure women reach facilities quickly when maternal crises arise would represent further critical steps towards improving maternal survival and well-being.

Finding 4: Fistula has severe, multi-faceted impact on affected women and their families.

The majority of women in the study who were married at the time they sustained fistula were subsequently divorced, and nearly all the women suffered isolation. In addition, the majority of women said that fistula affected their ability to work due to the health effects of the condition and the smell. About half said they could not provide for themselves and/or their families as a result of not being able to work. Women and their families also incurred substantial costs in seeking to access treatment and in purchasing essential supplies—soap, sanitary padding etc.—to manage the condition on a daily basis, often driving them into deeper poverty. The majority of the women also indicated that their family members suffered from stress and worry about how the fistula affected the woman’s life.

Recommendation: Broad-based educational and advocacy programs are needed to dispel negative myths about fistula and reduce the stigma associated with the condition, as well as to encourage social support for girls and women living with fistula. Consistent and reliable information on where and when repair services are available also needs to be disseminated to assist women to access treatment quickly. Radio and outreach through faith-based institutions may represent effective communication channels to reach women in rural areas.

Finding 5: Girls and women need fistula repair services that are available, accessible and affordable.

At the time of study, nearly all of the women had been living with fistula for over a year, and half of respondents had the condition for over 4 years. Sixteen women had endured fistula for more than 10 years. About half of the women had sought fistula repair at a facility, and among these, around half had gone to two or more sites before receiving treatment. One woman had made seven different visits seeking appropriate treatment. At the time of the study, only three women had been successful in achieving repair. A minority of the women had also not sought any type of repair services, primarily because they did not have sufficient funds to seek treatment. For the women who tried to access repair services, both they and their families sacrificed immense

³ Public healthcare facilities in Uganda are classified into two broad types: health centers (HC) and hospitals. Both types are then further categorized: Grade II health centers (at parish level) are responsible for out-patient care, antenatal care, immunization, and outreach. Grade III health centers (at sub-county level) provide all Grade II health center services plus in-patient care and environmental health, and should be able to provide basic emergency obstetric care services. They are the lowest level facilities where deliveries should be conducted. A Grade IV health center is the headquarters of a health sub-district, and provides all Grade III health center services plus surgery. Grade IV health centers and all hospitals—district/rural, regional referral and national referral—should be equipped to offer comprehensive obstetric care services, including caesarean section (Uganda Ministry of Health, 2007)

A national needs assessment into emergency obstetric care conducted by the Ugandan Ministry of Health in 2003 found that the average caesarean section rate surveyed was 1% and met need for EmOC was 5%. Only 2 of the 36 Health Center Grade IV facilities surveyed (or 5.6% of these facilities) were sufficiently equipped for comprehensive EmOC services and only 5 out of 124 Health Center Grade III facilities (or 3.9%) were able to provide basic EmOC services. The assessment surveyed 197 facilities in 19 out of Uganda’s 56 districts, covering an estimated 38.2% of Uganda’s population.

amounts of time and money in their attempts to get appropriate treatment. Money was often raised by selling land and livestock, driving families deeper into poverty.

Recommendation: Expanded access to fistula services are required to reach those in need. Referral systems managed by local authorities, communities and faith-based groups can arrange prompt transfers women with fistula to reach a facility providing repairs. But once a woman reaches the hospital, she must not be barred from care due to inability to pay. Therefore, repair services must be provided free or at minimal cost. Ideally, the costs of transportation to the facility and back home should also be covered. In addition, there is a critical need for more surgeons and other health practitioners specifically trained in fistula treatment to expand the availability of repair and reduce the current long waiting times for surgery.

I. Introduction

This year, over half a million women will die in pregnancy or childbirth, and a further 1.4 million will barely survive life-threatening complications (AbouZahr, 2003; Filippi et al., 2006). Hemorrhage, sepsis, hypertensive disorders of pregnancy, unsafe abortion, and obstructed labor are the five main causes of maternal deaths. This final cause—obstructed labor—is principally responsible for obstetric fistula, a devastating injury sustained by women during childbirth.⁴ As many as 130 000 new cases of fistula are occurring annually, and up to 3.5 million women may be living with the condition (Wall, 2006). The vast majority of these women live in resource-poor countries, and tragically, nearly all of these injuries could have been avoided if timely and competent obstetric care was available, accessible, and affordable. According to the 2006 Demographic and Health Survey in Uganda, an estimated 2.6% of women of reproductive age (15-49 years) had experienced obstetric fistula (UBOS, 2007). Based on the population of women of reproductive age from the most recent census, this equates to a national prevalence of over 142,000 women.⁵

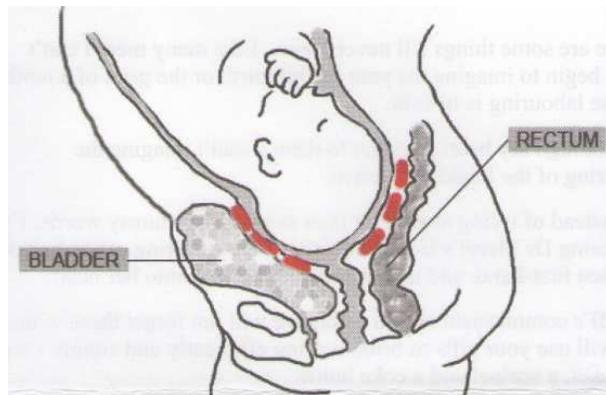
During prolonged obstructed labor, the presenting part of the fetus, usually the head, compresses the soft tissues of the mother's vagina, bladder, and rectum against the maternal pelvic bones (see Figure 1). Without prompt intervention—typically, a caesarean section to relieve the obstruction—the fetus is asphyxiated and the impacted tissues of the mother's vaginal wall sustain pressure necrosis, slough off, and leave a hole (or 'abnormal communication') between the vagina and the bladder (vesico-vaginal fistula) or between the vagina and the rectum (recto-vaginal fistula).

As a result, the girl or woman is left with uncontrollable leaking of urine and/or feces from her vagina, and constant and humiliating odor and wetness. Compounding this catastrophic physical trauma, in almost all cases, the woman suffers the loss of her baby. Without treatment, women are frequently ostracized or withdraw from their communities out of shame. Some are rejected or abandoned by husbands and families. Many are unable to work or earn a living, driving them deeper into poverty.

Obstetric Fistula in Context

Obstetric fistula first presents as a medical condition, but the condition is deeply rooted in women's social, cultural, and economic vulnerability. Most women with fistula are young, poor, live in rural communities, and have low social status, little or no formal education and no political influence (Muleta, 1997 & 2004; Wall et al., 2004). Trapped by physical isolation, poverty and

Figure 1: Diagram Illustrating How Obstetric Fistula Can Develop During Obstructed Labor



Source: UNFPA Campaign to End Fistula website.
http://www.endfistula.org/fistula_brief.htm

⁴ Over 80% of fistulas in developing countries result from neglected obstructed labor (Hilton, 2003). Data also indicates that fistula can be caused in hospital settings themselves, through accidental injury to the vaginal wall during difficult operative deliveries, or through surgical incompetence and negligence (Hilton, 2003; Nicol, 2005; Wall, 2007).

⁵ Population women of child bearing age (15-49 years): 5,476,435 (UBOS, 2002).

subservient roles in society, women face numerous barriers in accessing adequate health care: lack of knowledge to recognize pregnancy and labor complications; powerlessness to seek care; distance from facilities; lack of transport and poor roads; prohibitive costs of transport and health services; and low expectations of the care they deserve. Serious shortages of medical supplies and equipment, theater space, and particularly trained personnel, further undermine the timeliness and quality of the care they receive (Thaddeus & Maine, 1994; Wall, 1998; Grossmann-Kendall et al., 2001; Kyomuhendo, 2003; Gohou et al., 2004; Weeks et al., 2005; Women's Dignity Project & EngenderHealth, 2006; Galadanci et al., 2007).

For the same socio-economic reasons, once they have fistula, many women are unaware that surgical treatment is available, or cannot access or afford the treatment. As a result, they often live with the condition for years or decades. Lastly, even basic repair services are unavailable in most developing countries where the capacity to treat fistula cannot meet the demand for services (UNFPA & EngenderHealth, 2003; Women's Dignity Project, 2002; Wall, 2006).

Purpose of this Study

Appropriate programs and policies to prevent and treat obstetric fistula (and to avert maternal deaths and disabilities more broadly) rely on sound clinical and epidemiological data. They also require solid data on the socio-economic and cultural contexts within which mothers are left severely disabled without the prospect of treatment or rehabilitation. Despite this need, however, the voices of women with fistula are rarely heard, much less reported.

This study is a qualitative and participatory analysis of obstetric fistula in Uganda. The research was conducted to understand women's vulnerability to fistula through their own views and experiences, as well as the views of family and community members, and local health care providers. The study provided a platform for women to convey the devastating impact of fistula, and a means to capture their recommendations on ways to prevent and manage the condition. By courageously sharing their experiences, the women send an unmistakable signal that social and health systems are failing to meet their fundamental needs. Their stories are an urgent call for concerted action on the part of governments and donors to stop women suffering unspeakable complications and dying in childbirth.

II. Study Design and Methodology

A. Study Locations

The study was conducted in four rural districts of Uganda: Kasese, Masaka, Soroti, and Kaberamaido. Kasese is located in the far western part of Uganda, Masaka in central Uganda, and Soroti and Kaberamaido⁶ in the northeast of the country.

B. Study Partners

Community-based organizations (CBOs) were engaged as research partners in two of the study locations: Kasese and Soroti/Kaberamaido. The organizations were selected based upon their strong local presence and their capacity to follow-up with participating communities after the study, including referral of women with fistula for treatment. In addition, both organizations showed commitment to incorporate lessons learned from the research into their ongoing community work.

In Kasese, the research team worked with the Good Hope Foundation for Rural Development (GHFRD). The mission of GHFRD is to improve the health of people in the district and advocate for equitable and sustainable use of resources. In Soroti/Kaberamaido, the study partnered with the Association for Reorientation and Rehabilitation of Teso Women for Development (TERREWODE). This CBO seeks to empower women and girls to improve their own welfare, as well as the welfare of their families and communities.

In Masaka, the research team collaborated with Kitovu Mission Hospital, which provides fistula repair as part of ongoing hospital services. In addition to Kitovu Mission Hospital, the following healthcare facilities participated in the study: Bwera District Hospital, Kagando Mission Hospital, Rwesande and Maliba Health Centers in Kasese; and Soroti Hospital in Soroti. While the facilities in Kasese and Soroti were not research partners, they provided the locations through which to meet and interview women with fistula. Kagando, Bwera, and Soroti Hospitals also provided fistula repairs for women who participated in the study.

C. Study Instruments

Several different instruments were used for data collection: in-depth interviews, group discussions, problem trees, and freelist and ranking exercises. Table 1 provides an overview of the purpose of each instrument. All the tools were developed in English and translated into local languages: into Luganda for use in Masaka district; Rakai and Rukonzo for use in Kasese district; and Kumam and Ateso for use in Soroti and Kaberamaido districts.

In-Depth Interviews with Women on Pregnancy, Labor, and Delivery

These interviews explored women's pregnancy, labor, delivery and post-delivery experiences related to the pregnancy during which they sustained fistula. Women were asked about their health during pregnancy, availability of material and social support, and access to health services, including antenatal and obstetric care. In addition, women were asked for their recommendations on the information and services that should be available for pregnant women.

⁶ Kaberamaido only became a separate district in 2001. Prior to that date, it was the western part of Soroti. Findings are not disaggregated for these two districts but identified as 'Soroti' to refer to the whole area.

In-Depth Interviews with Women on Experiences with Fistula

These interviews were conducted to understand the personal and social impact of fistula. Women were asked how fistula had affected their lives and the lives of family members, psychologically, physically, financially, and socially. Additionally, women were asked about their coping mechanisms for alleviating the impact of fistula.

Table 1: Overall Purpose and Issues Explored for Each Study Instrument

Instrument	Overall Purpose and Issues Explored
In-Depth Interview with Women on Pregnancy, Labor, and Delivery	To explore the pregnancy, labor, delivery and post-delivery experiences related to the pregnancy that resulted in fistula
In-Depth Interview with Women on Experiences with Fistula	To understand women’s experiences of living with fistula, including impact and coping mechanisms
Discussions with Family Members	To understand family members’ perspectives and care-seeking behavior related to the pregnancy that resulted in fistula, as well as the impact of fistula on the woman and the family; and coping strategies used
Problem Tree Exercises with Women and Their Family Members	To understand participants’ perspectives on the causes of and beliefs about fistula, the impact of the condition, and coping strategies
Group Discussions with Local Healthcare Providers and Community Members	To understand the socioeconomic, cultural, and familial factors contributing to the risk of fistula, and means of prevention
Freelisting and Ranking with Community Members	To understand the three most important contributing factors to maternal health complications during labor and delivery

Discussions with Family Members

Discussions were conducted to understand family members’ perspectives and care-seeking behavior related to the pregnancy resulting in fistula. Specifically, discussions focused on the actions of the woman and her family during labor and delivery, and the woman’s access to material and personal support as well as health services. The discussions also explored the impact of fistula—personally, socially, and economically—on the lives of the women and family members, the coping strategies used to lessen the impact of fistula, and participants’ recommendations for preventing fistula.

Problem Trees on Obstetric Fistula

A problem tree is a participatory learning and action (PLA) tool that allows participants to explore the causes and consequences of a particular issue. Participants draw a “tree”, and the issue is written on the trunk of the tree. The roots of the tree then represent the causes of the problem, while the branches are the consequences or outcomes of the problem.

Problem trees were carried out with women with fistula and their family members to understand beliefs about the causes and consequences of fistula, and ways of coping with the condition.

Participants were also asked the local names for fistula and how these names were interpreted within their communities.

Group Discussions with Local Healthcare Providers and Community Members

Group discussions were also conducted with local healthcare providers, including traditional birth attendants (TBAs), and with community members. These discussions aimed to explore community knowledge and perceptions on the socioeconomic, cultural, and familial factors contributing to fistula, including the health risks faced by women during pregnancy, labor and delivery. In addition, participants were asked for recommendations on community-based strategies to prevent fistula and other maternal health problems, and on ways to support women living with the condition.

Freelisting and Ranking Exercises with Community Members

Freelisting and ranking is a PLA tool where participants brainstorm and list responses to a question. Responses are then ranked in order of importance.

In the study, community members identified and ranked factors contributing to maternal health complications during labor and delivery. Their opinions were also sought on the information and service needs of women of reproductive age, and on general healthcare services in their communities.

D. Study Participants

Study participants included women living with fistula, members of their families and communities, and local healthcare providers. Details on each of these groups are provided below. See Annex 1 for a list of all participants by district and by research activity. Participants belonged to several ethnic groups: Ateso, Ganda, Konzo, and Kumam.

Women with Fistula

Seventy-six women participated in in-depth interviews. On average, the in-depth interviews lasted two hours. The first hour focused upon the woman's experiences during the pregnancy that led to fistula, and the second hour upon her experiences living with the condition. All 76 women interviewed discussed experiences during the pregnancies that led to fistula, while 73 women discussed their experiences living with the condition. The 3 women who did not discuss their experiences living with fistula were unable to continue the interviews due to other personal commitments.

Twenty-six women also participated in problem tree exercises. In Masaka and Kasese, the 20 women engaged in these exercises were among those who had been interviewed. In Soroti, however, the 6 women engaged in problem tree exercises had not been previously involved in the study. Therefore, 82 women with fistula took part in the study overall.

The women were identified and invited to participate in two principal ways—through participating healthcare facilities, and through community visits.

