OBSTETRIC FISTULA DIGITAL STORIES

Facilitator's Guide



Women Confront Fistula in Rural Uganda





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This facilitator's guide is designed to help those who wish to have conversations about fistula and to educate groups such as health care providers, women with fistula, community members, and policy makers. Specifically, this is a guide to facilitating discussions about digital stories made about 11 women with fistula in which they share how fistula has affected their lives. They recount hardships and celebrate achievements related to their daily struggles with pregnancy, loss, and relationships, as well as their search for safety, acceptance, and dignity. Our hope is that after viewing the digital stories and discussing them in detail, people will come away with a greater understanding of what causes fistula, how women can be repaired, and why community members, the health sector, and policy makers all have critical roles to play in prevention.

HOW THE DIGITAL STORIES CAME TO BE

In August 2007, EngenderHealth partnered with the Center for Digital Storytelling (CDS) Silence Speaks initiative and with St. Joseph's Hospital in Kitovu, Uganda, to coordinate a workshop for Ugandan women who had experienced obstetric fistula. The facilitators of the digital storytelling workshop adapted the traditional structure of the workshop to suit the language, literacy, and technology resource challenges in the rural district where the session was held. Once the 11 interested women who had experienced fistula were identified by hospital staff and invited to participate, they came for an orientation and to see some sample digital stories. They were given cameras to take home to capture photographs that might illustrate the context of their daily lives. Some days later, the four-day workshop began. Participants were asked to recount their stories in a group setting, and each woman's story was audio-recorded. Participants were also asked to create drawings to illustrate their experiences with fistula. Various group processes and activities were conducted during the workshop, to mediate language and cultural differences and increase the therapeutic aspect of the workshop.

The workshop facilitators, staff, and interpreters then worked with the women to edit their voice recordings and to assemble the digital stories using these recordings, the drawings and photographs provided by the women, and short video clips of the women. While editing was underway, the women visited the hospital where they had been treated and offered advice and support to women awaiting fistula repair. The workshop ended with a screening of the stories and testimony by participants about their increased sense of self-worth and their desire to speak out in their villages about fistula repair and prevention.



ENGENDERHEALTH

These digital stories were made possible through support to EngenderHealth from the U.S. Agency for International Development (USAID), which began to support fistula repair services in 2004 through the ACQUIRE and the Fistula Care projects. EngenderHealth is a leading international nonprofit organization working to improve the quality of health care in the world's poorest communities. The Fistula Care Project supports fistula prevention and treatment services in 11 countries. It emphasizes increasing access to quality fistula repair services, increasing awareness of fistula and its prevention, and strengthening the environment to support prevention and treatment. For further information about the Fistula Care Project, please visit www.fistulacare.org.

CENTER FOR DIGITAL STORYTELLING AND THE SILENCE SPEAKS INITIATIVE

The Center for Digital Storytelling is an international not-for-profit community arts organization rooted in the craft of personal storytelling. It assists youth and adults around the world to use media tools to share, record, and value stories from their lives in ways that promote artistic expression, health and well-being, and justice. The Silence Speaks initiative is an international digital storytelling initiative of the Center for Digital Storytelling that offers a safe, supportive environment for telling stories that all too often remain unspoken. They hold intensive workshops in which participants share and bear witness to tales of struggle and courage, resulting in digital stories. For further information about the Center for Digital Storytelling or Silence Speaks, please visit www.storycenter.org or www.silencespeaks.org.

LEARN FROM MY STORY: WOMEN CONFRONT FISTULA IN RURAL UGANDA

The accompanying disc, *Learn From My Story: Women Confront Fistula in Rural Uganda*, has a total of 11 digital stories, all by women who attended the workshop in Uganda. In each video, a woman recounts her experience with fistula and how it has affected her life. The women speak of loss, relationships, social challenges, financial constraints, and losing hope, yet they also speak of love, family support, starting over, and reclaiming their dignity. Their powerful and moving stories provide a unique perspective on fistula, from the point of view of women who have endured this devastating injury.

The disc also contains a piece called "Provider Perspectives," which is a series of clips from interviews of health care providers and program staff who work with women with fistula. These interview clips provide invaluable insights into the larger programmatic, social, and logistical issues around the prevention and treatment of fistula. This piece may be particularly helpful during trainings of health care providers. For more information on using this section in trainings, see the section below on *Tips for Discussions with Health Care Providers*.

FACILITATING DISCUSSIONS ON THE DIGITAL STORIES

The digital stories of women with fistula are a valuable resource for understanding the effect fistula has on the lives of women, their families, and their communities. These stories also present an opportunity to help people learn more about the causes, prevention, and treatment of fistula. This guide will show you, the facilitator, how you can run a discussion after screening each story, in which your group can reflect on the story and learn important lessons about fistula. Specifically, you will find guidance for how to facilitate conversations with women with fistula, community members, and health care providers.

Below are guidelines on understanding the needs of your audience, proposals about which stories to screen for a given audience, and suggestions for discussion questions, as well as a list of key messages from each story. You will also find tips for leading discussions with specific audiences. The introductory section of the guide concludes with a miniglossary containing a few terms that are important for you and your audience to understand.

Knowing Your Audience

The format for facilitating discussions will be the same regardless of your audience. However, the vocabulary that you use may vary, depending on the language and literacy levels of your audience. Please keep your audience in mind as you facilitate the discussion and as you share key messages. The messages are worded very precisely, so please be careful not to alter the meaning or content of the messages if you paraphrase them for your audience.

You may wish to start by asking whether the audience has heard about fistula and, if so, what they have heard. This way you can gauge their level of understanding or experience with fistula. To have a productive discussion, it is recommended that your group be no larger than 35 people.