In the first approach, partner organizations requested staff at the facilities to identify any patients with fistula and invite these women to meet with the research team. Women were also recruited directly from among those waiting for fistula treatment at these facilities. The research teams met with interested women, explained the purposes of the study, and asked their permission to interview them and their families. If the women agreed, informed consent was obtained and individual in-depth interviews were subsequently conducted. After these interviews were

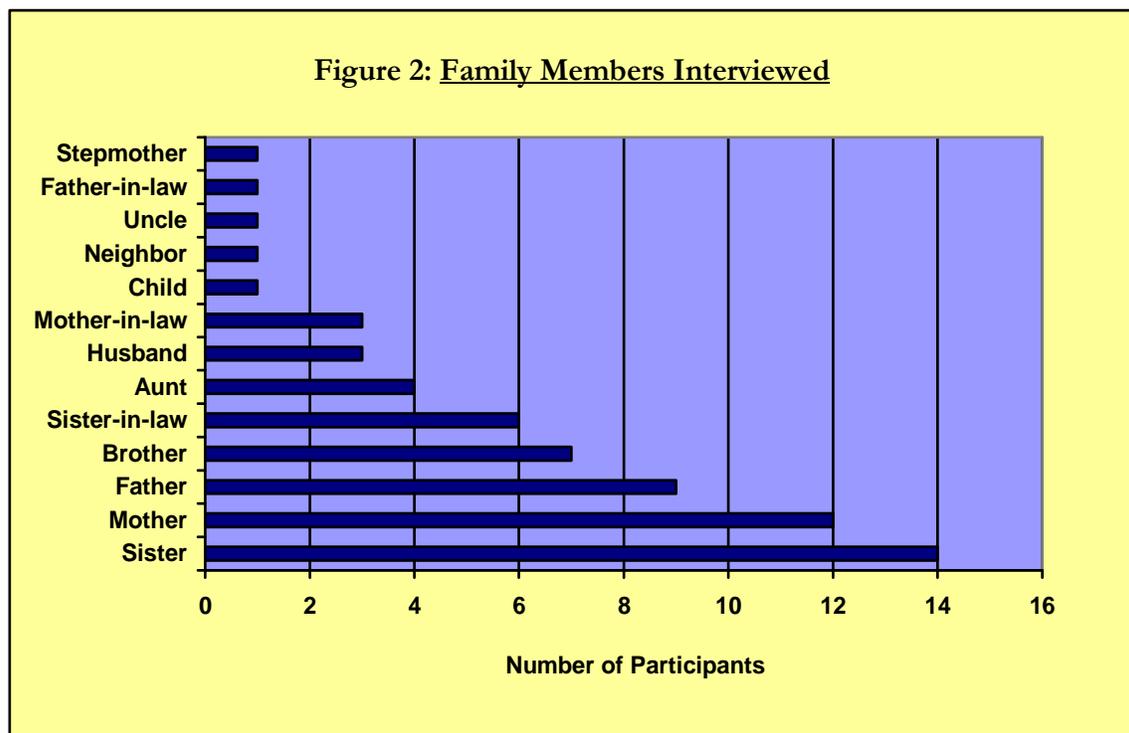
completed, and if the interviewees had given permission, the research teams traveled to the home communities of the women to talk with family members. Unfortunately, in some cases, visits were not feasible given long distances between healthcare facilities and home villages.

In the second approach, participants were recruited during the visits to the communities of women interviewed at healthcare facilities. Community members were asked if they knew other women with fistula. These women were then approached by the research team and invited to participate in the study. If they agreed, informed consent was obtained and in-depth interviews conducted.

Research activities for 57 women were completed at home. The remaining 25 participants were interviewed at healthcare facilities.

Family Members

In total, 63 individuals from the families of women with fistula participated in discussions and problem tree exercises. During community visits, researchers scheduled appointment times to visit family homes and, after explaining the study and obtaining informed consent, interviewed any family members present. Figure 2 details these participants.



Community Members

Community members living near the homes of women with fistula were included in the study to gain a broader understanding of the social factors contributing to a woman's risk of sustaining fistula. In total, 120 people took part in group discussions, problem trees, and freelist and ranking exercises.

Healthcare Providers and Traditional Birth Attendants

Researchers held discussions with 4 groups of healthcare providers from health centers near the homes of women with fistula. A total of 21 providers participated, including clinical officers, trained nurses, nursing assistants, nurse midwives, public health nurses, laboratory technicians, and psychiatric nurses. In addition, 4 group discussions were conducted with 54 traditional birth attendants.

E. Fistula Treatment

All of the women who participated in the study had their fistulas surgically repaired. Most of these procedures were performed at Kitovu Mission Hospital in Masaka, Bwera District and Kagando Mission Hospitals in Kasese, and Soroti Hospital.

The organizations conducting the research felt a strong ethical responsibility to offer repairs for all study participants, and to make every effort to ensure that other women living with fistula met during the course of the research also received the opportunity for repair.

F. Data Collection

Data collection was completed between April and July 2005 by the three local partner organizations: Kitovu Mission Hospital in Masaka, GHFRD in Kasese, and TERREWODE in Soroti/Kaberamaido. A team of two people from each organization—a principal interviewer and a note-taker—carried out the interviews and other study methods. Interviews were conducted in the local languages of participants and were not recorded. It was felt that participants would be more comfortable discussing a stigmatizing condition and voicing criticisms of the healthcare system, if interviews were not recorded.

The local research teams received one week of training from WDP and EngenderHealth staff before going to the field. The training consisted of a detailed orientation to the research objectives and to the multiple dimensions of obstetric fistula. The teams were also trained on how to use each study instrument. Following the training, the teams pre-tested the tools at Kitovu Mission Hospital with women either awaiting fistula surgery or in post-operative care. Appropriate changes were made to the tools based on these pre-test findings. A training manual was also developed and provided to each team for reference in the field.

Each study instrument had one or more guiding questions to start discussion, together with sets of related questions to help interviewers probe key issues further. The note-taker made detailed, hand-written notes of responses, including verbatim quotes where possible. Immediately following each interview, the research teams reviewed and amended their notes for consistency and accuracy. Notes were again reviewed at the end of each field day for completeness and then transcribed onto recording forms which were organized according to the guiding questions for each instrument.

G. Approvals for the Study

The Ministry of Health in Uganda approved the study as part of its institutional effort to address fistula. The Ministry requested the research team to provide ongoing updates on the status of the study, as well as copies of the final report.

III. Analysis and Reporting of the Findings

A. Data Analysis and Presentation

Completed recording forms were translated into English, and a second translator checked the text to ensure accuracy. In addition, two researchers from WDP examined all of the recording forms for accuracy and completeness against the original notes before data was input for coding and analysis. Any gaps identified or clarifications needed were discussed with local partners and corrections made. Lastly, in order to verify the accuracy and comprehensiveness of data captured on the recording forms, the hand-written notes from all of the interviews were translated and compared to the recording forms.

A team of four people from WDP and EngenderHealth developed a codebook using an iterative process. To begin, at least two individuals independently coded each text segment using Atlas-Ti. The team then discussed coding discrepancies, revised the codebook accordingly, and performed recoding to ensure consistency. Upon completion of coding, an initial report of findings was generated using Atlas-Ti, and the results shared with participating individuals and communities through community feedback meetings in each of the three study locations (see below for further description).

Lastly, this final report was written by staff of EngenderHealth and WDP. Throughout the report, percentages for each finding are calculated based on the number of respondents for relevant questions, and the results are expressed using the descriptive indicators described in Table 2.

Table 2: Descriptive Indicators

Descriptor	Associated Percentage
All	100%
Nearly All	80-99%
The Majority	More than 50%
About Half	Around 50%
Fewer than Half	Around 25-45%
Minority	10-25%
A few	Less than 10%

B. Community Feedback Meetings

As noted above, the research teams organized community meetings to share preliminary research findings with study participants and to solicit feedback on the accuracy and quality of those results. For each district, meetings were held in those locations where more than two women with fistula were interviewed, and in locations where focus group discussions with community members and healthcare providers were conducted. A total of nine feedback meetings were held—two in Masaka, four in Kasese, and three in Soroti/Kaberamaido. These follow-up visits also enabled researchers to talk with women about their experiences of reintegration into community life following fistula repair.

Suitable dates for the meetings were scheduled in conjunction with community leaders, who then informed community members of the agreed dates and times. Approximately 100 community members attended each feedback meeting. There was broad consensus that reported findings were correct. At these sessions, participants also reviewed the strategic plans they had developed for prevention and management of fistula in their communities.

C. District Feedback Meetings

The research teams held meetings with representatives from different departments within the administration of each district in which the study was conducted, including the District Director of Health Services, Chief Administrative Officer, Community-Based Health Coordinator, and District Education Officer. The teams also met with one village leader from each study site to share information and identify strategies for the prevention and management of fistula. At all of these sessions, the teams shared preliminary findings and reported on the community feedback meetings.

IV. Study Limitations

A. Length of Time Living with Fistula

At the time of interview, some respondents had lived with fistula for extended periods and, hence, were reporting on pregnancies from several years past. As a consequence, it was difficult for some of these participants to recall in detail the antenatal care they received and their experiences during labor and delivery.

B. Timing of Labor

The research teams did not ask women for the exact timings or step-by-step descriptions of their labor, as such information is difficult to recollect precisely, especially after significant lapses of time. The study, therefore, did not utilize a standardized definition to measure the onset of labor, and all labor and delivery times recorded reflect each woman's individual perceptions and memory of events.

C. Recording of Interviews

The research teams did not tape interviews as they felt that participants would be more comfortable discussing a stigmatizing condition and voicing criticisms of the healthcare system if discussions were not recorded. As a result, it was not possible to record participants' experiences verbatim.

D. Lack of Research Experience

To ensure that study findings would be used in ongoing programmatic work, a community-based organization in each study location was selected as a research partner. This choice had significant positive outcomes. Partner organizations established strong rapport with communities as well as trust among study participants. The organizations' understanding of, and capacity to address, maternal health problems were also enhanced. However, the lack of research experience of local partners was a limiting factor. For example, in some cases, data only provided partial summaries of participants' perspectives, and the research teams did not capture nuances surrounding certain issues.

V. Study Findings

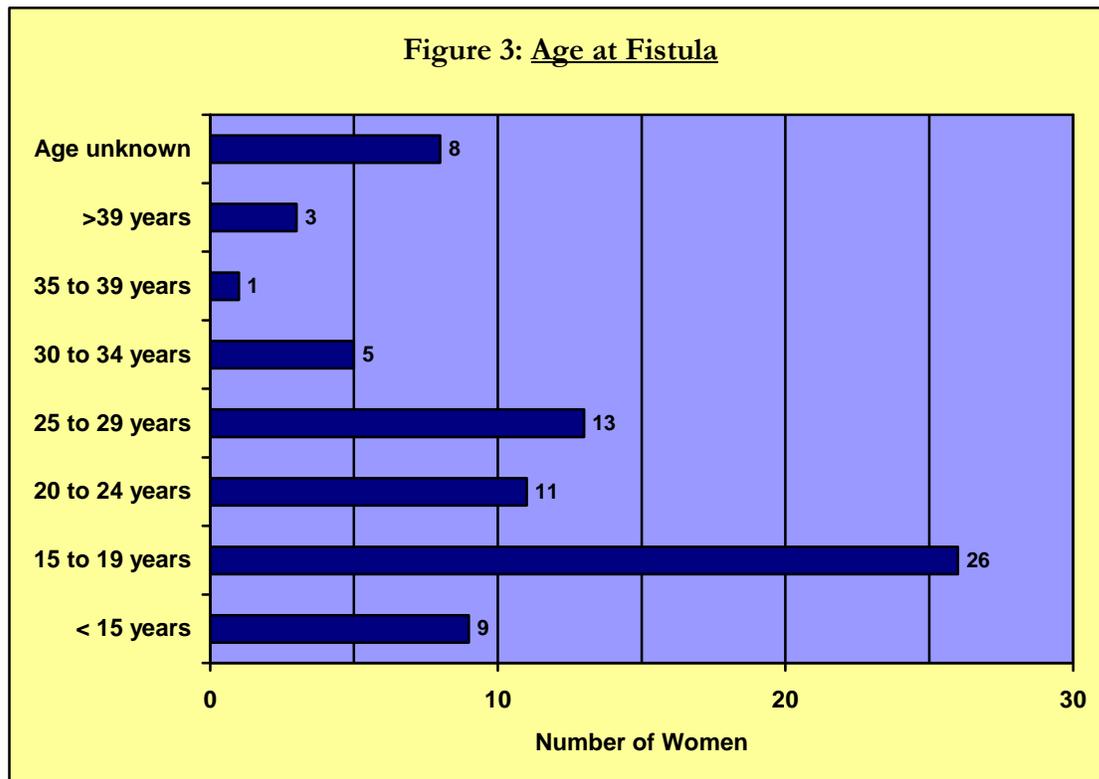
A. Age and Gravidity of Women with Fistula

Age at Interview

The mean age of the women at the time of interview was 28 years and the median age is 25. The youngest participant was 17 and the oldest was 70.

Age at Fistula

The median age of women at the time they sustained fistula was 19 years; the youngest was 13 and the oldest was 41. Of the 68 participants whose age at time of fistula was recorded, 35 women (slightly more than half of respondents) were aged 19 years or younger, while 33 women were 20 years or over. Nine women were 14 years old or younger at the time they sustained fistula, and three women were over 39 years. Figure 3 details the age at fistula for all women interviewed.



Gravidity

The majority of women were on their first pregnancy (primigravida) when they sustained fistula, while fewer than half were on their second to fifth pregnancy. Eight women were on their eighth or higher pregnancy when the fistula occurred.

B. Pregnancy History

The information in this section is based on women's reported experiences during the pregnancies that led to fistula.

Knowledge of Pregnancy, Labor, and Delivery

The majority of women knew about pregnancy, labor, and delivery prior to the pregnancy that resulted in fistula. A few women learned about pregnancy from local health providers, school teachers, and outreach workers from NGOs, but past pregnancies and observing/learning from other women were the most common sources of knowledge. One woman explained:

"I learnt about the issues surrounding pregnancy from my big sister with whom I lived for a while. She used to get pregnant and would deliver at home. I observed everything she went through and did from the beginning of labor through the delivery." (Woman B from Masaka, age unknown)

However, fewer than half of the women reported no prior knowledge. One woman related that she was very young when she got married: *"I had not started playing sex. I had not started menstruation and my marriage was forced." (Woman A from Soroti, age 18)* She added that no one from her family or her husband's family gave her any advice on pregnancy or labor. Another woman said she was not taught anything about pregnancy as it was considered *"taboo to talk about pregnancy and child birth, especially if a woman is expecting her first child, because people say it brings bad luck." (Woman B from Soroti, age 18)*

Antenatal Care (ANC)

ANC services are an important opportunity for women to receive information and counseling on pregnancy, labor, and delivery, and also provide the opportunity for healthcare providers to diagnose serious problems that women may face during pregnancy, such as pre-eclampsia. Officially, ANC is a free service in public facilities in Uganda; in private facilities, clients may have to pay. However, study findings detailed below indicate that the extent and quality of ANC services were seriously limited, representing a significant "missed opportunity" to deliver critical information and care.

Attendance: Nearly all of the women had attended ANC, and nearly all had gone at least twice. Fewer than half of the women had made four or more ANC visits.

Only three women reported not going for antenatal care. One woman remarked: *"I did not go for antenatal care. I had never done so for all previous pregnancies. I was pretty assured that I would deliver normally like I had always done." (Woman A from Masaka, age unknown)* Another woman, who became pregnant while in school, had run away from home in fear of her parents' reactions. She did not go to antenatal care because she did not have anyone to teach her about pregnancy, and she did not see other pregnant women attending ANC.

The Decision to Attend ANC: Of the women who mentioned how they made the decision to go for ANC, fewer than half decided to go by themselves. The decisions of these women were largely based on having seen other women attending ANC. One woman recounted: *"It was my own decision to go to the health facility because I had grown up seeing expectant mothers do so. Now it was my turn." (Woman from Masaka, age 23)*

However, fewer than half of the women also reported that their parents or their husband decided whether they should go for ANC. One young woman related: *“He [my husband] is a fishmonger and he was always up and down with his business. The ANC decision and all decisions always came from him and were approved by his old mother.”* (Woman from Soroti, age 17)

A minority jointly decided with their husbands or their in-laws had decided for them. One woman related that without her in-laws’ insistence she would not have been able to receive treatment for pregnancy-related illnesses and malaria. She said that her in-laws told her husband to take her for antenatal care. (Woman from Soroti, age 20). Lastly, a few women reported that other family members, such as an aunt or brother, made the decision for them to seek ANC.

A minority of respondents also mentioned constraints in seeking ANC. One woman said: *“I asked for money from my husband to sponsor antenatal care visits, but he released nothing, claiming he didn’t have.”* (Woman from Masaka, age 30). Fortunately, this woman had been employed and was able to afford antenatal care.

Quality of Services: According to the National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights issued by the Uganda Ministry of Health (UMOH), women should have at least four ANC visits during pregnancy.⁷ A woman’s first visit should be early in the first trimester, the second visit should be between 16 and 28 weeks, and the third and fourth visits between 28 and 42 weeks. On the first visit, for example, providers are expected to take a comprehensive patient history and to provide counseling on VCT and PMTCT, birth planning, danger signs during pregnancy, and future family planning goals. Urine analysis and testing for syphilis are also to be conducted. Additionally, pregnant women are supposed to receive immunizations as well as iron and folic acid supplements.

However, the type and quality of ANC services that the women reported receiving were inconsistent and inadequate. Fewer than half received any type of immunization services, and a minority of women reported that the health worker listened for the fetal heartbeat. A few women had their blood pressure checked, were advised to eat a balanced diet, or were weighed. Nearly all of the women reported being given some type of tablets/medicine—which may have been iron/vitamin supplements or medicines for malaria—but a minority of women reported being given vitamin tablets only. No hemoglobin tests, urine analysis, syphilis screening, voluntary counseling and testing for HIV, or counseling on risk factors and warning signs and symptoms during pregnancy were reported.

Moreover, only three women were told anything related to delivery. This again represents a significant discrepancy from UMOH guidelines as providers are expected to develop delivery plans with the women during their first visit, and to review these plans in the third and fourth visits. The three women who were given information related to delivery were advised to deliver at a hospital. The reasons offered by providers for these assessments included that the woman was too young or on her first pregnancy, the woman had a prior history of caesarean section, or the baby was too big. But, as one woman from Masaka explained, the unit to which she was referred did not have a doctor or surgical facilities:

“Yes, I went to a government clinic for antenatal care three times. On examination the midwife told me that the baby was very big. Although she treated me she told me that I should

⁷ See Annex 2 for the Ministry’s “Goal Oriented Antenatal Care Protocol” which shows the information and services that women should receive during ANC visits according to UMOH guidelines.

go to the health unit at Buyoga for delivery, but there was no doctor or operating theater there.” (Woman from Masaka, age 33)

Health Status, Food, and Workload During Pregnancy

Health Status: The majority of the women reported no serious health problems during pregnancy, as illustrated by one woman from Masaka: *“During this pregnancy, I felt very okay. I had no problem apart from lower abdominal pains that I had when I was four months pregnant. I was treated and the pain subsided.” (Woman from Masaka, age 21)*

Generally, participants mentioning any difficulties with the pregnancy reported experiencing weakness, general malaise, frequent dizziness, breathing troubles, or body pains. However, fewer than half of the women mentioned conditions such as malaria, anemia, frequent heavy bleeding, and vaginal sores, and a few women reported being treated at a health facility as they were in danger of miscarriage.

Food: The majority of women also said that they had enough food during pregnancy. However, a minority reported insufficient food supply as a consequence of poverty, famine, and/or conflict. One woman described her experience during pregnancy in a camp for internally displaced persons: *“There was poverty in the camps. Food, firewood and any other things weren’t there. People ate only once a day, which was not even enough to satisfy them.” (Woman C from Soroti, age 18)*

Workload: The majority of women performed all of their usual chores throughout the entire pregnancy, including farming, washing, cooking, caring for children, collecting firewood, and walking long distances to fetch water. The words of a woman from Soroti illustrated a typical workload: *“I did my housework as before. I even worked in my gardens, planting and weeding my crops. I was strong and did everything without difficulty. I fetched water, which is about a half a mile away. I also fetched firewood.” (Woman from Soroti, age 25)*

Use of Traditional Medicine

The majority of women reported taking traditional medicine at some point during pregnancy, labor, or delivery. These were taken orally in the form of teas and pills, or topically/vaginally in the form of lotions and bath tonics. Of the women using traditional medicine, nearly all took herbs during pregnancy to prevent diseases, jaundice, excessive body heat, and/or bad luck. Other reasons cited for taking herbal preparations included cleaning the baby in the womb, soothing body pains, treating malaria and morning sickness, and preparing the mother for delivery by giving her strength and softening her pelvic bones. One woman reported using herbal medicine when six months pregnant on the advice of a relative:

“She told me that, at this period, the fetus is already grown up and these herbs help to clean its body while inside the mother’s womb. [The herbs] treat jaundice and syphilis. I had no problem with these herbs. At seven months, I was also given other local herbs for [a] bath twice a day for thirty minutes to help me prepare the pelvic bones for prompt and safe delivery. I had no problem with these herbs either.” (Woman from Masaka, age 22)

Another woman reported using traditional medicine as people in her village believed that *“pregnant women (need to be) given local herbs to help them deliver normally.” (Woman from Soroti, age 35)*

The majority of women using traditional medicine also took herbs during labor. Reasons cited for their use included stimulating/intensifying contractions, reducing pain, giving strength and/or re-

adjusting the baby's breech position. One participant related: *"I drank some tea with a herb called 'akeyeeyo'. I swallowed its root. We say it quickens labor and delivery if used mixed with black tea."* (Woman C from Masaka, age unknown)

C. Birth Preparation

Preparation for the Baby

The majority of women interviewed did not prepare for the baby in any way. The most common reasons cited were lack of money and that preparing for a baby was against their traditions. The women wanted to wait until the baby was born because they did not know if it would be born alive. One woman observed:

"There was no special preparation for the baby. I did not have the money. I learnt from my husband and mother-in-law that it was taboo for them to prepare for a baby they had not seen. They said that if a baby was born in good health they would initially use hand-me-downs and old bed sheets." (Woman B from Masaka, age unknown)

Fewer than half of the women did make some preparations for the baby. These women typically bought clothes, special bed sheets or towels for the infants, or purchased powder or soap to wash the baby's clothes.

Women's Planned Delivery Site and Actual Place of Birth

About half of the women had planned to deliver at a healthcare facility, although the specific type of facility—that is, health center, district hospital, or regional referral hospital—was not always clearly defined by the respondents. The main reasons cited for wanting to deliver at a facility were based on the woman's own beliefs that the facilities would provide quality care, or on the advice given by health workers or family members to do so. However, nearly all of these women started at a lower level health facility, with a TBA at home, or went to the hospital too late after trying to deliver at home. Nearly all of these women completed their deliveries at a higher level facility.

A minority of women had planned to deliver at home. Again, several principal reasons were cited: the women felt they would deliver safely at home with the help of other women experienced in deliveries; they lacked money for transportation and delivery costs; or they had previous experience delivering safely at home. Nearly all of these women started their delivery at home and the majority sought the help of a TBA or family member. In the end, the majority completed their deliveries at a facility.

Additionally, fewer than half of the women had not discussed their plans for delivery with anyone. As one woman related:

"I did not discuss with my husband where to deliver. I did not even share with the family on this matter. But I knew I would deliver from home since I had experience delivering at home. My first two children were produced from home." (Woman from Soroti, age 25)

A minority of these women felt no need to discuss arrangements because home delivery was their cultural tradition. One woman remarked: *"In those days people never bothered delivering in hospitals, although we were near Lwala hospital. It was our tradition."* (Woman from Soroti, age 27).

Other women did not discuss the place of delivery because their families lacked money for a facility-based delivery, and one woman mentioned that she had no access to health facilities as she was living in a camp for internally displaced persons. Of the women who had not discussed plans for delivery, fewer than half delivered at a facility.

Who Made the Decision on Where to Deliver?

The majority of women said they were involved in making the decision about where to deliver, and most of these women decided jointly with their husbands and/or with other family members. However, fewer than half of the women were not involved in the decision as to where to deliver, and only a minority of women made the decision on delivery site by themselves. Fifteen women did not respond to this question. One woman related a story of powerlessness:

“I had gone back to my parents and it was mummy and daddy who made the decision as to where I would deliver from. I could not contribute to the decision because I was not employed and since I had become pregnant while still at school I was even afraid to say anything to attract the anger of my parents.” (Woman D from Masaka, age unknown)

Constraints in Planning Facility Based-Delivery

About half of the women expressed facing constraints in planning for facility-based delivery. The most common constraints cited were lack of money, high transportation costs, and high hospital costs. Indeed, the majority of the women planning to deliver at a facility had set aside some funds to cover expenses, but still did not go when labor started. One woman from Masaka explained:

“Yes, the problem of not having money stopped me from going to a health center for delivery because my spouse and my mother-in-law had said they had no money to pay for hospital bills. Even my mother had no money to take me to a hospital. If I had my own money I would not have delivered in the village because during antenatal care the midwife had advised me not to deliver in the village.” (Woman from Masaka, age 26)

Another woman described the prohibitive cost of transportation: *“The cost of transport to the health center was so high— Ugandan shillings (UShs) 25,000 (US\$14)—and we never had money to go.” (Woman from Masaka, age 19)*

Lack of access to transport, insufficient knowledge about labor, and fear of treatment at the facility were also mentioned. As one woman reported: *The reputation of nurses and midwives regarding care for delivering women in this community is also not good and many women are scared of their bad behavior.” (Woman A from Soroti, age 45)*

A second woman from Soroti echoed this view: *“Villagers are aware that nurses are particularly strict on clothing, gloves, cotton wool, and panties for mothers and their babies, and because most men can’t buy these things, women prefer to deliver at home.” (Woman from Soroti, age 37)*

A third woman related: *“Most men fear to take their wives to hospitals because they fear to spend money to buy a night dress, knickers and other basics for a mother from the hospital. There are cases when nurses refuse to deliver a woman just because she doesn’t have gloves. (Woman B from Soroti, age 45).*

A few women also reported that community norms were significant constraints in planning for facility-based delivery. A woman from Soroti commented:

“I wanted to deliver from hospital but I never discussed this with my husband. Our culture discourages us from planning for a baby who is not yet born. Prior planning is believed to bring bad luck so we avoided it. We did not make special arrangements for transportation to hospital because we did not have the money. We were also discouraged by relatives not to shop for a baby who is not yet born as it would bring bad luck... What influenced our decision the most was the belief that anything to do with pregnancy should remain a secret. In fact one night my husband told me to stop discussing life after giving birth before I had delivered.” (Woman from Soroti, age 29)

Another woman elaborated on this point:

“The fact that many women from our surroundings deliver from home also had influence on our decisions to deliver from home. You would look a fool to go to hospital before labor starts. People would think that you are only being stubborn and lazy.” (Woman A from Soroti, age 45)

Funds Set Aside for Transport, Delivery, or Post-Delivery Expenses

Transport: In all, fewer than half of the women had set aside money for transport. The average amount set aside was US\$40,000 (US\$23). The primary reasons given by women for not setting aside funds for transport were that the costs were too high, they were going to use the family bicycle, or they were planning to deliver at home. One woman from Soroti related:

“We left it for circumstances to determine where I would deliver. Most women in my village deliver from home, so I did not think that it is important to discuss where to deliver. There were no special arrangements for transportation to a health facility if needed during delivery. I knew that in an emergency, my brother-in-law’s bicycle would be used to call a TBA or rush me to hospital.” (Woman from Soroti, age 20)

Delivery or Post-Delivery: Similarly, the majority of women had not set aside any money for delivery or post-delivery expenses. Primary reasons cited by these women were poverty, cultural beliefs, the unwillingness of families to use resources for birth preparation, and expectations that they would deliver at home. As one woman from Soroti explained: *“We did not have any money to put aside for such emergencies... My mother-in-law told my husband to sell a goat when I’m due.” (Woman B from Soroti, age 18)*

Some families undertook special work or sold crops to raise money for potential birth expenses. A woman from Masaka related her experience: *“My husband had already saved money to fuel his motorcycle... This money was from sales of our jointly produced maize. In all, we had saved US\$50,000 (US \$29) which was meant to cover transport and any other child-birth expenditures.” (Woman from Masaka, age 23)*

D. Labor and Delivery

Onset of Labor

Nearly all of the women started labor at home, and fewer than half went into labor during the evening or night when it was more difficult to obtain assistance. A minority of women started labor at home alone, and a few began labor outside the home while doing chores or visiting relatives. A few women were also at the hospital when they commenced labor.

Delivery Trajectory

Of the 76 women interviewed, 71 started labor at home. Of these women:

- Fewer than half were assisted by a traditional birth attendant, the rest by family and friends; and
- Nearly all ended up delivering at a health facility, in most cases, a hospital.

Only two women started and completed their delivery at a hospital, whereas half of respondents (38 women) made two or more moves to get emergency care. Table 3 shows the number of moves the women made from the onset of labor until delivery of the baby, and Annex 3 details the delivery trajectories.

Table 3: Number of Moves from Initiation of Labor to Final Delivery

Number of Moves	Number of Women
0	15
1	23
2	26
3	9
More than 3	3

Who Made the Decision to Move?

After the onset of labor, the majority of women were helped by others—most often, husbands, mothers, mothers-in-law, TBAs or midwives—to make the decision to move to another place for delivery. Only one woman made the decision by herself. A young woman from Masaka described her experience: *“It was my mother’s decision to get help because she never trusted the traditional birth attendant’s advice to wait all night.”* (Woman from Masaka, age 19)

Unfortunately, family members were not always helpful. In one case, a woman was kept at her mother-in-law’s house and told to be patient. She related: *“I felt my life gradually coming to an end, especially on the second day of labor at my mother-in-law’s house.”* (Woman from Masaka, age 20)

Healthcare providers also played significant roles in decisions about moving women. One woman shared her experience at a health center:

“The midwife decided to refer me to Kitovu Hospital because she could not handle the situation. She also told my husband and mother-in-law within my earshot that I was most likely to kill the baby for failing to push. I could not say anything because I was very tired.”
(Woman B from Masaka, age unknown)

Life-Threatening Delays

Two-thirds of the women faced multiple delays in reaching and receiving the necessary emergency care. Table 4 shows the number of delays experienced by respondents, and Table 5 details the types of delays experienced.

Inability to access transport was the most frequently cited delay. Participants reported that transport was unavailable or unreliable, road conditions were poor, or traveling at night was extremely difficult if labor commenced in the evening. Additionally, as described earlier, the majority of women had not set aside any funds to meet transportation costs.

Table 4: Number of Delays Experienced by Women in Reaching and Receiving Emergency Care

Number of Delays	Number of Women
0	12
1	14
2	25
3	15
4	10

Over one-third of women also suffered delays through the failure of family, friends or the woman herself to recognize complications during labor at home. One woman from Soroti related: “*I spent three days in labor. I had pains in the pelvic bones. I felt as if my bones were opening up.*” (Woman from Soroti, age 40). Another woman explained: “*I realized that there was a problem with my labor when I started passing out a lot of blood continuously and we had to rush to hospital.*” (Woman from Soroti, age 22)

The failure by community-based providers or staff at health facilities to recognize and/or act on problems, including the referral of patients with serious complications to higher level facilities, was another critical delay faced by women. One woman spent three days at a dispensary attempting to deliver. (Women E from Masaka, age unknown). Another woman described the failure of both her TBA and a health centre midwife to correctly recognize complications:

“[After failing to deliver for eleven hours with the assistance TBA at home, the TBA accompanied the woman to a health centre where] the midwife and the traditional birth attendant discussed and brought a razor blade. They cut my vaginal wall saying that I was going to deliver because the baby was very near. But at this time the labor pains had stopped and I could not push for I was very tired. Blood was running profusely and the hands of the traditional attendant were soiled with blood.” (Woman from Masaka, age 22)

Overall, the length of time mentioned by women as a sign of delivery problems varied from 6 hours to approximately 6 days. Other signs of problems described by the women included bleeding, stopping of labor pain, and partial emergence of the baby.

Table 5: Type of Delays Experienced by Women with Fistula

Type of Delay	Number of Women
Delay in transportation	46
Delay by community-based provider, typically a TBA	29
Lack of recognition of problem by woman or family/friend	27
Delay by provider at facility (Sites cited: private practitioner, 2; health center, 12; and hospital, 5)	19
Delay in care-seeking	15
Delay at health facility (Sites cited: dispensary, 1; health center, 3; and hospital, 9)	13

Case Study 1: Over Five Days in Labor

In Masaka, a 30-year-old woman spent five and a half days in labor before reaching a hospital equipped to handle obstetric emergencies. Her story illustrates the multiple delays faced by poor women in identifying complications and reaching appropriate care.

The woman began labor at midnight. She informed her husband next morning, but he urged her to prepare food for the Christmas festivities. She did as he asked but the labor pains intensified. By mid-afternoon, the woman told her husband that she was experiencing severe pain, so he advised her to go to his mother who was a traditional birth attendant.

At her mother-in-law's home, the woman was examined and given herbal medicine together with a strong black tea concoction. She remained there for an entire day and night without delivering, during which time her mother-in-law verbally abused her. Her mother-in-law claimed that she was too lazy to push and intended to waste the family's money by delivering in a hospital. Finally, on the third day, the mother-in-law told her son to take his wife to a healthcare facility.

Her husband sold some chickens, hired a motorbike, and took her to a private midwife. The midwife examined her and said she would deliver by 1:00pm. When that time came she pushed again but still did not deliver. At this point, the woman was shocked to discover that the midwife had left her alone in the clinic to attend a function in a neighboring town. When the midwife returned late in the evening, she questioned why the woman had started pushing even though it was this midwife who had told her to begin pushing at 1:00pm. The midwife then instructed the woman to push again but she was exhausted and her legs were swollen.

On the fifth day, the midwife admitted that she could not deliver the baby and referred the woman to another health facility. The woman recounted: *"My legs were swollen and I was breathless. The midwife finally admitted failure and advised my husband to take me to another health facility...I saw death was just around the corner, but could not do or say anything."*

The family hired a vehicle to take her to the hospital. She was immediately attended by midwives who called a doctor to remove the baby. However, these nurses accused the woman of delaying delivery and complained of her smell, saying: *"This time they have brought us a rotten person."*

By the time the doctor performed a caesarean section the woman was unconscious and the baby was dead. She related with sadness: *"I did not see my baby, but learned it was a big healthy baby boy. By the time I regained consciousness the body was in the mortuary, from where it was taken home for burial soon afterwards."*

Outcome and Mode of Delivery

Nearly all of the women lost their babies. Of the 76 deliveries, 57 babies were stillborn and a further six died shortly after birth. Another child died after four months. At the time of interview, only seven children were still alive, and one of these children was reported as disabled.⁸

⁸ The health status of 5 babies was not reported or not clear from recorded data.

The majority of women delivered via caesarean section. The remaining women reported instrument or vacuum deliveries, or related that the baby was pulled out by the TBA.

Of additional note, a majority of women reported that they could not pass urine during labor, passed only small amounts, could only urinate at the beginning of labor, or urinated only once during labor. The high percentage of women that reported difficulty urinating during labor may indicate that bladder distention contributes to obstructed labor and the risk of fistula.