Choosing Which Stories to Screen

Before sharing these digital stories, you should watch or read all of them and choose stories that you feel are most appropriate for your audience. The table below outlines general themes covered in each story and can help you decide which stories you would like to show. Showing a total of three to four stories at one sitting is ideal. More than this may make the session too long and may become repetitive.

	Rose	Federes	Mastuls	Kahara	4//en	Jane	/rene	Mary	Sifa	Medius	Silvia
Video length*	3:46	4:20	3:29	3:00	3:05	3:30	3:21	3:53	3:20	3:06	3:08
Antenatal care/birth plan							•			•	
Causes of fistula		•									
Community awareness	•		•		•	•			•		
Family support	•								•	•	•
Financial constraints	•		•						•		
latrogenic fistula						•					
Living with fistula			•	•			•	•			•
Myths and misconceptions					•						
Outreach efforts								•		•	
Pregnancy/delivery after fistula	•				•						•
Psychological consequences					•		•	•			
Reintegration									•	•	
Role of men					•				•		
Social stresses		•		•					•	•	
Success of fistula surgery			•	•							
Traditional beliefs/ practices		•		•	•		•	•			

^{*}Video length is represented in minutes:seconds. For example, 3:05 means three minutes and five seconds long.

Facilitating Discussions

It is suggested that you have a separate discussion after showing each digital story. The complete text of each digital story is provided in this guide. Some stories have a note in the guide immediately following the text of the story that explains certain clinical details that are unclear in the story. This note is provided for your

understanding, so that you may clarify the story for your audience. Please keep in mind that these digital stories are told by the women themselves, not by health professionals. Therefore, the medical facts in their stories are not always clear or completely accurate in regard to the duration, sequence, or causes of the clinical event. This may be due to the client's misunderstanding, recollection, perception, or interpretation of events. The clinical details we provide are therefore an estimate based on the woman's story. However, the value of these stories lies not in their medical detail, but in the fact that they are personal accounts of women's experiences with fistula.

Following the text of each story, you will find a series of discussion questions that are provided as a guide to help you facilitate a group conversation about the story. The questions are designed to steer the discussion toward important lessons that can be learned from that story.

The ORID Method

The *discussion questions* for each story follow the ORID method (Objective, Reflective, Interpretive, Decisional), which is a method for focused conversation that was developed by the Institute of Cultural Affairs. The ORID method consists of a series of four types of questions. The initial *objective* questions are meant to confirm facts and objective data about the story you've viewed. Next, the *reflective* questions invite the participants to share their imaginative, intuitive, and emotional responses to the story. The *interpretive* questions that follow are meant to elicit the sharing of experiences and individual meaning, to uncover the meaning, values, significance, purpose, and implications of the story. Finally, the *decisional* questions are meant to develop collective opinions or resolve that may lead to future action. You will notice that the discussion questions provided in the guide are grouped according to these four types.

Following the discussion questions, you will find a number of *key messages* for each story. Each of these messages brings out an important lesson that can be learned from the story. Some of these lessons may come up during your group's discussion. Otherwise, you will want to find a way to touch upon each key message, either during or at the end of the discussion.

You may find that prior review of the discussion questions and key messages for the stories that you choose to screen will help prepare you for the discussion.

Note: While most discussion questions and key messages are appropriate for all audiences, a few that are designated are most appropriate for use in discussions with health care providers.

Tips for Discussions with Women with Obstetric Fistula

When facilitating a discussion with women who have fistula, please be sensitive to the fact that some issues raised in the stories may be difficult for the women to discuss. Also, depending on their language and literacy levels, the wording of key messages may need to be adapted.

Tips for Discussions with Community Members

Depending on the language and literacy levels of your audience, the wording of key messages may need to be adapted.

Tips for Discussions with Health Care Providers

Please be sure to include the questions/messages marked when facilitating discussions with health care providers. Also, following the 11 digital stories on the accompanying disc is a section called "Provider Perspectives," which is divided into six segments—Inspiration, Prevention, Challenges, Fistula Care, Reintegration, and Program Impact (see table below). Each segment was pieced together from interviews with health care providers and program staff and contains important information that can provide some perspective to those who work with women with fistula. For example, the interviewees mention issues such as the importance of staying in school to increase the age at marriage, how counseling women with fistula can be very helpful, how women may face stigma even after their fistula is healed, how overall knowledge about prevention is very limited, etc. Altogether, these six segments run for approximately 17 minutes.

You might find it useful to watch this section and decide, based on time constraints and your specific audience of health care providers, whether you feel this section would be useful to screen. This guide does not have discussion questions or key messages for the Provider Perspectives section.

The last piece in the Provider Perspectives segment (called "Patient Stories, Provider Perspectives") is a 30-minute-long compilation of six digital stories, with excerpts from the provider pieces in between.

Title	Length*	Topic
Provider Inspiration	2:01	Staff and providers' motivation and inspiration and inspiration to do their work.
Prevention	1:57	Insight on how to prevent fistula from occurring.
Challenges	4:03	Challenges of maternal and obstetric care in Uganda.
Fistula Care	4:34	Importance of providing counseling and emotional support to fistula patients.
Reintegration	1:42	Issues of stigmatization, sensitization, and reintegration.
Program Impact	2:01	Overall impact of fistula programs.

^{*}Video length is represented in minutes:seconds. For example, 3:05 means three minutes and five seconds long



A birth plan is a type of proactive advance preparation that describes the shared roles and responsibilities of the woman, her partner, the family, the community, and the skilled birth attendant to identify and organize necessary resources (human, financial, logistical, and others). This preparation should allow her to address potential causes of delay at various levels throughout pregnancy, labor, delivery, and the postpartum period that may hinder timely access to appropriate normal and emergency care.