Case Study 2: Life-Threatening Delays at a Hospital

The story of a 21-year-old woman from Masaka shows how women can experience delays in receiving care even when they reach a health facility.

During antenatal visits, the woman was told by her doctor that she might experience difficulty in delivery due to her short stature. The doctor advised her to come to the hospital in her seventh month of pregnancy and to wait there until she delivered.

When her labor began, she was already in the hospital's maternity ward. The woman tried to call her doctor but he did not come, so she was attended by midwives on the ward. She was examined and told to walk around to help the baby descend. However, the nurses were rude to her. When she asked one midwife to help, this midwife told her to go call someone else. The woman called another midwife who said she would come shortly but never arrived. No one would attend to her. She recounted: *"I spent one week with pain. I tried to explain to the midwife that the pain is too much. They told me to wait, that I would be able to deliver."*

Finally, the woman phoned her aunt who was a medical professional. Her aunt arrived 6 hours later and told the staff that her niece needed an operation because the baby was already dead and she did not want her niece to die as well. Only at this point did the midwives attend to the woman, because they feared the aunt who also worked at the hospital. The aunt was furious and placed her niece on a stretcher and took her to the operating theatre herself. She had a caesarean section, but it was too late—the baby had already died. The following day, the woman discovered that she was leaking urine.

Roles of Caregivers During Labor and Delivery

Family and Friends: Nearly all of the women reported receiving support from family or friends during labor and delivery. Mothers-in-law, mothers, and husbands were the most common caregivers, and the types of assistance most frequently cited were helping during delivery, bringing community-based providers to assist, or accompanying the women to health facilities. One young woman succinctly described: *"My mother and husband were there to take care of me."* (Woman from Soroti, age 21)

Unfortunately, in several instances, the roles played by family members were negative. One woman related:

"[My mother-in-law said that] I had various traditional ailments which the midwives at the health center may not be able to handle during delivery... that this might cause me to die if I insisted to deliver there. Nevertheless, I wanted to deliver from the health facility as the midwife had advised. But my mother-in-law and husband refused and when labor started they

took me to the traditional birth attendant...I could not effectively disagree with them because I did not have any money and I was young.” (Woman from Masaka, age 20)

Another woman recounted that after being in labor for over 24 hours, an elderly village member recommended she be taken to the hospital. However, her mother-in-law replied that: *“She was not going to sell land to take her daughter to the hospital, and that if she was to die, then she better do so.” (Woman from Masaka, age 23)*

Traditional Birth Attendants: The majority of the women were attended by TBAs at some point during labor, and about half of the women reported that the TBAs used their hands to check if the cervix was dilated and then tried to help them deliver. In fewer than half of the cases, the TBAs inserted their hands inside the woman to check the baby. Upon realizing that they could not assist delivery, TBAs typically referred the women to a health facility, but this was often after several hours of labor.

In Soroti, a young woman was upset with the care she received from her mother-in-law and two birth attendants. She described that they massaged her and pushed their hands into her vagina and tried to pull the baby out, but in vain: *“Three people tried to deliver me [at home]. My mother-in-law tried first but failed and then she sought help. She called for a TBA who also failed. She then sought help from another TBA. In all, my mother-in-law, the first and second TBAs all failed.” (Woman from Soroti, age 17)*

Facility-Based Providers: In general, the care provided depended on the type of facility. The majority of the women who sought help at the health center or dispensary level reported that these providers examined and referred them to other facilities. These sites were not equipped to deal with emergencies, and referrals were made when attending staff realized they could not help the women. At hospitals, nearly all of the women said that the providers’ main role was to help deliver the baby either via caesarean section or instrument delivery.

Transport Costs Incurred

Transport costs incurred by women to reach health facilities ranged from US\$ 2,000 (\$US1) to US\$ 80,000 (\$US46). Of the 58 women who mentioned incurring transport costs, fewer than half said this expense affected their ability to reach a service delivery site.

The means of transport varied greatly. The types mentioned included car, public taxi or bus, motorcycle, bicycle, ambulance, stretcher, and a wheelbarrow. Twenty women reported having to walk to service sites during their labor. Women also described other transport-related problems that led to delays:

“We moved on foot up to the bus stop, but it took us too long because I could only move a bit...Even before we left my mother had to first sell a goat, and getting a willing buyer wasn’t easy. Then when we got to the taxi stand, we had to wait one hour to get to the nearby health center.” (Woman from Masaka, age 19)

Another woman related that the car her husband had hired broke down on the way:

“We hired a car. It was very costly—Ushs 60,000 (\$US34)—for the journey to the hospital. The car broke down along the way and the driver went on foot to search for a mechanic...My husband decided to hire another car, but had already fully paid the first driver, who would not refund a shilling. The mechanic took nearly three hours.” (Woman from Masaka, age 21)

Delivery Costs Incurred

Thirty-eight women mentioned delivery-related costs. Of these, fewer than half incurred some type of delivery fee. The average amount reported was UShs 46,000 (\$US26). The lowest fee mentioned was UShs 7,000 (\$US4), while the highest fee reported was UShs 185,000 (\$US106) for a caesarean section at a private hospital. Four women mentioned paying providers in kind—with chickens, goats, or a half a bar of soap—instead of cash.

Opinion of Care

About half of the women were not satisfied with the care they received, because they were not treated well or were not treated in a timely manner. One woman from Soroti described her experience upon arriving at a hospital:

“The nurses checked me. They advised that I might not have normal delivery. That it would be by operation... but the doctor was not at the hospital. They tried to reach him but I had to wait for another 24 hours before the doctor came to carry out the operation.” (Woman from Soroti, age 19)

A second woman from Soroti had to go to three separate medical facilities in search of blood necessary for her operation. She said: *“The care was not good because I wasted so much time running from one hospital to another searching for blood.” (Woman from Soroti, Age 29)*

Another woman recounted how a midwife told her to sit and wait until she had finished doing her laundry:

“[Then after about 30 minutes] the midwife admitted me, checked me, and assured me that I would deliver before 1:00 pm. At 1:00 pm without delivery, the midwife instructed me to push but to no avail. It approached 4:00 pm and still nothing came out, yet the pain was so much. I had neither eaten nor drunk anything. I felt the baby literally kicking my heart and awkwardly positioned. I again passed out. On regaining consciousness, the midwife checked me and later told me the baby had died! While there, I passed out 4 times. When the delivery did not take place before 1:00pm, she should have referred me immediately to the hospital. But she carelessly waited until 4:00pm when I passed out.” (Woman from Masaka, age 23)

However, this woman added that: *“The care [at the hospital] was so nice as I was immediately attended to and rushed to the operating theatre. Medics were readily available. This made me feel I was important and respected.”*

Indeed, nearly all of the women were satisfied with the care at their final place of delivery because the facility had saved their life and/or their baby’s life or because staff identified the problem they were experiencing. One woman from Masaka described her experiences at a health center: *“The care was good because the midwives attended to me quickly and they were very kind hearted. All women were treated kindly.” (Woman D from Masaka, age unknown)* Another woman from Soroti reported on the quality of care she received at the hospital: *“The health workers did everything they could at a lightning speed to save my life.” (Woman from Soroti, age 21)*

Case Study 3: Fear of Abuse Leads to Reluctance to Seek Timely Care

The story of one young woman from Kasese, aged 18, shows how fear of abuse from health providers may contribute to women's reluctance to deliver in facilities. In this case, the mistrust of providers led to the reluctance of women and their families to seek care outside of the village, with tragic consequences.

Her labor began at home in the middle of the night. Her husband's aunt, who was a TBA, checked the woman to see if she was ready to deliver, and asked if she wanted to deliver at home or at the hospital. However, her relatives warned that if she went to the hospital too early, the nurses would scream and order her to stop pushing. The fear of abuse scared the woman about going to the hospital unless she was sure she couldn't deliver at home.

By the second day of labor, the woman was only experiencing sporadic contractions. She realized that she could not deliver at home, and that there was no other choice but to go to the hospital. Finally, her husband and aunt agreed and took her to a hospital on her third day of labor. The trip by vehicle took another hour. Upon reaching the hospital, the woman was left to wait for a further three hours until staff decided that she needed an episiotomy. By this time, the baby had died.

Although the woman expressed disappointment with the lack of urgency of hospital staff, she said that it was the fear and pressure from her family and the TBA that delayed her delivery. The woman said she would have gone to the health center had she known that the nurses do not verbally abuse pregnant women as she had been warned about by her in-laws.

Looking Back Now, What Would the Women Have Done Differently

Nearly all of the women who answered this question (34 respondents in total) indicated that they would have gone to the hospital earlier, while a minority said they would have set aside money for an emergency. One woman tearfully said: *"I wish I had money and the energy. I would have not waited for my husband to take me to hospital."* (Woman from Soroti, age 37)

Other responses included staying closer to the place of delivery, utilizing ANC services, following advice given during ANC visits, and not using traditional medicine. Two women also indicated that if they had known their pregnancy would result in fistula, they would have had an abortion. The first woman asserted: *"If there were women's groups teaching mothers on the risks of pregnancy, I would have been able to detect a problem and aborted to avoid what I have experienced."* (Woman from Soroti, age 37)

The second woman would have opted for a hysterectomy, or if she had known about family planning methods would have chosen an abortion:

"I wish I knew that I was going to have another pregnancy. I would have gone to remove my uterus at the hospital. I thought I had finished producing because I had spent five years without conceiving. I thought I had reached menopause... When I asked fellow women what family planning method they used, they discouraged me from using any. If I could do things differently I would have opted for an abortion." (Woman A from Soroti, age 45)

Family Reactions to the Delays

It was clear from a number of statements that family members felt guilt for not having done something differently. For example, during a focus group in Soroti, one mother said that her daughter sustained fistula because her family took her to a TBA despite the fact that she was very young, only 15 years of age. This girl tried to deliver for two days with the TBA. One father expressed remorse for not helping his daughter: *“I wish we had any information about what causes fistula. We did not even know that such thing could happen during delivery. We wished we had this information.”* (Focus group discussion with family members, Soroti)

A couple of family members blamed the TBAs for delays. One woman’s mother lamented the reluctance of her daughter’s TBA and mother-in-law: *“They should have advised her husband to rush her to hospital. Three days was too long. Moreover, the hospital is only 12 kilometers away.”* (Focus group discussion with family members, Soroti). She also related that the TBA had refused to give her daughter a referral even after she fell into a coma.

One set of parents blamed the nurses at the hospital, saying that if the nurses had called the doctor in time for the operation, they could have saved the baby’s life. Their daughter had waited three days at the hospital before the nurses and the doctor attended to her. The father added:

“Most women today get this condition from the hospitals because our doctors have developed the ‘I don’t care attitude towards the patients’. Doctors, like other civil servants, have become corrupt and are only after money which is why they are delivering most mothers by an operation.” (Focus group discussion with family members, Soroti)

E. Perceptions of Causes of Fistula

Women’s Perceptions of Causes of Fistula

During the in-depth interviews, women were asked for their views on what caused their fistula. Table 6 summarizes their responses. Some individuals reported multiple reasons.

Nearly all of the women believed their fistula was caused by an injury to the bladder due to the clinical procedure or instruments used during delivery, or by the doctor accidentally piercing the bladder. As one woman from Soroti explained: *“This problem happened to me at the hospital when the doctor was pulling the baby out of my womb. It seems the machine the doctor was using scratched my bladder.”* (Woman B from Soroti, age 45)

Fewer than half of the women also believed that the traditional birth attendant caused their fistula. A second woman related: *“Probably I got fistula when the TBA was pulling out the child. I felt her fingers prick inside of my vagina.”* (Woman from Soroti, age 29)

However, fewer than half of respondents attributed their fistula to delivery delays, including not accessing services quickly enough or not getting prompt care at health facilities. Home delivery, the baby being too big, and the mother being bewitched were other causes noted during interviews. One respondent stated: *“My partner thinks that the problem is from my parents’ home. He thinks that my ancestors cursed me.”* (Woman from Soroti, age 25)

Problem tree exercises confirmed findings from the interviews but women cited additional reasons at these sessions. These reasons included: living far from the hospital, the use of traditional medicines to speed up labor, not having the means to go to hospital, reluctance to deliver at a facility due to cultural beliefs, being short, malnutrition, and early marriage or sexual debut.

Table 6: Women’s Perceptions of Causes of Fistula

Perception of Cause of Fistula	Number of Women
Doctor accidentally pierced bladder/Injury caused by clinical procedure or instruments used during delivery	64
Delay in delivery	29
Injury caused by TBA	20
Big baby	8
Use of fingers during delivery	7
Bewitched	6
Home delivery	6
Pregnancy	4
Too young	2
Economic reasons	2
Baby pressed bladder	2

Family Members’ Explanations of Fistula

In discussions with family members, hospital procedures and providers’ mistakes were the reasons cited most frequently for fistula. One father from Soroti stated unequivocally: *“There is no doubt about the fact that the doctor accidentally cut her bladder during an operation.”*

Delivery delay was the next most common explanation. The family of one woman from Masaka described the lack of access to facilities that leads to life-threatening delays:

“Because they are delayed in the village, they have no access to the health facilities where they attended ANC. In the villages, this work is left to traditional birth attendants who are not reliable. So, by the time the attendants fail, the situation is beyond control. That’s why when they send them to hospital the baby inside is dead and the bladder damaged. The woman is also very much exhausted.”

Table 7: Family Members’ Perceptions of the Causes of Fistula

Perception of Cause of Fistula	Number of Respondents
Hospital procedure	12
Provider mistake	12
Delivery delay	10
Too young	7
Mistake by TBA	5
Bewitched	4
Unsupportive husband	4
Poverty	3
Lack of transport	3

Table 7 summarizes family members’ responses. Other causes cited for fistula included: the young age of women giving birth, the mother being bewitched, mistakes by TBAs, economically and socially unsupportive husbands, poverty, and lack of transportation to health facilities. One mother from Soroti remarked: *“Many people associate it with witchcraft. They say if a woman*

steals from somebody's garden when she is expecting and steps on witchcraft, she is likely to get the condition."

Community Members' Perceptions of Causes of Fistula

Eight focus groups were held with community members, and, in every group, participants were aware of fistula and knew women in their communities with the condition.

The reasons for fistula most commonly reported were the woman being too young and lack of skill/mistakes by TBAs. One older community member from Soroti observed that teenage girls were the most vulnerable to fistula, and a participant from Kasese remarked: *"Other women do not get fistula because they are lucky, they get pregnant at the time when their bones and body are mature enough to bear the pregnancy."*

Table 8: Community Members' Perceptions of the Causes of Fistula

Perception of Cause of Fistula	Number of Focus Groups Mentioning Perception
<ul style="list-style-type: none"> ▪ Too young ▪ TBA 	8
<ul style="list-style-type: none"> ▪ Home delivery ▪ Hospital procedures ▪ Provider mistake ▪ Delivery delay 	7
<ul style="list-style-type: none"> ▪ Sharp fingernails ▪ Lack of economic and social support from family ▪ Poverty 	6
<ul style="list-style-type: none"> ▪ Sexually transmitted diseases 	5
<ul style="list-style-type: none"> ▪ Produced too many children ▪ No ANC ▪ Big baby ▪ Bad luck 	4
<ul style="list-style-type: none"> ▪ Family planning pills ▪ Short and narrow-waisted women ▪ Too much intercourse ▪ Witchcraft 	3
<ul style="list-style-type: none"> ▪ Sex during menstruation ▪ Lack of education or information ▪ Poor transportation or roads ▪ Nutrition ▪ No quality care at hospital ▪ Far from health facility 	2
<ul style="list-style-type: none"> ▪ Women don't keep their bodies clean ▪ Born with abnormality ▪ God's plan ▪ Working too much 	1

On the issue of traditional birth attendants, another woman from Kasese commented: *"Other women get fistula because they deliver in the village and are helped by untrained and unskilled people who pretend to be traditional birth attendants."*

Other reasons frequently cited by community members included home delivery, delivery delay, hospital procedures or mistakes made by providers, and lack of support and resources for women which restricted their access to healthcare services.

A diverse range of other perceptions and misconceptions on the origins of fistula were also noted during discussions. Sexually transmitted diseases, too many children, no antenatal care, bad luck, witchcraft, use of family planning pills, and too much intercourse were all cited as causes of fistula. Table 8 details the perceptions of community members.

Local Healthcare Providers' and TBAs' Knowledge About Fistula

Four focus groups each were held with local healthcare providers and with traditional birth attendants. The providers and TBAs who took part demonstrated knowledge of fistula, and in all but one group, participants knew of women in their communities with the condition. However, providers in Masaka reported that they were aware of a woman with fistula in a nearby community, but that fistula did not occur in their own community.

No providers reported experiencing fistula when helping women deliver, but two groups mentioned that women tend to hide their fistula and so may difficult to identify. One provider in Soroti said: *“Most women with fistula starve themselves before they go to public places, so we cannot know which patients have fistula.”* This comment additionally highlights the practice of women with fistula of not drinking water at times to avoid leaking urine in public, or avoiding food so they will not leak feces. Only one TBA mentioned that she had seen fistula when helping women deliver.

Providers in each group described their practice of routinely referring women with labor complications to hospitals with trained professionals and the equipment necessary to prevent fistula. A midwife in Soroti said: *“Those that need operations, I refer them to Soroti Regional Referral Hospital immediately to avoid them having fistula or losing their babies.”* Another provider in the same district explained that on occasions he had used his own money to fuel the ambulance to take women to the main hospital.

During discussions, providers cited multiple causes of fistula. The most common factors advanced were a lack of money and women having children at young ages. Participants reported that women and their families are often unable to access services as they cannot obtain transport or pay delivery fees. A nursing aid in Soroti also remarked on women’s lack of nutrition during pregnancy: *“Most pregnant women can’t afford to eat well during pregnancy. When the time comes to push the baby, they are very weak.”*

A provider from Masaka described the risk of fistula for young women: *“Some of the women who get fistula are those who get pregnant at an early age, below 20. At that age, the body is not well prepared to bear the rigors of pregnancy, labor, and delivery.”* A health worker from Soroti elaborated on how girls who become pregnant at school are particularly vulnerable to fistula:

“Many girls feel guilty and fear to be laughed at by their peers. Others fear harassment by midwives and therefore prefer to keep at home. In most cases, parents do not bother to help these girl-mothers to seek proper medical care. Instead, they are treated as outcasts not worth spending on anymore after dropping out from school.”

For traditional birth attendants, the most common causes of fistula cited were delivery delays and providers’ use of instruments. Other reasons mentioned included having a fat baby, women who have too many partners, and women whose pelvic bones are too small.

A nursing aid in Soroti also described that women in general are reluctant to go for health services unless they suspect a problem with their labor or delivery. She said: *“The influence of culture is deeply rooted in society, which makes utilization of health services generally low among women. Others even have the false belief that medical officials harass them.”*

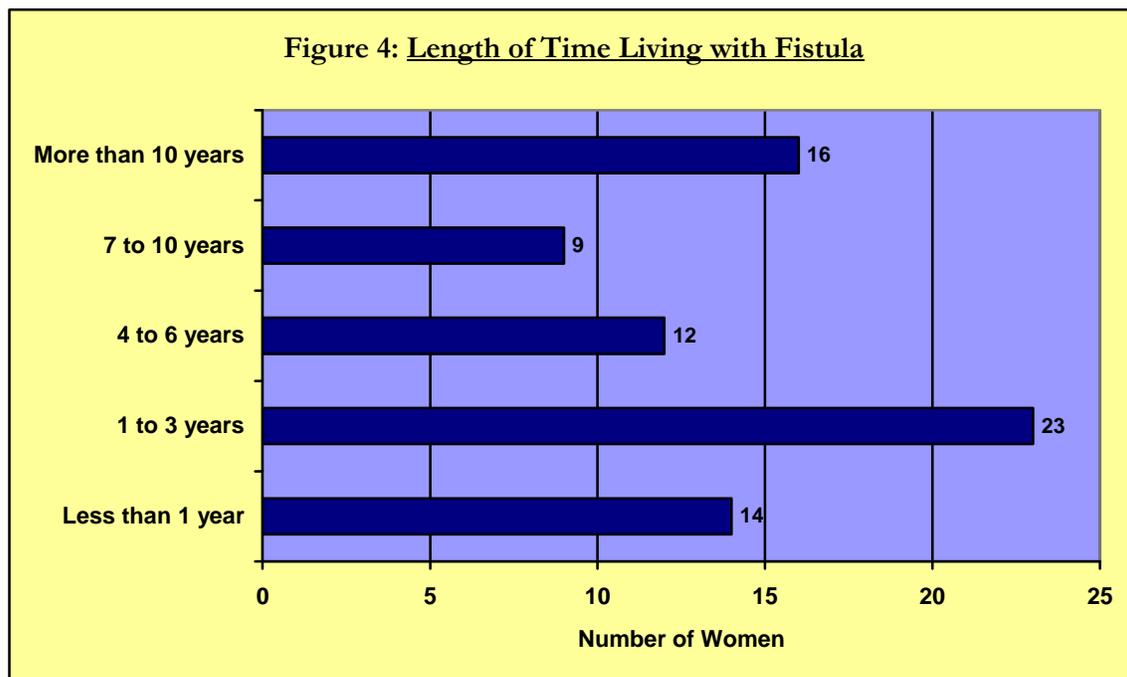
Other risk factors for fistula frequently cited by providers included delivery delay, not delivering at a hospital, delivery by TBAs, and lack of knowledge of pregnancy, labor, and delivery. A psychiatric nurse from Soroti observed: *“In our community, people have more confidence in the TBAs than hospitals. They only come to hospital when they have problems with delivery.”* Another health worker from the same focus group said:

“Some women get fistula because they delay to go to hospital either due to ignorance, poverty, or because of fear that they will be laughed at by older and experienced mothers. Illiterate women are vulnerable to fistula because they don’t get information on safer motherhood.”

F. Impact of Fistula on Women

Years Living with Fistula

The study recorded a vast range in the length of time that participants had lived with fistula. The shortest time was one month; the longest span was 52 years.



At the time of the study, nearly all of the women had been living with fistula for over a year, and half of the respondents had the condition for over 4 years. Sixteen women had endured fistula for more than 10 years. Figure 4 summarizes the periods that women had lived with this debilitating condition.⁹

⁹ Information not available for two women

Health Impact

A majority of women said that fistula had detrimentally affected their health and well-being. Most of these women reported suffering sores, inflammation, and dehydration. A minority also mentioned chronic sickness, constant wetness, and pains in the uterus, back, head, or abdomen. Others cited loss of appetite and weight, fever, irregular menstrual periods, and the inability to walk normally. One woman described: *“Presently, I am allergic to sanitary pads. I feel inflammation within my sore genitals. I am generally weak and dehydrated with occasional dizziness.”* (Woman from Masaka, age 68)

Another woman related her chronic poor health since sustaining fistula: *“My life has changed so much because I now fall sick so often, and have backache, headache and lower abdomen pains. The padding burns me every day and I cannot walk easily.”* (Woman from Masaka, age 32)

In addition, a majority of women reported an adverse impact on their stress levels related to the condition. They suffered constant anxiety and depression, and expressed many deeply held fears, such as losing their current partner, not being able to have more children, never being able to marry again, or never being repaired. Of these women, fewer than half also reported a significant loss of appetite and weight. One young woman spoke of her mental trauma and loss of weight: *“I’m suffering from self-pity. I feel I’m useless. I’m now thin because of worries.”* (Woman from Soroti, age 22)

A second woman related her fears that she would never have children or never recover: *“I did not know how I would deliver other children in that condition. I did not have hope that I would ever recover because I had not known of any woman with fistula that was repaired.”* (Woman from Soroti, age 17)

Another participant deeply regretted the opportunity she had lost to secure an education: *“My life has changed drastically because I cannot go back to school. I’m always regretting why I ever went into a relationship when I was still at school.”* (Woman from Soroti, age 21)

In one extreme situation, a woman attempted suicide as a result of the harsh treatment of her family. After two years living at home, her brother and sister-in-law started isolating and abusing her, saying she would spread her incurable disease to their children. The woman went twice to a well with the intention of throwing herself in. She then bought and swallowed sleeping pills, but fortunately did not die. She explained: *“Maybe they did not give me sleeping tablets. I slimmed to the size of a stick with a pool of thoughts especially those of terminating my life of suffering and isolation.”* (Woman from Masaka, age 23)

Fewer than half of the women also indicated that they could not access health services post-fistula because they no longer had sufficient income, or because they were ashamed of going to facilities. One woman explained that her monthly income decreased from 10,000 to 3,000 shillings as a result of her fistula. She related that she could no longer afford medical services, further undermining her well-being: *“Even when I get malaria, I now prefer using herbal medicine that is locally available.”* (Woman from Soroti, age 25)

Other women described the shame they feel and the disdain they encounter when attending service sites. One young woman said: *“Whenever I go, I am harassed by fellow patients, even by doctors, and told that I smell. Despite this, I force myself to go because there is no one to do it for me.”* (Woman D from Soroti, age 18)

Discussions with family members, community members and local healthcare providers all confirmed the adverse impact of fistula on women’s health. Participants described the painfulness of the condition due to chronic sores/rashes and bodily aches, as well as the other deleterious effects on the woman’s health, such as dehydration, fatigue, weight loss, difficulty walking, and their increased susceptibility to opportunistic infections.

A majority of family members also explicitly mentioned the stress and depression suffered by women living with fistula, compounded by the loss of their babies, their isolation, and their belief that there was no cure for the condition. One family member from Masaka said:

“After three years with fistula, she lost hope of recovery. [This] and other people’s views made her stay at home only to wait for her death.”

Impact on Marital Status

The majority of women who were married at the time they sustained fistula were subsequently divorced. Of these separations, nearly all were for reasons related to their fistula. Moreover, nearly all of the women who were unmarried when they sustained fistula remained single. Table 9 details the marital status, pre- and post-fistula, for all of the women interviewed.

Table 9: Impact of Fistula on Marital Status¹⁰

Marital Status Pre-Fistula	Marital Status Post-Fistula	Number of Women
Married	Married	22
Married	Divorced ¹¹	41
Not married	Not married	7
Married	Divorced, remarried without treatment	2
Not married	Married after treatment, divorced	1

In tears, one woman from Masaka recounted:

“After my husband came to know about this problem he got another wife, while I was still in hospital. My husband regarded me in a different light and asked me why such a problem happened. I had already become disgusted and did not answer. He walked away and, since then, I have never seen him.” (Woman F from Masaka, age unknown)

Another woman depicted the shame that her boyfriend felt for her condition: *“Ever since I got fistula, I am so worried. I also think this is the reason why my boyfriend has refused to officially marry me. He prefers to skillfully come to my house at night and disappears before sunrise.”* (Woman from Soroti, age 35)

A third woman described perceptions in her community after her husband divorced her:

“[The community] knows he divorced me because of fistula and married another woman. Many people praise him as a hero for the bold step to marry another woman when still a young man. But a few people associate him with bad luck and say even his second wife will end up with fistula.” (Woman from Soroti, age 19)

¹⁰ Marital status for three women unavailable

¹¹ Two cases of divorce were not related to the fistula and the cause of one divorce is unknown.

This close connection between fistula and divorce was echoed during focus group discussions with community members. In all groups, participants mentioned divorce as one of the impacts of the condition. As one participant in Soroti explained: *“It [fistula] can cause divorce because of the shame and smell that the man cannot tolerate.”*

Stigma and Isolation

Nearly all the women with fistula experienced isolation. Either they isolated themselves due to feelings of shame or were cut off from normal participation in their communities as a result of stigma surrounding the condition. They lacked self-confidence to participate in public activities—such as funerals, weddings, community meetings, and church services—for fear of wetting themselves and smelling badly in public, or they were not welcome to attend. One woman described her exclusion from village activities:

“I stopped joining all social events at the village. My weak mother used to delegate to me, but I can no longer help her. People who knew about the problem never wanted to eat with me. Anything to do with associating with other people like taking care of others, attending village council meetings, I feel I cannot manage them because I know people do not believe in me. They do not regard me as their fellow person. I deserted village meetings knowing that I cannot contribute to decisions. Even weddings, I could not attend them. I only watch as others have fun. I stay at home with my mother because she could not leave me there alone.”
(Woman C from Masaka, age unknown)

A majority of women mentioned not being able to attend religious gatherings, while others reported attending but sitting outside the church or mosque: *“As for prayers, I go there but I only stand outside. I don’t want to sit lest I become wet and people see me. I stand out when my pad gets wet and I return home even if mass is still going on.”* (Woman from Masaka, age 19)

Women also described not being able to receive visitors or eat with others, going very early to fetch water, and no longer having community members and friends visit them. One woman explained: *“I go for water as early as 6:00am before any woman is there. In fact, people do not know where I get water from.”* (Woman from Soroti, age 29)

A woman from Masaka sadly related her separation from family life: *“I could no longer share meals with my family. They put cold food on a plate, and I had to collect it myself and eat alone. But when medics attended to me and I recovered a bit, we started sharing the room and meals.”* (Woman F from Masaka, age unknown)

While another woman expressed her shame and isolation even from close friends: *“I do not even visit my friends because I fear to let them know about my condition. I think that when they begin to smell urine from me, they will know. I have concealed this problem from many people because it will bring big shame to my husband.”* (Woman from Soroti, age 21)

Fewer than half of the women also reported being insulted and ridiculed by others in the community, which made these women isolate themselves. One woman recounted the ridicule she experienced and the abiding loneliness of her life totally secluded from others:

“I live alone because my father said that he cannot tolerate my smell and expelled me from his house. I stay in the kitchen. Since all my other sisters and brothers live far away, I stay there alone. My partner also never took me for marriage when I got this problem. So I am miserably lonely most of the time. I am unable to talk with community members because most

of them abuse me. They curse me that I smell and even call me names like 'ever-wet', 'urinator', and 'ever-flowing'. I can't even go to social gatherings like parties, prayers, or meetings. I fear smelling in front of people and being wet, even at home. I am always indoors or hide in the banana plantation all day. I don't want people to see me." (Woman from Masaka, age 32)

During focus group discussions, family and community echoed the women's statements on the social and emotional impact of living with fistula. They commonly reported that the women experienced isolation, shame, rejection, and ridicule. One family member in Masaka said: *"She cannot participate in social gatherings like weddings, prayers, funerals and other social functions. She is wary of wetting herself and becoming a public ridicule. This makes her a social outcast. A wedding can be in the village and everybody goes there but her."*

Economic Impact

The majority of women said that fistula had affected their ability to work. Only a minority of respondents were able to work as they had before. Reasons cited by women for their reduced capacity to work included the debilitating health effects of the condition as well as the smell resulting from the continuous leaking of urine and/or feces. Table 10 summarizes participants' responses. One woman described her limitations as a result of her injury: *"I do not do heavy work. I wash clothes, sweep the courtyard, cook, but I cannot do any work in the garden because of my painful lower limbs and backache." (Woman D from Masaka, age unknown)*

Another woman explained: *"I cannot dig enough food for my family like I used to do. I also spend a lot of my time washing myself and clothes. Instead of waking up at 6:00am to go to the garden, I waste an hour or two cleaning myself." (Woman from Soroti, age 35)*

In other cases, women were fired from their jobs, could not get work, or were unable to conduct income-generating activities due to community stigma towards them. One woman related: *"I was a shopkeeper but I am no longer working there. [The shop] was some distance away from home and because of leaking urine I left the job." (Woman from Masaka, age 21)*

The majority of women also reported having no income they controlled themselves, and about half indicated that they could no longer provide for themselves and/or their families. One woman described her family's deteriorating economic circumstances as a result of not being able to work: *"For the whole period with fistula, I've not done any development activity to generate money. I do not dig as before. This means we shall not have enough food to eat soon. It is now expensive for my husband alone to run the family." (Woman from Soroti, age 29)*

Women with fistula also incurred significant expenses to keep themselves clean every day and to pay for treatment. One woman stated:

"A lot of money is used to buy soap, sugar and cloths for pads. This has contributed to my family's poverty. We had a shop that ran out of stock as the family struggled to meet expenses. It is only my husband and children who do most of the work. Our situation has generally worsened; we are poorer than before." (Woman A from Masaka, age unknown)

Overall, fistula led to an abrupt reduction in women's sources of income, and to their dependence on others. One woman poignantly expressed: *"I am not able to fulfill other needs because I am physically weak and psychologically tortured. I do not have any money. I depend on my aunt." (Woman from Masaka, age 33)*

Table 10: Impact of Fistula on Women’s Capacity to Work

Impact on Work	Number of Women
Can’t work as before	24
Don’t do much work	16
Working as before	14
Can’t dig on farms	12
Fired from job	12
Can’t conduct income-generating activities	12
Unable to care for children	7
Can’t lift heavy things for fear of urine leaking	7
Can’t find a job	6
Can’t sell beer because of smell	6
Can’t work with others because of smell	5
No longer resourceful	4
Depending on others	4
Impaired	3
Able to take care of herself	2

Focus group discussions with family and community members reiterated the negative economic consequences for women with fistula and their families. One government official in Soroti stated: *“Fistula is expensive for women. They have to buy soap for washing their dresses and for bathing frequently if they are to keep clean and avoid smelling.”* (Focus group with community members, Soroti).

Another community member described fistula’s impact on women’s ability to work: *“It’s difficult for these women to do developmental activities, like business, as people fear to buy from them.”* (Focus group with community members, Soroti).

Case Study 4: Robbed of Income and Independence

The story of a young woman from Masaka, aged 21, illustrates how fistula robs women of their health, income, and independence.

Before suffering her fistula, the woman earned money as a shopkeeper. With this income, she supported her grandmother and some orphaned grandchildren who lived at home. She also assisted a number of other orphans from her village.

She used to control her money, buy things for the household, and was even working to construct her own home. However, the shop was some distance away, and she had to leave the job because of leaking urine. The condition robbed her of her own livelihood as well as the means to support her grandmother. Her hopes and plans for the future were dashed.