Skilled birth attendant

A skilled birth attendant is an accredited health professional—such as a doctor, midwife or nurse—who has been trained to competence in safe management of normal pregnancy, delivery, and the immediate postpartum period for mother and newborn, as well as early detection and management or referral for complications to the mother or newborn.

Skilled care

Skilled care refers to the process by which a pregnant woman and her baby receive adequate care during labor, delivery, and the immediate postpartum period., whether the place of delivery is the home, the health center, or the hospital. For the process to take place, the attendant must have the necessary skills (see definition of **skilled birth attendant**) and must be supported by an enabling environment at various levels of the health system. An enabling environment will include a supportive policy and regulatory framework, adequate infrastructure, equipment, and supplies, and an efficient and effective system of communication and referral.



At one time, I was worse off than you would believe. I almost died. I want you to learn from my story.

What brought my problems on was a pregnancy in 2004. We didn't have much money, so we decided to deliver in the village. I was very sad because the baby died. Afterwards, my belly got swollen because I could not pass urine. I also could not feel anything in one of my legs. Though I tried my best to lift it, I could not.

My husband saw this and took me to the hospital. I spent two weeks there, with tubes being put in and out. They were trying to remove the urine, but the urine leaked out instead. We were charged a lot of money, so we had to sell our bicycle to pay the bill.

People around me lost hope, and my in-laws almost chased me away. Even my mother, when she saw how sick I was, she abandoned me. But my husband was loyal and stayed with me.

Because I had trust in God, I hoped I'd be cured and could have more children. The doctors said I had three holes in my bladder, and this scared me. Later they said there was just one, and this gave me hope. But they said they couldn't operate because I had just delivered two weeks before. So they gave me medicine for my leg.

After two and a half months, I came back for an operation. The leaking was cured, and I could move my leg well. One year later, I had another baby. I had an operation for the delivery.

I ask all women who have the same problem to come forward and learn from me. I will be glad if they do.

DISCUSSION QUESTIONS

What is Rose's story about?

- What happened to Rose in the hospital?
- How was Rose treated by her various family members?
- When did financial constraints play a role in Rose's story?
- How does Rose's story end?

How did you feel as you heard Rose's story?

- Can you relate to parts of it?
- How do you think Rose felt when her urine continued to leak uncontrollably? And when her family abandoned her? How might her husband have felt?
- How do you think Rose's family members and community felt about Rose once she developed a fistula?

What can we learn from Rose's story?

- Could Rose have done anything differently at the time her baby was delivered?
- How would you want to be treated by your family and community if you were in Rose's situation?
- Can life take a positive turn for women with fistula?

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?



A woman should seek out skilled care as soon as she begins labor. Delivering a baby in the village without skilled care can lead to adverse outcomes, such as fistulas and foot drop, as in Rose's case.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

Immediate catheterization during or closely following obstructed labor and delivery can prevent or treat some fistulas.

Women with fistula have to deal with not just the loss of their baby (in most cases), but also with the many physical, social, and psychological consequences of having a fistula.

Cost can be a serious limitation both for women who want to give birth with skilled care and for women who need treatment for fistula or other conditions. Rose and her husband had to sell their bicycle to pay for her care.

Fistula surgery may or may not be performed immediately after a woman develops a fistula. The surgery will be delayed until there is no evidence of infection, necrotic tissue, or other contraindications. However, other treatment and/or support can be provided to a woman in the time leading up to surgery.

Even close family members may shun and abandon a woman with a fistula. Many are unaware of obstetric fistula or might harbor myths and/or misconceptions about their causes and treatment.

Women with fistula need the support of their families and communities. In Rose's case, her husband's support was instrumental in her receiving treatment.

After fistula surgery, women are encouraged to wait three to six months before resuming sexual activity.

Once a woman's fistula is repaired (closed), she is often able to get pregnant again and have a baby. Rose had a baby a year after her fistula was closed.

When a woman who has had a fistula is ready to deliver another baby, most surgeons recommend a planned cesarean section.

FEDERESI

My name is Federesi Nakalyango. I come from Sembabule District. I got pregnant in 1990. At the end of two days of pushing, the midwife told me I had failed to deliver and sent me to a big hospital. They operated, but the baby was already dead.

In the hospital, they had put in a tube [a catheter]. When the tube was taken out, I started leaking urine. Urine and feces were just coming out freely.

After two months in the hospital, I was allowed to go home. The feces had stopped dripping, but the urine continued. When I went back to my husband, at first he didn't know what had happened. But he saw that whenever I sat down, urine would come out.

I decided to separate our beds because of the leaking. My husband started tearing up small pieces of blankets so I could pad myself [soak up the urine]. He tried to get me some traditional medicines, but they failed to work, so he sent me home.

I tried my best to hide my problem so no one would notice. I was a choir member. Sometimes I was sent by the church to sing at workshops.

Sometimes I refused to go, trying to hide my problem. If I did agree to go, I wouldn't drink anything. I would pad myself to keep the urine from



leaking. Sometimes I had to go and wash my pads.

People used to tell me of different hospitals where I could get help for this problem. I could not believe my problem would be cured. Finally, I agreed to go to the hospital, and the very first operation was successful.

Women should not get scared, because after 15 years with the problem, I'm now OK. I thank God—he alone does all things.

DISCUSSION QUESTIONS What is Federesi's story about?

- What happened to Federesi during labor? And in the hospital?
- How was Federesi treated by her husband?
- How did having a fistula affect Federesi's involvement in church choir?
- How does Federesi's story end?

How did you feel as you heard Federesi's story? Can you relate to parts of it?

- How do you think Federesi felt when she leaked urine in the bed she shared with her husband? And how do you think she felt around members of her choir?
- Why do you think Federesi's husband eventually sent her home?

What can we learn from Federesi's story?

- Could Federesi have done anything differently when she went into labor?
- How would you want to be treated by your family and community if you were in Federesi's situation?
- Can life take a positive turn for women who have had fistula for many years?

How can we use what we have learned to:

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide quality care for women with fistula?



KEY MESSAGES

A woman should seek out skilled care as soon as she begins labor.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

Catheterization does not cause fistula; on the contrary, immediate catheterization can prevent or treat some fistulas. In Federesi's case, she may have had a fistula that did not become evident until the catheter was removed, or else her fistula might have developed while the catheter was in place.

A fistula is an abnormal opening (a hole) between the bladder or rectum and the vagina. Traditional medicines cannot cure this condition; surgery is necessary, unless the fistula has been treated by catheterization soon after delivery.

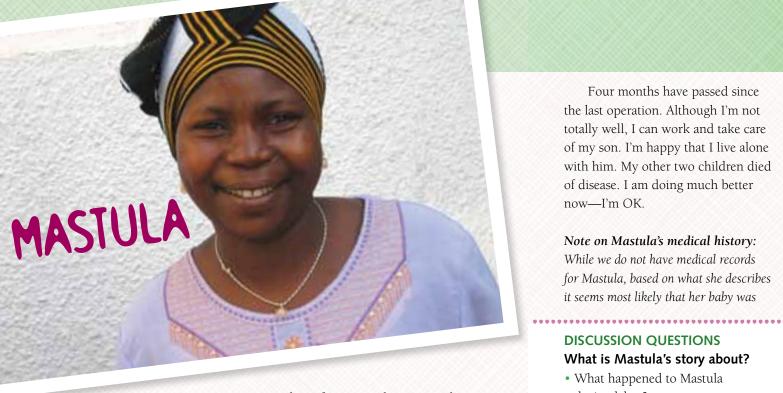
Despite lack of knowledge about fistula, family and community members may try to help using traditional means. When these efforts fail, the woman with a fistula may lose hope, as well as those around her. Community awareness about the causes of fistula and possible treatment for it can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts

Social situations can be stressful for women with fistula. People around them may be put off by the odor. Community members may also harbor myths and misconceptions regarding the causes of fistula. Sensitization of communities can help reduce stigma.

Especially in rural settings, there is generally no easy way to soak up leaking urine (such as with disposable pads). The dampness can lead to rashes and infection. Women are left to their own devices to find hygienic ways to soak up the urine to reduce their discomfort and odor.

Even if a woman has had a fistula for many years, the fistula may still be closed via surgery.





My name is Mastula Katushabe. I got a problem in 1999. I was pregnant and about to deliver, but I was in the village. I had successfully delivered three children there, so I thought it would be the same with my fourth. I spent four days with labor pains. I got very weak, and was taken to the hospital.

When I got there, I had an operation. The baby was taken out dead. This upset me so much. When the stitches were being taken out, my belly ripped open. I was badly off and didn't know what was happening. I was like dead [in a coma] for three months.

When I woke up, I realized I had no feeling up to my waist, and I was leaking urine and feces freely. They

took me for a second operation, but the stitches did not heal. I was getting worse every day. All my relatives left me at the hospital. I could not eat or drink—I was fed through a tube.

The doctor prescribed a drug that cost 18,000 [Ugandan] shillings, but my husband was not able to buy it. When he learned I was alive, he came and took me home without permission from the hospital. In the village, he tried to hide me under the bed and locked the room. I thought he was trying to kill me. He took me to the home of his other wife, who denied me food.

Then my husband took me to my family home, because he didn't want to care for me. I was operated on three times without getting well.

Four months have passed since the last operation. Although I'm not totally well, I can work and take care of my son. I'm happy that I live alone with him. My other two children died of disease. I am doing much better now-I'm OK.

Note on Mastula's medical history:

While we do not have medical records for Mastula, based on what she describes it seems most likely that her baby was

delivered via cesarean section once she arrived at the hospital. After this, it is probable that she developed severe infection, possibly even of the blood, which delayed the healing of her abdominal tissue and could also have led to her feeling limited consciousness for some time. Her second operation was probably to repair her abdominal incision, and the three additional surgeries she had after returning to her parents' home were most likely attempts at repairing her fistula.

DISCUSSION OUESTIONS What is Mastula's story about?

- What happened to Mastula during labor?
- What seems to have happened to her in the hospital?
- How was Mastula treated by her husband?
- How does Mastula's story end?

How did you feel as you heard Mastula's story? Can you relate to parts of it?

- How do you think Mastula felt when she was in the hospital? And how did she feel when her relatives left her alone at the hospital?
- What might have been going through Mastula's mind, given the way she was treated by her husband and his other wife?
- Why do you think Mastula's husband treated her as he did?

What can we learn from Mastula's story?

- · Could Mastula have done anything differently when she went into labor?
- What factors do you think could have changed the course of Mastula's story (in terms of community awareness or health care services)?
- What factors could have changed the course of her delivery and the manner in which she was treated by her husband and relatives?

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?

Pregnancy and labor are unpredictable. Women should always seek skilled care for labor and delivery. In Mastula's case, having three successful deliveries in the village did not guarantee a fourth successful delivery.