The woman was also unable to access health services because she was not working, and could not afford to purchase sanitary pads to manage the leaking as these were too expensive. She was forced to use cloths which burned her skin but there was nothing else she could do. Now the grandchildren must support her by fetching water from a nearby tap so she can bathe and wash her clothes frequently.

Impact on Education

A minority of women specifically mentioned having to drop out of school due to their pregnancies and not being able to return after sustaining fistula. One woman sadly related: *“I left school and I don’t do any work because I am always sick. My peers are now in Senior Five and this hurts me so much.”* (Woman from Masaka, age 18)

G. Impact of Fistula on Families

Economic Impact

Expenses for treatment and for the basic items needed for daily management of the woman’s condition were the most significant costs borne by families. The following quote illustrates just one woman’s experience: *“Ever since I suffered fistula, poverty continues to attack us. We spent much of our time raising the UShs 100,000 (US \$50) required for the repair in Kumi Hospital.”* (Woman from Soroti, age 17)

Another described the burden of ongoing costs to manage her condition: *“My family has been affected in many ways. First of all, I use a lot of money buying soap and Vaseline. Most of the family’s money is used catering for me.”* (Woman from Soroti, age 21)

In addition to direct expenses, families were often affected by the loss of the woman’s capacity to work at home, on the farm, or in income-generating activities. Therefore, the remaining family members had to take on this additional work or forgo the income the woman previously contributed. Moreover, another member of the household was often needed to assist the woman or accompany them for treatment, resulting in further financial loss. One woman explained how this problem had severely affected her whole family: *“This problem has tortured my family in many ways. My mother has left working because of me and she sometimes fails to eat. My sisters and brothers have also been equally bothered.”* (Woman D from Masaka, age unknown)

Another woman from Masaka described her family’s precarious economic circumstances and told the research team that all eight of her children had to drop out of school:

“As I am regularly sick and have constant backache, I cannot do my duties efficiently. I have a big family of 8 children to feed but I cannot cultivate as I used to do which has caused food shortages. I also have no job to earn a living because I spent three and half months in hospital and my shop collapsed during that period. Now, I cannot fully meet the needs of my family and all of my children have dropped out of school due to lack of school fees.” (Woman A from Masaka, age unknown)

Other women described that their families had spent savings set aside for expansion of their agricultural activities, and in several cases, women reported that their children were financially contributing to their care. Please also see the “Fistula Repair” below for further detail on the substantial costs incurred by families in seeking repair.

Case Study 5: Loss of Health Brings Economic Hardship

An elderly woman from Masaka, aged 68, described that fistula greatly limited her ability to work. Her story illustrates how fistula brings economic hardship and forces women to rely heavily on family members for support.

The woman related that she was chronically sick and remained at home most of the time. Even ordinary household tasks—washing clothes and dishes, and cleaning the house—were extremely difficult for her.

Without work, she is no longer the breadwinner for the family; no longer able to raise any income to assist her family. Indeed, she relies heavily on a daughter who lives nearby and her other children to provide money for food and her everyday needs to cope with the leaking, such as pads, soap, and paraffin. The woman used to grow beans and ground nuts but cannot manage farming work, so is now forced to buy these staples. Sometimes, her daughter must also remain at home to look after her, so her daughter's capacity to work is restricted as well.

The woman said her fistula had led to endless medical bills for treatment, and due to her weakened health status, she gets malaria frequently. Her children have to buy drugs for her, and transport to the hospital is also very expensive.

Emotional, Social, and Psychological Impacts on Family Members

The majority of women indicated that their families suffered from stress and worry arising from their condition. One woman described her mother's sadness at her lost opportunity to obtain an education: *"My family feels so bad about my problem because I was still young and their expectation of me as a school girl is not what I am now. My mother especially is always crying whenever she sees my peers going to school, while I am at home leaking urine."* (Woman from Masaka, age 18)

Another woman related her family's abiding concerns: *"My family sympathizes with me sincerely. They really feel bad to see my urine leaking like this. They had hoped I would bear and bring children and happily live in marriage. Now all that is no more."* (Woman from Masaka, age 23)

Fewer than half of the women also indicated that family members faced ridicule or endured negative community gossip. Some families became socially isolated. One woman shared: *"[My family] do not eat with other people and they no longer attend social events. My children are also stigmatized by the community. They are mocked and made fun of. People shout at them that their mother urinates on her bed and yet she is a mature person [not a baby]."* (Woman from Masaka, age 28)

In another case, a woman's mother had to tolerate constant pressure and questioning from the community about her daughter.

"Some people came to our home saying sorry to my mother because they knew that fistula is irreversible and cannot be treated. This has further worried her as they are doing it non-stop. When I see them coming, I hide myself inside the house until they leave. Sometimes they bother my mother so much by asking her why it is that her daughter does not come out of the

house. She sometimes tells them I am not around. Others have asked: 'Do you not get problems because of her at meals or at night while sleeping.' She replies no, but honestly my situation has become unbearable to everybody at home." (Woman D from Masaka, age unknown)

Another woman's children were also badly affected by other community misconceptions about fistula: *"Initially many people despised my children and they even thought that some of them would inherit my condition. My two girls had problems settling in their marriages and my two sons also met difficulties convincing their wives that they would not get my fistula."* (Woman from Soroti, age 70)

H. Coping with Fistula

Women's Coping Mechanisms

Various coping mechanisms were used by the women to manage their fistula. Fewer than half of the women mentioned the importance of strict hygiene, cleanliness and padding. One woman related:

"At first, I hesitated to join groups of people ... until my husband encouraged me by asking: 'For how long shall you keep back and not interact with other people? Be courageous, pad yourself and go to your friends'. However, I only became used to visiting people after seven years. And still, whenever I go, I have to return soon before wetting the pads." (Woman A from Masaka, age unknown)

One young woman described how keeping clean became a significant and time-consuming part of her life: *"It is a difficult life and don't know whether I will get over it. I have to bath from time to time and I have to wash the clothes daily. If I don't keep myself clean, I smell a lot."* (Woman from Soroti, age 17)

A few women also mentioned that they cope with fistula by being courageous, ignoring other people's comments, praying and going to church, doing exercises, and eating less. One woman said: *"My doctor told me to do exercise, and I think that is why I managed to visit some of my friends."* (Woman from Masaka, age 21)

Fewer than half of the women also told the research teams that they coped with their fistula by seeking treatment. These experiences are detailed in the "Fistula Repair" section below.

Family members confirmed many of the same strategies used by women with fistula, including frequent bathing and washing clothes, constant use of sanitary padding, and treatment for the condition. The brother of one woman in Masaka remarked: *"Until death, she will continue to seek treatment until healed."*

However, several family members mentioned isolation as one coping mechanism. For example, the aunt of a woman in Soroti explained: *"I think she isolates herself from friends as one strategy to overcome the problem. Sometimes, she preoccupies herself by making mats and tablecloths."*

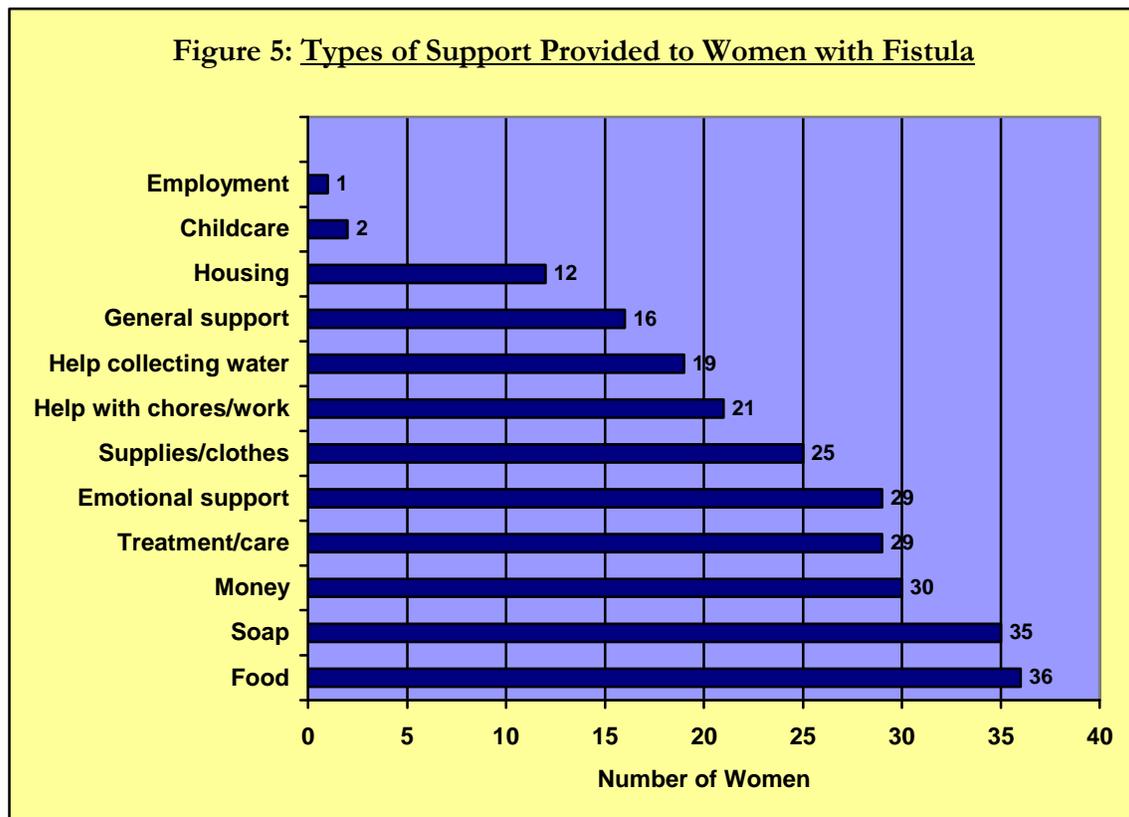
Impact of Water Scarcity

A minority of women reported difficulty accessing or collecting water, as illustrated by this respondent: *"Unfortunately, carrying a small amount of water can use up what little energy I have. There is no helper at home yet the water requirement is high for laundry, cooking and bathing. So at times I pay young men to fetch 2 jerry cans for us."* (Woman from Masaka, age 38)

Moreover, in areas where water supplies were scarce, women with fistula and their families had to allocate what little water they collected between the consumption needs of the family (for drinking, cooking, etc.) and the needs of the woman for bathing and washing her clothes.

Support Structures

Nearly all of the women were supported by at least one person in their family or community. Only four women did not receive any support or did not mention receiving support during their interviews. However, this high incidence of support may be a function of the study’s recruitment methods which may not have identified and included more isolated women with fistula. Figure 5 summarizes the types of support provided to the women interviewed.

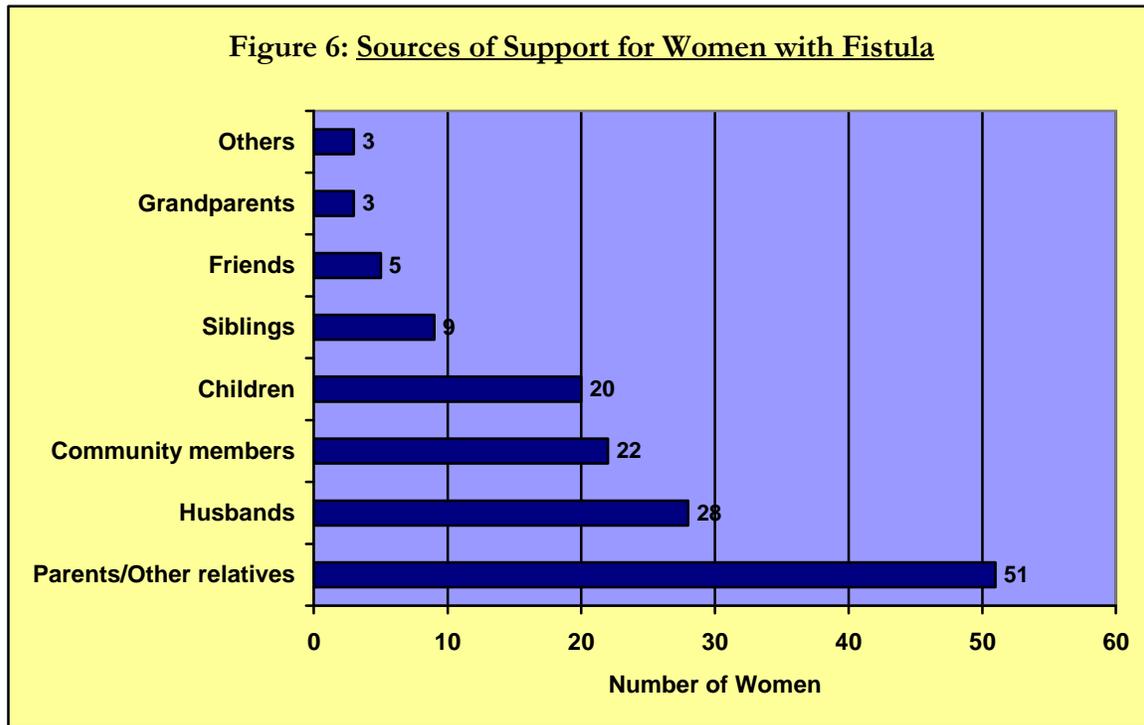


The types of support most frequently offered were food, soap, and money. One woman recalled: *“In the first stages of my fistula problem, just after I had been discharged from hospital, I received assistance from the community in the form of money, foodstuffs, and fruit for a month.”* (Woman A from Masaka, age unknown)

Several women also received help to seek treatment from a traditional healer or at a facility, while others described the emotional support of family members and help with their chores and work, as the following quote illustrates: *“My father has so far sold his only cow and a goat taking me for repair and maintaining me in Soroti hospital.”* (Woman from Soroti, age 19)

Figure 6 depicts the different sources of support mentioned by the women interviewed. By far the most frequent sources cited were parents and other relatives, such as aunts and uncles. A woman from Masaka explained:

“My family gives me help, especially my mother. She buys me soap and clothes and food. She has stood with me from the time I got fistula up to this day. Even here at the hospital, she is the one who nurses me. I also got some support from the community members. They paid me for casual work like digging, which I used to buy soap. It is only a small amount of money but it is helpful to me.” (Woman from Masaka, age 19)



Family support appeared to reflect the woman’s overall relationship with her family, and the majority of women reported positive relationships. One woman said: *“I live with my brothers and sisters who easily cope with me. I can prepare meals, which they partake. We share the house and they do not insult me. They know I am their relative whether healthy or sick.” (Woman from Masaka, age 23)*

Another woman demonstrated how her family did not blame or abandon her for sustaining a fistula: *“Instead, they sympathized with me. They thought that the machine the doctor used accidentally cut my bladder.” (Woman from Soroti, age 17).*

Of the 22 women who stayed married after fistula, the majority received support from their husbands. In general, spouses helped their wives with chores, such as washing, cooking, fetching water, and taking care of the children. Others addressed basic needs, such as getting soap, and several women expressed how their husbands provided them with emotional support and encouragement. A woman from Soroti related: *“I do domestic work like digging and keeping children but I fear to go to the well. I think that urine may leak into the well accidentally while I draw water. So it is my husband who goes to the well. He understands my problem. He listens to me and avoids any nonsense.”(Woman from Soroti, age 27)*

Community members were mentioned as additional sources of support. In Soroti, a woman described the moral support she received from her community: *“In most cases, they encourage me to be strong hearted. When I was in the hospital for repair, they used to pray for me to get well.”* (Woman from Soroti, age 19)

One woman told the research team how a neighbor informed her about where to go for fistula repair:

“Before you came, my neighbor had informed me of the announcement made by Kitovu Hospital about the imminent treatment of fistula patients. She pleaded for me not to lose this chance. However, I had not yet secured the means of reaching the hospital. Overall, community members do not treat me badly. Although, I fear to interact with them, they usually visit me.” (Woman A from Masaka, age unknown)

Unfortunately, fewer than half of the women mentioned negative family relationships as typified by the experience of a young woman in Soroti: *“My uncles threw me out of their homes even before many of the people in the village learned of my condition. Instead of sympathizing and giving me support, they were the first to chase me out of their houses.”* (Woman D from Soroti, age 18)

A few married women also did not receive any support from their husbands. In some cases, husbands neglected their wives, were involved in other relationships, or treated the women badly because they blamed them for the fistula. One respondent sadly explained: *“My husband has lost his love for me. He has even neglected me. His temper is now very high. Whenever he talks to me, he is always backbiting.”* (Woman B from Soroti, age 18)

I. Fistula Repair

Use of Traditional Medicine

A minority of women used traditional medicine to heal their fistula, often at substantial cost. One woman related extensive and expensive periods of treatment: *“My father took me to one witchdoctor for 6 months. When I failed to heal, he took me to another witchdoctor where I spent another 8 months, also in vain. In all, my father paid US\$ 200,000 (\$US114), 3 cows, and 3 chickens to witchdoctors.”* (Woman B from Masaka, age unknown)

A second woman told the research team that her parents had sold two bulls to pay for local herbalists and witchdoctors (Woman from Soroti, age 25), while a third respondent was taken to a traditional healer and stayed for a full year to receive treatment (Woman from Masaka, age 30).