A woman should seek out skilled care as soon as she begins labor.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

Cost can be a serious limitation both for women who want to give birth with skilled care and for women who need treatment for fistula or other conditions. Mastula could not afford the costly medication that the doctor prescribed for her.

Most fistulas can be closed, but depending on the complexity of the fistula, it may take more than one surgery. Even after a fistula is surgically closed, the woman may experience residual incontinence.

Community awareness about the causes of fistula and possible treatment for fistula can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts. Had Mastula's husband been informed about fistula, he might have treated her differently.

The probability of surgical closure of a complicated fistula decreases with each successive attempt at repair. Therefore, the degree of complexity of the fistula is crucial to the decision as to who should operate and where. Complicated cases should be reserved for surgeons with a higher skill level, at a higher level facility.

Even if a woman's fistula cannot be repaired, she can lead a productive life. Despite the fact that Mastula is not totally well, she has not given up. She is still able to work and care for her young son.





I am called Kahara Dinah and I'm from Mbarara District. It was in 1986 that I spent three days in labor. On the third day, I delivered a dead baby. I felt bad because of giving birth to a baby that was dead.

Afterwards, I spent five days with pain in my belly. My elders told me to walk around. I felt like I needed to pass urine. When I passed it, it would not stop. After that, I began to have the problem of leaking.

I went to a traditional healer for five months but never got better. I didn't want to be around people. I felt ashamed because I was smelling.

For about five years, I lived at home, without doing anything. I used

the hides of animals [to soak up the urine], but they all stuck to my skin. People would run away—they didn't want to be near me.

In 2005, a friend took me to the hospital. They examined me and sent me to another hospital, where I was operated on and got better. I was sent home, but after a month, the leaking started again. I went back to the hospital for another operation, and now I'm OK.

These days I'm doing well, though I still have pain in my belly. I spent 21 years with my problem. In the past, I couldn't put on a dress. Now I can put on a dress and stand in front of you without shame.

DISCUSSION QUESTIONS What is Kahara's story about?

- What happened to Kahara during labor? And afterwards?
- How does Kahara's story end?

How did you feel as you heard Kahara's story? Can you relate to parts of it?

- How do you think Kahara felt when she was incontinent and lived at home doing nothing for five years?
- How do you think she felt when those around her ran away due to the smell?
- And how do you think Kahara felt once she was no longer leaking?

What can we learn from Kahara's story?

- Could Kahara have done anything differently when she went into labor?
 Or after delivering her baby?
- How would you want to be treated by those around you if you were in Kahara's shoes?
- Can life take a positive turn for women who have had fistula for many years?

How can we use what we have learned to:

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?



KEY MESSAGES

A woman should seek out skilled care as soon as she begins labor.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

After prolonged labor and delivery are over, if a woman has not already sought skilled care, she should. This is true for both the woman and the baby, regardless of the birth outcome.

Immediate catheterization during or closely following obstructed labor and delivery can prevent or treat some fistulas.

A fistula is an abnormal opening (a hole) between the bladder or rectum and the vagina. Traditional medicines cannot cure this condition; surgery is necessary, unless the fistula has been treated by catheterization soon after delivery.

Women with fistula have to deal with not just the loss of their baby (in most cases), but also with the many physical, social, and psychological consequences of having a fistula.

Especially in rural settings, there is generally no easy way to soak up leaking urine. Women are left to their own devices to find hygienic and effective ways to soak up the urine, thereby reducing discomfort and odor.

Social situations can be stressful for women with fistula. People around them may be repelled by the odor, and community members may also harbor misconceptions regarding the causes of fistula. Awareness-raising in communities can help reduce stigma.

Kahara's first fistula surgery left her dry for a month, but her leaking resumed for unknown reasons. This could have occurred due to a variety of factors—an infection that breaks down healed tissue, insertion of an object into the vagina, early resumption of sexual intercourse, or even a suture left behind that irritates the repair site.

Even if a woman's fistula is not closed during the first surgery, subsequent surgeries can still result in a closed fistula. However, even after a fistula is surgically closed, the woman may experience residual incontinence.

When a woman who has suffered from fistula undergoes surgery and is finally closed and dry, she may require support to regain her place in society. Efforts are necessary to reintegrate these women, as well as women who cannot be completely continent, back into society.

ALLEN



I am Allen Arinaitwe, and I'm from Mbarara. I have been pregnant four times, but two of the children died.

On my fourth pregnancy, I spent the whole night pushing but the baby didn't come. In the morning, my private parts were very swollen. I thought I was going to die with my baby still inside. They brought a car and took me to a local hospital.

When we got there, I was taken right away for surgery. They removed a baby who lived for an hour and then died. The doctor told me that if I get pregnant again, I should not try to deliver in the village.

After giving birth, I had no feeling in my lower body. I could not walk,and I leaked urine. I was given some medicine and my legs got better. But I still leaked urine.

I was scared, because I had very bad pain in my belly. I planned to kill myself but didn't try it. My brother who cared for me gave me some herbs. He said I should soak in them, but I didn't get well. What happened was that maggots came out from inside me.

When my brother saw the maggots, he took me back to the hospital. I arrived there, had one operation, and got well. I no longer leak urine.

My co-wives told me my uterus had been removed and I would never have another baby. But now, I thank God that I'm four months pregnant. I thank my husband; he looked after me during this problem.

DISCUSSION OUESTIONS

What is Allen's story about?

- What happened to Allen after delivery of her baby?
- What happened to her when she tried traditional cures?
- How does Allen's story end?

How did you feel as you heard Allen's story? Can you relate to parts of it?

- How do you think Allen felt when she had pain in her belly and her urine continued to leak uncontrollably?
- How do you think her brother and her husband felt?
- How do you think her co-wives felt about her operation?

What can we learn from Allen's story?

- What kind of effect did her fistula have on Allen's life and on her will to live?
- What kind of misconceptions (of her brother and her co-wives) played a role in Allen's story?

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?



A woman should seek out skilled care as soon as she begins labor.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

A fistula is an abnormal opening (a hole) between the bladder or rectum and the vagina. Traditional medicines cannot cure this condition; surgery is necessary, unless the fistula has been treated by catheterization soon after delivery.

Neurological damage to the lower body is usually reversible. Time and physiotherapy are most important for the healing of neurological damage (foot drop and paralysis); medication alone is not enough.

Women with fistula may experience feelings of demoralization and severe depression. Allen considered committing suicide when she continued to leak urine.

Myths and misconceptions about care at health facilities can prevent women from seeking care at a facility. After her fistula surgery, Allen's co-wives believed that her uterus had been removed and therefore she would no longer be able to have children.

Community awareness about the causes of fistula and possible treatment for fistula can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts. Health care providers can also identify and dispel any myths about fistula during counseling.

Men have an important role to play in access to skilled care for labor and delivery, support for women with fistula, and access to treatment. Therefore, it is crucial that men have accurate information about prevention and treatment of this condition.

When a woman who has had fistula is ready to deliver another baby, most surgeons recommend a planned cesarean section.





I am called Jane Namuddu. In 1971, when I was 20 years old, I began having pain in my belly. At the hospital, they said I had a problem with my fallopian tubes. They said I needed an operation.

Four days after the operation, when I squatted down [to urinate], something came out from inside me. It looked like a piece of plaster. Maybe it was something they had used to stop the bleeding. I started leaking seriously after that.

I told the nurses about my problem, that I was full of urine everywhere. I spent a month in the hospital. I felt so bad because I didn't smell nice.

When I came back [to the hospital] for a review, they confirmed I had a hole in my bladder. It seems the doctor tore my bladder during the operation. They told me they were going to repair it.

The operation did not work. My parents decided to sue the doctor, but later they changed their minds.

I was taken to another hospital and examined by three doctors. They also confirmed that there was a hole in my bladder. I was operated on again, and got some relief. I was still leaking but in very small amounts. I didn't tell anyone except family members, for fear of rumors being spread.

Then, in 2005, I heard on the radio that there were doctors operating on bladders with holes at a local hospital. They said they could help me. This time, when I was operated on, I recovered perfectly. At the time of the operation, I was 52. I had lived with the problem for 35 years.

I live with my sisters and their children, and I can sleep in a dry bed. My family and I are so happy now.

Note on Jane's story: While we do not have detailed information on Jane's medical history, the object that came out of her after her operation may have been something left behind by the surgeon during surgery.

DISCUSSION QUESTIONS

What is Jane's story about?

- What happened to Jane during her first surgery?
- What happened to her during subsequent surgeries?
- How does Jane's story end?

How did you feel as you heard Jane's story? Can you relate to parts of it?

- How do you think Jane felt when she realized her fistula was caused by the doctor?
- Why do you think she hid her problem from her community?

What can we learn from Jane's story?

- Could anything have been done to prevent Jane from developing a fistula?
- How did Jane's fear of stigma affect the course of her story?

How can we use what we have learned to:

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?

KEY MESSAGES

Jane's fistula is an iatrogenic fistula, caused unintentionally by health care providers during surgery.

In some countries, iatrogenic fistula can account for up to 10–15% of fistula cases overall. Surgical teams should be aware of the possibility of iatrogenic fistula during surgery. Early recognition can allow for immediate management of the condition.

Quality training of surgical teams in emergency obstetric care and gynecologic surgery is essential to preventing new cases of iatrogenic fistula.

Community awareness about the causes of fistula and possible treatment for fistula can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts.

Jane kept her fistula secret for fear of rumors.

Surgery can still succeed for women who have had a fistula for many years, with attempted repair early on. In Jane's case, she was finally repaired and dry after 35 years with a fistula.

Sleeping in a dry bed is something most people take for granted, but for a woman who has had a fistula, it is not a trivial matter. Jane chooses to mention this particular benefit of surgery as she ends her story.





My name is Irene Tindiwegi. In 2002, when I was 25 years old, I got pregnant with twins. I went to the hospital for check-ups, and they said the babies were OK.

But during delivery, I had very bad pain. I delivered one twin, then the other came out arm first. The village elder women helped me. They thought a spell had been cast on me. I was given herbs, but they didn't do anything. I began to lose hope. This was my sixth pregnancy, but only the second born was alive.

They put me on a stretcher and took me to the hospital. I was praying I would arrive and be saved from the pain. I was taken for an operation. They found the baby dead.

While in the hospital, I failed to pass urine. A doctor put in a tube to drain the urine. When she took out

the tube, the urine kept coming. The doctor never told me what was wrong with me.

My husband spent lots of money on cures, but nothing helped. One day, a car stopped on the roadside near our home. They were people looking for women who were leaking. They said there was treatment and gave me a day to go there.

The villagers told my husband not to let me go. But he said he would pay for my cure.

I love my husband for being patient with my sickness. My sister and I both went for the operation. I had spent five years leaking. Now I'm OK.

I want to tell people in my village to go to the hospital when they have a problem, because that is where I got help.

DISCUSSION OUESTIONS

What is Irene's story about?

- What happened to Irene during her delivery?
- What happened at the hospital?
- How did she finally have her f istula repaired?

How did you feel as you heard Irene's story? Can you relate to parts of it?