Seeking Fistula Repair

The majority of women had sought fistula repair or were seeking fistula repair at the time of interview. Only three had been successful in achieving repair. Table 11 summarizes the treatment history of women participating in the study.

Of those who had sought repair at a healthcare facility, around half had gone to two or more sites. One woman had attended sites on seven occasions seeking appropriate treatment. Table 12 gives a summary of the number of times women had sought repair.

Table 11: Women’s Treatment History¹²

Action	Number of Women
Sought repair at healthcare facility	30
Sought assistance from traditional healers	10
Sought repair at healthcare facility and from traditional healers	6
Unclear where repair sought	1
Did not seek repair	13

Table 12: Number of Times Women Sought Treatment/Repair

Number of Times Women Sought Treatment/Repair	Number of Women
Once	13
Twice	5
Three times	6
Four times	3
Six times	1
Seven times	1
Unclear	6
Money stolen before woman could seek repair	1

These women and their families sacrificed immense amounts of time and money seeking help. Funds were needed not only for treatment, but also for transportation to service sites, and for food while in hospital. Money was often raised by selling land and livestock, driving families further into poverty. However, in many cases, these expensive efforts were in vain. One woman indicated that “I was admitted [to the hospital] for repair but I had no money to [eat in] the hospital for three weeks” prior to the surgery. (*Woman A from Soroti, age 45*)

A minority of the women had also not sought any type of repair services mostly because they lacked money for the surgery. Others did not know where to go, feared discrimination by providers, or feared smelling while traveling to, or waiting for, treatment. Table 13 summarizes the reasons given for not seeking repair.

One woman related how it was nearly impossible to access treatment without funds: “*There were as many as 200 cases of fistula and some of these patients had waited 5 months without treatment because they did not have the colossal sums of money the doctors were asking for.*” (*Woman E from Masaka, age unknown*)

Another woman from Soroti explained that she could only access services only they were free of charge: “*Unfortunately even in government hospitals, if they prescribe treatment and I’m asked to pay, I have walk away because I have no money.*” (*Woman from Soroti, age 21*)

¹² There was no mention of fistula repair in ten interviews and it was unclear whether four women had sought fistula repair.

Table 13: Reasons for Not Seeking Repair

Reasons for Not Seeking Repair	Number of Women
Did not have sufficient funds	9
Did not know where to go	2
Embarrassed to sit in taxi with other people when going for treatment	1
No one to look after house and children	1
Fear of discrimination by doctors and fear of leaking while waiting in long queues for attention	1
Informed by community there was no cure for fistula	1

Case Study 6: Multiple Attempts to Seek Repair

A 19-year-old from Masaka described repeated attempts to get treatment over the two-year period following her traumatic delivery. Her story illustrates the extraordinary determination of many women and their families to seek fistula repair despite the immense obstacles faced in affording and accessing timely and quality care.

When the woman was discharged from hospital following delivery, she was instructed by her doctor to return after two months for repair. However, when that time came, she could not afford to go back. Her mother-in-law said she had no more money, and that she had already spent enough on her while delivering.

So the woman went to her mother for help. Eventually, after four months, her mother raised 60,000 shillings by selling two goats and took her to a government hospital. This site was nearer and treatment was free unlike the mission hospital where she had been referred by her original doctor.

She was admitted to the government hospital and waited to see a doctor for two days. When the doctor finally came he checked the woman and told her that her bladder had been damaged and required surgery to fix. She waited for another month before being operated upon.

Unfortunately, upon regaining consciousness following the surgery, her mother told her that she had been fighting and kicking her legs everywhere. This split the fistula open once more and, despite another month in hospital, the woman returned home still leaking.

After another year at home, she could no longer tolerate the problem. A friend told her about a surgeon who could repair fistulas. This time her mother sold land to raise 100,000 shillings, and they went to yet another hospital. However, the nurses at the facility explained that this surgeon was private and charged a minimum of 300,000 shillings. So again the woman went back home miserable as she could not afford this fee.

Finally, a friend referred her to a second mission hospital for treatment. Her mother sold another piece of land for transport and upkeep at the hospital. However, she related that there were other women with fistula in her sub-county who could not come for repair because they lacked transport.

Case Study 7: Fourteen Years of Suffering

In this narrative, a 32-year-old woman from Masaka with both vesico- and recto-vaginal fistulas describes her struggle over 14 tortuous years to have her fistulas repaired. Despite repeated costly attempts to secure treatment, all of her efforts and the sacrifices of her family were to no avail.

Three months after delivery, the woman's father forced the man who made her pregnant to raise money to treat her fistulas. The man raised US\$ 30,000 and her father took her to a mission hospital. Here, the nurses sat her in salty water 3 times a day and gave her tablets. However, after 2 weeks, the woman's condition had not improved and the US\$ 30,000 had been used up on medical bills and food. So she was discharged and they went home.

Another month passed and the woman could no longer tolerate the problem. Her father was also much disturbed by her condition, so he sold a cow for US\$ 70,000 and took her to a government hospital. Here, the doctor prescribed tablets, injections, and the salt water treatment again. But after one month stool and urine were still leaking, and the US\$ 70,000 was exhausted from the transport costs and medical bills. In addition, the woman could not eat well and had lost a lot of weight. So the doctor discharged the woman and told her to go home to gain strength.

After 3 months at home, she had regained some energy, and once more her father sought treatment. This time, he sold a piece of his land for US\$ 200,000 so they could travel to a bigger hospital in another district. There, the doctor just examined the woman and told her to return the following month for treatment. However, her father had no more money for the return journey and was tired of going from hospital to hospital without success.

So the woman sat at home for three more years until her aunt sent for her. Her aunt had heard that some doctors near to her village could treat fistula. So the woman traveled to her aunt's home village. There she stayed for one year. At the end of that year, they went back to the first government hospital, as her doctor had suggested 4 years before, but still without success.

Ten more years passed. Then, in 2005, a friend came with news she'd heard on the radio that some white doctors were working to repair fistulas at another mission hospital. The friend also reported that the treatment was free; the woman just had to get there. The woman told her father, but he replied that he had no more money to waste. So she sold some beans she'd cultivated as well as both of her goats to raise the US\$ 30,000 needed for transport to the hospital. Finally, after 14 long years of suffering, she hoped that she would finally be repaired and could return home healed.

VI. Recommendations of Study Participants

Study participants—women with fistula, family and friends, community members, health care providers and TBAs—all offered their recommendations for preventing fistula. The women with fistula also offered their suggestions for managing the condition. This section provides a summary of major recommendations. For further detail on responses see Annexes 4 and 5.

A. Preventing Fistula

The majority of women interviewed recommended that families provide pregnant women with social and financial support, as well as transportation to health facilities. The need for women themselves to generate and save income for transport and delivery costs was also highlighted. One woman explained: *“They should have their own income generating activities to enable them to have control over finances and to save money to help them in case of an emergency.”* (Woman from Masaka, age 33)

Hospital-based delivery and attending antenatal care were other common suggestions to prevent fistula. In addition, community education on the importance of pregnancy and antenatal care, maternal complications, and hospital-based delivery was recommended. One woman stated: *“Women should stop delivering in villages. They should always deliver at hospitals with the help of trained health workers.”* (Woman from Kasese, age 19)

Family members also recommended hospital-based delivery, support for pregnant women (including transport to facilities), and community education as ways to prevent fistula, but also stressed referral of women to facilities in the event of complications as another means of prevention.

Community members suggested community education, women’s attendance at ANC, hospital-based delivery, and family support for pregnant women, but also identified the need for regular training of TBAs and for women to avoid marriage or pregnancy at a young age.

Local healthcare providers recommended family support, and the need for women themselves to save money for transportation and delivery costs. Other common suggestions were attendance at ANC, referral of women to facilities in the event of complications, hospital-based delivery, and staying close to health services. Providers also mentioned that women should not marry or bear children at a young age.

B. Management and Treatment of Fistula

The most frequently cited recommendation by women for managing fistula was to keep clean. Women also indicated that family, friends, and community members should not isolate women and should help them with their cleaning and treatment needs. One woman remarked:

“Women with fistula mostly need support because it requires one to be clean all the time. Families and communities should develop the spirit of helping women with fistula, financially, emotionally, and socially. We need to be reassured that we are still useful despite our bad condition.” (Woman from Soroti, age 25)

Another common recommendation was to seek treatment, and the words of one woman offered light and hope for all women suffering fistula: *“Search for fistula specialists wherever they could be. Fistula can be cured if knowledgably treated.”* (Woman from Masaka, age 38).

VII. Key Findings and Recommendations

Obstetric fistula is a clear marker of how health and social systems threaten the capacity of women to deliver safely. While fistula presents as a medical condition, its true causes are grounded in women's acute socio-economic vulnerability which denies them access to timely and appropriate care. Underlying fistula, therefore, are its real determinants: the severe shortage of qualified health workers, the unavailability of roads and transport to facilitate emergency referrals, searing poverty that denies people cash to afford health care, and a lack of education regarding basic reproductive health and the complications of childbirth. More tragically, however, fistula is caused by the continuing and unabated acceptance that women naturally die in childbirth, or are left with devastating disabilities.

This study illustrates the social, cultural, economic, and medical complexities of obstetric fistula. The findings are based on the experiences and views of 82 girls and women living with fistula, 63 family members, 120 community members, 21 health workers, and 54 traditional birth attendants. Their perspectives provide vital information for policymakers, health workers, donors and communities on how to prevent fistula (and maternal mortality and morbidity generally), and how to support girls and women affected by obstetric complications.

The five major findings drawn from the research are listed below with accompanying recommendations:

Finding 1: Fistula is not only a problem for adolescent girls but for women of all ages.

Slightly more than half of the women in the study whose age was reported (35 women out of 68 respondents) were 19 years or younger when they sustained fistula, and the majority of respondents were on their first pregnancy. These findings indicate the potentially serious health effects of early pregnancy. It also highlights the need for girls and young women to possess the fundamental rights to determine freely when they will marry and when they will begin having children.

At the same time, slightly less than half of respondents (33 women) were 20 years or older when they sustained fistula, and fewer than half were on their second or higher pregnancy, indicating that fistula is not primarily a problem affecting young girls who are pregnant for the first time. While it remains vital to recognize the severe impact of fistula on adolescent girls, the findings expand on the widely held assumption that fistula predominantly affects very young women on their first pregnancy.

Recommendation 1: Public education on fistula, and programs seeking to prevent it, must target all women of reproductive age.

Health education and services should provide basic information on pregnancy and childbirth—including the risks of early pregnancy—for all women of reproductive age. Clients and their families should receive accurate and timely counseling on the danger signs of pregnancy and delivery. They must also be encouraged to have a birth plan in place as well provisions for handling emergencies, including transportation to a facility providing emergency obstetric care. Preparations are needed to ensure fuel for the vehicle, sufficient cash, and other resources required in an emergency.

Health workers need to be supported, through training and supervision, to provide this essential counseling, and services should be monitored to ensure the information is reaching clients. In cases of clients with fistula, the women and their families must also be given comprehensive information on the medical nature and cause of their condition to dispel any misconceptions about the condition and to enable them to access prompt and appropriate treatment.

TBAs also need to be informed about how fistula occurs and how it can be prevented and treated, since there were many misconceptions about fistula. Additionally, TBAs need to be informed about when and where to refer women in case of prolonged obstructed labor and other emergencies.

Finding 2: Neither antenatal or delivery care meet standards of professional service delivery.

Nearly all of the women in the study reported being given some type of tablets or medicine during antenatal care (ANC) visits, possibly iron and folic acid supplements or malaria prophylaxis, and a few had their blood pressure checked. Fewer than half received any type of immunization services, and only a minority of women reported that the health worker listened to the fetal heartbeat. No hemoglobin tests, urine analysis, syphilis screening, or voluntary counseling and testing for HIV were reported. Moreover, no counseling on risk factors and warning signs and symptoms during pregnancy were cited, and only three women were told anything related to delivery.

These findings contrast with Ministry of Health guidelines which call for, among other key tests and services: provision of iron and folic acid supplement, screening for pre-eclampsia and syphilis, encouraging voluntary counseling and testing for HIV, urine testing, immunization against tetanus, early case referral in the event of complications, and assistance with delivery planning.

With respect to delivery care, nearly all of the women were satisfied with the care they received at their final place of delivery, because the facility had saved their life and/or their baby's life or because staff identified the problem they were experiencing. However, about half of women reported they were not treated well or were not treated in a timely manner. In addition, nearly all of the women believed that the cause of fistula was provider's mistakes or hospital procedures, and family members cited these reasons most often as well.

Recommendation 2: Training for health workers on clinical skills, as well as on client-provider interaction, is critical to ensure high quality, professional ANC and delivery services. Supplies and equipment must be available to health workers, and supportive supervision instituted to monitor service delivery standards.

ANC services are a significant opportunity to provide women with education and counseling on pregnancy, labor, and delivery. In particular, the danger signs of pregnancy and labor (excessive bleeding, swelling of hands and legs, etc.) and the need for skilled delivery assistance should be emphasized to prevent fistula and maternal crises overall. Women should also be encouraged strongly to deliver in a health facility so they can receive emergency care promptly if needed. This life-saving measure is currently contrary to the norm in Uganda; only 40% of women deliver in a health facility and 42% of women deliver with the help of a trained health professional (UBOS et al., 2007).

The study is not able to confirm independently the reports of negligence leading to fistula, or abuse of patients at any point in the service delivery cycle. However, the negative experiences of women regarding care they received and the belief among many participants that the fistula was caused by providers requires a thorough investigation into the quality of maternity services. Similarly, focused efforts must be made to recruit more, qualified health workers to improve the extremely difficult working conditions that providers currently face. The combination of over-work and low morale with the absence of necessary drugs, supplies, equipment and supportive infrastructure that affects most health facilities can seriously undermine the attitude of health workers. Providers need training and support to enable them to offer quality care. Performance should be monitored and abusive health workers need to be accountable for mistreatment of clients.

Lastly, prevention techniques such as insertion of catheters for women who have experienced prolonged labor should be considered. The training and infection-control aspects of this measure would need to be carefully addressed, but such early management of fistula can enable up to 20 percent of fistulas to close without surgical repair, and an even higher percentage among small fistulas (Waalwijk, 2004).

Finding 3: Girls and women face multiple barriers in accessing adequate care during delivery, including life-saving caesarean section.

About half of the women in the study described constraints they faced when planning for facility-based delivery. The top three limitations were lack of money, high transportation costs, and high hospital costs. The majority of women did not set aside any funds for delivery expenses, principally because they were too poor to save money or because their families were unwilling to use financial resources for birth preparation. Other reasons for not setting aside money included cultural beliefs or the women had planned to deliver at home. Fewer than half of the women set aside funds for transport, and again a key reason was the cost.

In addition, two-thirds of the women faced multiple delays in reaching a facility with the necessary services to enable them to deliver safely. Inability to access transport was the most frequently cited delay. Participants reported that transport was unavailable or unreliable, road conditions were poor, or traveling at night was extremely difficult if labor commenced in the evening. Even among the sub-group of women in the study (about half) who specifically planned to deliver in a health facility and who set aside money for transport and other costs, they did not go immediately to the facility when labor started. They were similarly restricted by a lack of money or transport, and by insufficient knowledge about danger signs of labor.

Recommendation 3: Concrete strategies must be introduced to reduce the barriers to safe delivery, and to expand access to skilled intrapartum care, including caesarean section.

Available and accessible delivery services, including emergency caesarean section, will significantly reduce maternal mortalities and morbidities, including fistula. Study respondents consistently cited distance to facilities, lack of transport, and the cost of both transport and health care, as the major barriers to accessing timely care.

Therefore, Government authorities at all levels, together with health workers and communities, should institute realistic measures to eliminate these key barriers. Life-saving interventions could include emergency transport systems to ensure speedy referral to sites providing emergency obstetric care; monitoring the provision of free services (both official and “unofficial” fees and bribes) for delivery as per Government policy; establishment of selected additional facilities

providing caesarean section in the most under-served areas; and training of health workers to provide skilled maternal care.

In particular, urgent efforts are required to expand the availability of comprehensive emergency obstetric care (CEmOC), including caesarean section. According to the National Health Sector Strategic Plan, all Level IV Health Centers and above are required to provide comprehensive emergency obstetric care (CEmOC) including caesarean section, but a needs assessment by the Ugandan MOH found that only 5.6% of these facilities were sufficiently equipped to do so (UMOH, 2003). Universal CEmOC coverage is an ambitious goal, and likely not attainable in the near term given extreme shortages of skilled health workers and financial resources. However, selectively strengthening Level IV Health Centers and hospitals to provide CEmOC—starting with those in the most under-served areas of the country—could dramatically improve maternal survival rates by ensuring quality intrapartum care (i.e., management and care during labor and delivery). Increasing the availability of basic emergency obstetric care at Level III Health Centers and improving referral systems at all levels would be further critical steps towards reducing maternal death and disability in Uganda.