- How do you think Irene felt when she was leaking and did not know why?
- Why do you think the villagers told Irene's husband not to let her go for surgery?

What can we learn from Irene's story?

- What kind of impact can traditional beliefs about care at modern health facilities and about fistula have on women's lives?
- What kinds of outreach programs can help women with fistula get access to treatment?

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?



Antenatal care is essential for all pregnant women, and developing a birth plan should be part of antenatal care. This was particularly important in Irene's case, given that she was carrying twins.

Of Irene's six pregnancies, only her second resulted in a baby being born alive. While the reasons for the poor obstetric outcomes are not known, it is important to discuss pregnancy history during antenatal care visits.

A woman should seek out skilled care as soon as she begins labor.

Increasing the minimum age at marriage and delaying childbearing through the use of family planning can reduce the risk of obstetric fistula.

Traditional beliefs sometimes get in the way of medical treatment. Had the elder women in Irene's village not thought that she had a spell cast on her, she might have sought skilled assistance or gone to a health facility sooner.

The catheter inserted by the doctor to help drain Irene's urine was not the cause of Irene's fistula. On the contrary, immediate catheterization during or closely following obstructed labor and delivery can prevent or treat some fistulas.

Health care workers should communicate with their patients and keep them informed of their condition. Irene's doctor should have explained to her why she was leaking urine.

Myths and misconceptions about care at health facilities can prevent women from seeking care at a facility. Villagers told Irene's husband not to let her go for fistula surgery.

Outreach efforts to find women with fistula and to bring them in for treatment are important. Without these, Irene might not have become aware that surgery could repair her fistula.

Community awareness about the causes of fistula and possible treatment for fistula can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts.

Men have an important role to play in ensuring access to skilled care for labor and delivery, support for women with fistula, and access to treatment. Therefore, it is crucial that men have accurate information about prevention and treatment of this condition.

Individuals with health problems should seek care at a health care facility. Irene encourages her fellow villagers to go to a hospital as she did.





My name is Kyomuhangi Mary. I come from Mbarara District in Uganda. My father is still alive, but my mother died. My husband and I have one child, who is in P seven.

I got the problem of leaking urine from my first pregnancy, in 1985, when I was 20 years old. I failed to give birth after being in labor for four days. This was during the war that brought Museveni to power. I looked for a place to give birth, but I could not find one. There was too much gunfire.

I sought a traditional healer, who gave me some herbs. He passed them from my forehead down to my belly. Then he told me to kneel and push, and I pushed out a dead baby. My whole body was swollen. When the healer pressed my belly, the urine started running out.

People in the village wondered what was happening. They had never seen such a thing. They didn't think the problem was caused by my hard labor. They thought the baby died due to

witchcraft and that the leaking was due to a sexually transmitted disease. They tried to get more herbs, but the leaking didn't stop.

It was a bad thing for me, and I lost hope. I prayed to God to kill me.

I saw three different doctors, but nothing helped. I was given appointments for operations that didn't happen. I heard there were doctors in Tanzania helping women like me. When I went there, they had already left.

I had an operation at a local hospital but didn't get well. I went back two more times, but still didn't get fully well.

Although I'm not yet healed, I'm better than I was at first. I can support my family. I'm waiting for another operation so I will be OK. I have spent 23 years with this problem.

My sisters: I'm asking you that if you get the problem of leaking urine, don't stay in the village, go straight to the hospital. Free treatment is there.



DISCUSSION QUESTIONS What is Mary's story about?

- What happened to Mary during her delivery?
- What did others think had happened to her?

How did you feel as you heard Mary's story? Can you relate to parts of it?

- How do you think Mary felt when people in the village did not believe her fistula was due to her prolonged labor?
- How do you think she feels about the fact that she is still leaking, after trying so hard, even going all the way to Tanzania, to get help?

What can we learn from Mary's story?

- What kind of external factors can affect a woman's access to skilled care?
- Did the beliefs of Mary's fellow villagers get in the way of their helping her?
- What all has Mary had to endure in her efforts to get better?

How can we use what we have learned to:

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?

KEY MESSAGES

A woman should seek out skilled care as soon as she begins labor.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

Political conflicts can have a serious detrimental impact on people's health. Mary could not find a place to give birth as a result of the violence around her.

Traditional healers can do harm during prolonged labor, especially if they administer herbs orally, rectally, or vaginally.

Excessive pressure on the abdomen during labor can be harmful. In Mary's case, however, her fistula was probably not caused by the pressing of the traditional healer.

Sexually transmitted diseases rarely cause fistula. Obstetric fistula is caused by prolonged labor.

When a woman is in labor for many days, the baby usually dies, mostly due to asphyxia (suffocation). Witchcraft is not responsible for the baby's death.

When family members' efforts to help fail, the woman with fistula may lose hope. Community awareness about the causes of fistula and possible treatment for it can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts.

Women with fistula may experience feelings of demoralization and severe depression. Mary wanted God to kill her when her fistula could not be cured by traditional means.

Some fistulas are very difficult to repair. Sometimes, even after the fistula is closed, the patient may continue to "leak" urine due to stress incontinence. Stress incontinence can usually be treated in various surgical and nonsurgical ways.

Mary was persistent in seeking treatment for her fistula. Health care facilities should communicate with clients about the services they offer and should respect clients' appointments.

Once a woman's fistula is repaired (closed), she is often able to get pregnant again and have a baby. Mary gave birth again despite the fistula that she developed from her first pregnancy.

Even if a woman's fistula cannot be repaired, she can lead a productive life. Despite the fact that Mary is not totally well, she is able to support her family and has not given up.