Finding 4: Fistula has severe, multi-faceted impact on affected women and their families.

The majority of women in the study who were married at the time they sustained fistula were subsequently divorced, and nearly all the women suffered isolation. The women stopped socializing or participating in public events for fear of wetting themselves, smelling bad, and/or due to their lack of self-confidence. In addition, the majority of women said that fistula affected their ability to work due to the health effects of the condition and the smell. In some cases women lost their jobs or could not get work because of the stigma associated with fistula. About half said they could not provide for themselves and/or their families as a result of not being able to work.

Families, too, were significantly affected by fistula, primarily due to the costs of treatment and for basic items such as clothing and soap. The majority of the women also indicated that their family members suffered from stress and worry about how the fistula affected the woman's life.

Nonetheless, while the stigma was profound, nearly all the women mentioned being supported by at least one person, usually parents or other relatives. The most frequently mentioned types of support were food, soap, and money.

Recommendation 4: Educational and advocacy programs are needed to reduce the stigma associated with fistula and encourage social support for girls and women living with the condition.

The stigma surrounding fistula and its negative impacts can be reduced as increasing numbers of people learn about fistula, know that it can be treated, and see women return home after repair. Broad-based educational programs about fistula can help to dispel negative myths about fistula and “normalize” the condition. In addition, consistent and reliable information on where when repair services are available can assist women to access treatment quickly and reduce the time they are forced to live with this highly stigmatizing condition. In particular, media outlets and other distribution channels that reach rural areas, for example radio and outreach through faith-based institutions, should be utilized.

Finding 5: Girls and women need fistula repair services that are available, accessible and affordable in order to get prompt treatment without incurring substantial financial and other costs.

At the time of study, nearly all of the women had been living with fistula for over a year, and half of respondents had the condition for over 4 years. Sixteen women had endured fistula for more than 10 years. About half of the women had sought fistula repair at a facility, and among these, around half had gone to two or more sites before receiving treatment. One woman had made seven different visits seeking appropriate treatment. A few of these women said they sought treatment at a facility, but were not being able to go back for the repair because of lack of money. At the time of the study, only three women had been successful in achieving repair. The obstacles cited by women in accessing repairs included the cost of treatment as well money for food and other expenses while in the hospital.

A minority of the women interviewed had not sought any type of repair services, primarily because they did not have sufficient funds to seek treatment. For the women who tried to access repair services, both they and their families sacrificed immense amounts of time and money in their attempts to get appropriate treatment. Money was often raised by selling land and livestock, driving families deeper into poverty.

Recommendation 5: Expanded access to fistula services is needed to reach those in need, and these services must be provided free or at minimal cost.

Referral systems managed by local authorities, communities and faith-based groups can arrange prompt transfers women with fistula to reach a facility providing repairs. But once a woman reaches the hospital, she must not be barred from care due to inability to pay. Given the poverty in which virtually all girls and women with fistula live, treatment must be provided free or at minimal cost. Ideally, the costs of transportation to the facility and back home should also be covered. Funding can be sourced from donors, district health budgets, or in-kind and financial support from faith-based institutions and community groups. Overall poverty reduction efforts, if effectively instituted, can also leverage additional resources for households to use in emergency situations such as obstructed labor.

In addition, there is a critical need for more surgeons and other health practitioners specifically trained in fistula treatment so as to expand the availability of repair and reduce the current long waiting times for surgery.

VIII. Conclusion

Reducing maternal mortality and morbidity in Uganda requires concerted action on the part of Government leaders and policy makers at the highest level, donors, health workers and communities. Robust policies and targeted, evidence-based interventions are urgently needed to reduce the barriers women face in accessing adequate obstetric care, to improve the quality of services they receive, and to ensure that women who suffer disabilities in childbirth, including fistula, are fully supported to recover lives of health and dignity.

The countries that have successfully managed to make motherhood safer have three things in common. First, policy-makers and healthcare managers were aware that a problem existed, knew it could be tackled, and acted on the information. Second, they chose comprehensive strategies: not just antenatal care, but intrapartum and post-partum care by skilled health professionals—midwives, nurse-midwives or doctors—backed up by hospital care. Third, they expanded access to these services to all child-bearing women (WHO, 2005).

Effective and efficient strategies are known to dramatically reduce maternal mortality and morbidity, and strong political will and commitment can make this happen. By safeguarding maternal health and well-being (and by direct association, newborn and child survival) the health, economic and societal benefits will be enormous, far outweighing any investments made.

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Annexes

Annex 1: Total Number of Participants by Research Activity and District

Research Activity	Masaka	Soroti	Kasese	Totals
In-depth interviews with women on the pregnancy, labor, and delivery resulting in fistula	30	30	16	76
In-depth interviews with women on experiences living with fistula	30	30	13	73
Problem trees with women with fistula	9	6	11	26
Problem trees with family members ¹³	35			35
Discussions with family members	42	14	7	63
Focus group discussions with local healthcare providers	2 ¹⁴	15 ¹⁵	4 ¹⁶	21
Focus group discussions with TBAs	8	30	16	54
Focus group discussions with community members		49	54	103
Freelisting and ranking with community members	17	49	39	105

¹³ Problem trees, focus groups, and freelisting and ranking exercises were not conducted in every site as the research teams were not able to recruit sufficient participants in all sites.

¹⁴ 1 midwife and 1 nurse

¹⁵ 2 nursing aides, 1 student nurse, 2 midwives, 2 laboratory assistants, 1 medical assistant, 1 clinical officer, 1 anesthetic assistant, 1 health visitor, 1 psychiatric nurse, 1 medical records registrar, and 2 positions not known

¹⁶ Positions unknown

Annex 2: Ministry of Health, Uganda: Goal Oriented Antenatal Care Protocol

(Important: Goals are different depending on the timing of the visit. 4 visits are aimed for in an uncomplicated pregnancy. If a woman books later than in the first trimester, preceding goals should be combined and attended to. At all visits address any identified problems, check the BP, and measure the Symphysis-Fundal Height (FSH)

	TRIMESTER	GOAL	TIMING OF VISIT	HISTORY TAKING	EXAMINATION	LABORATORY INVESTIGATIONS	HEALTH PROMOTION	ACTION
FIRST VISIT	First Trimester 0-16 weeks	<ul style="list-style-type: none"> -Patient assessment -Health education -Plan for delivery 	Anytime < 16 weeks	<ul style="list-style-type: none"> -Medical -Surgical -Obstetric -LMP -Confirm period of gestation -Contraceptive? -Date of conception? -STI -Social: smoking/alcohol/drugs 	<ul style="list-style-type: none"> -General exam -Vulva exam (speculum if indicated) -SFH (Symphysis-Fundal height) measurement -Abdominal exam -Vital observation *Mood *Evidence of trauma 	<ul style="list-style-type: none"> -Syphilis test (RPR) -Urine-albumen, glucose -Discuss STD/HIV AIDS -RTC/RCT for HIV -Syphilis 	<ul style="list-style-type: none"> -Address any problems -Involve husband in ANC -Draw up delivery plan -Future PP, FP, TL, condom use -Symptoms of miscarriage & PIH -PMTCT & VCT -Nutrition and hygiene -Infant feeding -ITN use -Danger signs 	<ul style="list-style-type: none"> -TT (UNEP) - Ferrous SO₄ -Folic acid -Treat incidental ailments -Dual protection for FP/HIV -Debriefing mother
SECOND	Second Trimester 16-28 weeks	<ul style="list-style-type: none"> -Action on abnormal lab results -TT -Exclude multiple pregnancy -Assess for signs of PIH -Check foetal growth -Exclude anaemia 	24-28 weeks	<ul style="list-style-type: none"> -Ask for problems -Date of 1st foetal movements -APH 	<ul style="list-style-type: none"> -BP -SFH -Abdominal exam— rule out multiple pregnancy 	<ul style="list-style-type: none"> -If BP > 140/90 -Urine albumen -HB 	<ul style="list-style-type: none"> -Address problems -Discuss laboratory results and need to treat partner -Symptoms of PIH -APH -PMTCT/HCT -ITN Use -Danger signs 	<ul style="list-style-type: none"> -TT - Ferrous SO₄ -Folic acid -IPT dose -Mebendazole -Treat incidental ailments -Dual protection for FP/HIV -Debriefing mother
THIRD	Third Trimester 28-42 weeks	<ul style="list-style-type: none"> -Check foetal growth -Exclude anaemia -Assess for signs of PIH -Review delivery plan 	< 36 weeks	<ul style="list-style-type: none"> -Ask for problems -APH 	<ul style="list-style-type: none"> -BP -Palm (conjunctival pallour) -SFH -Abdominal exam 	<ul style="list-style-type: none"> -If BP > 140/90 -Urine albumen 	<ul style="list-style-type: none"> -Address problems -Discuss labour/EROM -Discuss APH -Review delivery plan -Re-discuss FP -PMTCT/HCT -ITN Use -Postpartum care -Infant feeding -Danger signs 	<ul style="list-style-type: none"> - Ferrous SO₄ -Folic acid -IPT₂ dose -Treat incidental ailments -Dual protection for FP/HIV -Debriefing mother
FOURTH		<ul style="list-style-type: none"> -Check foetal growth -Assess for signs of PIH -Exclude abnormal presentation/lie -Review delivery plan 	> 36 weeks	<ul style="list-style-type: none"> -Ask for problems 	<ul style="list-style-type: none"> -BP -SFH -Abdominal exam -Check lie -Presentation 	<ul style="list-style-type: none"> -If BP > 140/90 -Urine albumen 	<ul style="list-style-type: none"> -Address problems -Discuss labour/Infant feeding -Review delivery plan -PMTCT/HCT -ITN use -Sex and postpartum care -Pap smear -Danger signs and cord care 	<ul style="list-style-type: none"> - Ferrous SO₄ -Folic acid -Treat incidental ailments -Dual protection for FP/HIV -Debriefing mother

Source: National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights, Uganda Ministry of Health, Reproductive Health Division, Department of Community Health, May 2006, p.49.

Annex 3: Delivery Trajectory from Initiation of Labor to Final Delivery

Number of Moves	No. of Women	Totals
Women making no moves		15
Labor started at home with TBA, delivered at home	12	
Labor started at hospital, delivered at hospital	2	
Labor started at home with mother-in-law, delivered at home	1	
Women making one move		23
Labor started at home with TBA, delivered at hospital	10	
Labor started at home with support from family/friends, delivered at hospital	7	
Labor started at home with support from family/friends, delivered at TBA's home	1	
Labor started at home with support from family/friends, delivered at health center	1	
Labor started at home with support from family/friends, delivered at mother-in-law's home	1	
Labor started at home, delivered at hospital	1	
Labor started in the bush with TBA, delivered at health center	1	
Labor started at the maternity house, delivered at hospital	1	
Women making two moves		26
Labor started at home with TBA, woman then went to health center, then to hospital	9	
Labor started at home with support from family/friends, woman then went to health center, then to hospital	5	
Labor started at home with support from family/friends, woman then went to TBA, then to hospital	6	
Labor started at home with TBA, woman then went to dispensary ¹⁷ , then to the hospital	3	
Labor started at home with TBA, woman then went to midwife, then to hospital	1	
Labor started at home, woman then went to health center, then to hospital	1	
Labor started at a shop, woman went home and got help from TBA, then to the hospital	1	

¹⁷ A dispensary is classified as a Level III health center, the lowest level of health facility where deliveries should be conducted.

Annex 3: Delivery Trajectory from Initiation of Labor to Final Delivery (cont.)

Number of Moves	No. of Women	Totals
Women making three moves		9
Labor started at home, woman then went to TBA, then to health center, then to hospital	4	
Labor started at home with support from family/friends, then went to TBA, then to health center, then to hospital	2	
Labor started at home with support from family/friends, then went to hospital 1, then to hospital 2, then back to hospital 1 ¹⁸	1	
Labor started at home with support from family/friends, then went to health center, then to TBA, then to hospital	1	
Labor started at home with support from family/friends, then went to health center, then to hospital 1, then to hospital 2	1	
Women making four moves		1
Labor started at home, then delivery trajectory was health center, TBA, health centre, hospital ¹⁹	1	
Women making six moves		2
Labor started at home with support from family/friends, then went to TBA, back home, private practitioner 1, back home, private practitioner 2, hospital ²⁰	1	
Labor started at home with family and friends, then went to the TBA, then back home, TBA, home, private practitioner, hospital ²¹	1	

¹⁸ The woman left the first hospital as staff informed her that the facility did not have her blood type. She then went to a second hospital, but they also did not have her blood type, so she had to return to the first hospital.

¹⁹ Woman was en route to a health center but she ran into a TBA, who convinced her to divert to the TBA's house for assistance

²⁰ Woman started her labor at home and then went to a TBA. She was advised to go to a health center, but returned home. The next morning, she went to the first private practitioner, but was uncomfortable with the midwife examining her vagina, so she went back home. After one day, she went to another practitioner, but she didn't like that they had to use an intravenous drip, so she walked out. Her grandmother then hired a car to take her to the hospital.

²¹ Woman started labor at home with her husband. In the morning, she went to a TBA. The TBA said the baby was not due and gave her tablets and told her to go home. The following morning the woman saw blood and went back to the TBA. She was again examined and told that the baby was still not ready and told to go home once more. The next day, she went to a private practitioner, and was referred to a hospital the following afternoon.

Annex 4: Participants' Recommendations for Preventing Fistula

Women with Fistula

Recommendation	Number of Women
Family should assist women with financial and social support and transport to health facilities	8
Women should work and save money for transport and delivery costs	7
Community education on importance of ANC, maternal complications, pregnancy care, delivery in hospitals, and managing fistula	7
Deliver in hospital	6
Attend ANC	6
Refer women with complications to hospitals/avoid delays	2
Stay close to health services	1
Improve quality of care	1

Family Members

Recommendation	Number of Groups Citing Recommendation
Family should assist women with financial and social support and transport to health facilities	4
Deliver in hospital	3
Community education on importance of ANC, maternal complications, pregnancy care, delivery in hospitals, and managing fistula	2
Refer women with complications to hospitals/avoid delays	2
Women should work and save money for transport and delivery costs	1
Attend ANC	1
Don't give birth or marry at a young age	1
Sex and family planning education in schools	1

Community Members

Recommendation	Number of Groups Citing Recommendation
Community education on importance of ANC, maternal complications, pregnancy care, delivery in hospitals, and managing fistula	6
Deliver in hospital	6
Attend ANC	6
Family should assist women with financial and social support and transport to health facilities	5
Don't give birth or marry at a young age	5
Regular training of TBAs	5
Improve roads/public transport	2
Get treatment for other illnesses such as STDs, malaria and anemia	2
Women should work and save money for transport and delivery costs	1
Don't give birth at a mature age	1
Sex and family planning education in schools	1
Avoid traditional medicine	1

Annex 4: Participants' Recommendations for Preventing Fistula (cont.)

Local Healthcare Providers

Recommendation	Number of Groups Citing Recommendation
Women should work and save money for transport and delivery costs	5
Refer women with complications to hospitals/avoid delays	5
Community education on importance of ANC, maternal complications, pregnancy care, delivery in hospitals, and managing fistula	4
Deliver in hospital	4
Attend ANC	3
Improve quality of care	3
Family should assist women with financial and social support and transport to health facilities	2
Plan place of delivery	2
Don't give birth or marry at a young age	1
Regular training of TBAs	1
Get treatment for other illnesses such as STDs, malaria and anemia	1
Urinate frequently during labor and/or insert catheter	1
Administer enemas	1
Avoid traditional medicine	1
Eat balanced diet throughout pregnancy	1
Avoid pushing during obstructive labor	1

Traditional Birth Attendants

Recommendation	Number of Groups Citing Recommendation
Family should assist women with financial and social support and transport to health facilities	4
Women should work and save money for transport and delivery costs	4
Refer women with complications to hospitals/avoid delays	4
Attend ANC	3
Don't give birth or marry at a young age	3
Regular training of TBAs	3
Stay close to health services	3
Deliver in hospital	2
Provision of food by family during pregnancy so woman can be strong	2
Community education on importance of ANC, maternal complications, pregnancy care, delivery in hospitals, and managing fistula	1
Improve quality of care	1
Don't deliver in the hospital because doctors can pierce the bladder	1
Families should encourage women to be strong and push the baby out	1
Consult with spirits	1
Don't give birth at a mature age	1
Avoid illness through pregnancy to be strong for delivery	1
Eat balanced diet throughout pregnancy	1
Limit food intake so baby is not too big	1
Stop adultery and polygamy which facilitate the spread of fistula	1

Annex 5: Women's Recommendations for Managing Fistula

Recommendation	Number of Women
Keep clean	65
Financial and social support from family, friends and community	62
Seek treatment for fistula	23
Persevere	18
Income (raise money for living/treatment)	7
Abstain from intercourse	5
Pray to God	2
Women should not isolate themselves	1
Women with fistula should educate young girls	1
Women with fistula should form support groups	1
Attend seminars on reproductive health and family planning	1
Do not waste money or time on traditional healers	1