If a woman leaks urine, she should go to a health facility to determine what is wrong. Mary encourages her fellow sisters to seek treatment at a hospital.

SIFA



I am called Sifa Nansamba. I got married at age 16, while I was working as a house girl in Kampala. My husband was quarrelsome. When I got pregnant, I went for regular check-ups. The health workers told me to go to the hospital when I was due. But my husband gave me money and told me to go back to the village to deliver.

The day I started having labor pains, I told my older sister I wanted to go to the hospital. I had given her my money for the expenses, but she had already spent it on other things. So we walked to the home of a traditional birth attendant instead.

I spent five days having labor pains. I was told to push, but the baby died while I was pushing. The birth attendant was afraid—she thought she might be arrested for harming me. She hired a car right away to take me to the hospital.

When I got there, I was taken for surgery, and the baby was removed. I started leaking urine like tap water after that.

I suffered a lot, during that time. My husband left me, my mother hated me, and I couldn't fit in with people. People would ask, "What smells like a goat's urine?" I had no money, and my mother refused to give me any. Finally, I sold my goat and managed to get to a hospital.

When I reached the hospital, they counseled me and told me I would be OK. They operated on me, and it was successful. I'm happy now. I want to tell pregnant mothers who hear my story that they must always go to the hospital instead of delivering in villages.

I've got another husband now, and I hope soon to have another child.

DISCUSSION QUESTIONS What is Sifa's story about?

- What happened to Sifa when her time came for delivery?
- How was she treated by her family and community?
- How did she finally get the help she needed?

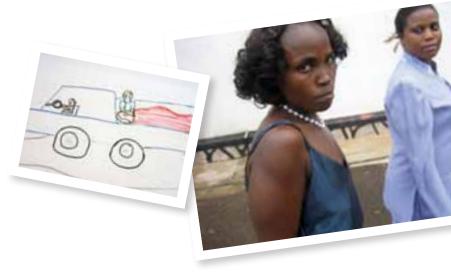
How did you feel as you heard Sifa's story? Can you relate to parts of it?

- How do you think Sifa felt when her husband made her return to the village to have her baby?
- How do you think Sifa felt when her sister used the money for the hospital for other things?
- How do you think Sifa's husband and mother felt about Sifa's fistula?
- Why do you think Sifa's community made fun of her odor?

What can we learn from Sifa's story?

- Why might have Sifa's husband sent her back to village for her delivery?
- How did financial constraints play a role in Sifa's story?
- How did the lack of awareness of others (of her husband, her mother, her community) affect Sifa?

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?



A woman should seek out skilled care as soon as she begins labor. Sifa's traditional birth attendant let her stay in labor for too long, and her cesarean section was too late to save the baby.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true whether the woman is laboring at home or at a facility.

Increasing the minimum age at marriage and delaying childbearing through the use of family planning can reduce the risk of obstetric fistula.

A woman may not have the power to decide where she wants to go to deliver. Sifa's husband made the decision for her to return to her village to deliver. And Sifa could not go to a hospital in the village because her sister used the money that Sifa had put aside for the delivery.

Men have an important role to play in ensuring access to skilled care for labor and delivery, support for women with fistula, and access to treatment. Therefore, it is crucial that men have accurate information about prevention and treatment of this condition.

Community awareness about the causes of fistula and possible treatment for it can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts.

Even close family members may shun and abandon a woman with a fistula. Many are unaware of obstetric fistula or might harbor myths and/or misconceptions about its causes and treatment.

Social situations can be stressful for women with fistula. People around them may be put off by the odor. Community members may also harbor myths and misconceptions regarding the causes of fistula. Sensitization of communities can help reduce stigma.

Cost can be a serious limitation both for women who want to give birth with skilled care and for women who need treatment for fistula or other conditions. Sifa had to sell her goat to get to a hospital for treatment.

When a woman who has suffered from a fistula undergoes surgery and is finally closed and dry, she may require support to regain her place in society. Efforts are necessary to reintegrate these women, as well as women who cannot be completely continent, back into society.



My name is Medius Namaganda. I have two sisters and one brother. I got married when I was 15.

About 17 years ago, I faced a problem. I spent two days in labor but failed to deliver. I was sent to the hospital. They removed a dead baby.

After three days, I realized I was leaking urine. I spent three months in the hospital, unable to walk. My sisters were caring for me.

After I was allowed to go home, my husband and mother got fed up with me. At home, I reached a point of lying on the floor to avoid spoiling the bed. People couldn't drink water at my house because of the bad smell.

After some years, the health workers from a local hospital came. I had no family member to attend to me at the hospital, but the nurses cared for me well and even washed my clothes.

I praise God for them. The doctors operated on me nine times, and after the ninth time, the leaking improved.

I'm now very happy because of that. I went back to my village and am welcome there. I'm now married to another man who loves and cares for me. When my relatives see me in nice clothes, they are so grateful.

I urge all women with this problem to go for treatment, and to those who are pregnant—to see a qualified health worker.

Note on Medius's story: Medius states that she was operated on nine times. While her medical history is unknown to us, what is known is that it is unusual to have so many surgeries. Perhaps, of the nine surgeries that Medius mentions, some were clinical examinations under anesthesia that she misunderstood as surgery.

DISCUSSION OUESTIONS

What is Medius's story about?

- What happened to Medius when she went into labor?
- How was she treated by her family and community after she developed a fistula?
- How did she finally get the help she needed?

How did you feel as you heard Medius's story? Can you relate to parts of it?

- How do you think Medius felt when she lost her baby, could not walk, and developed a fistula?
- How do you think Medius felt at home?
- How do you think Medius and her family and community felt after she was repaired and remarried?

What can we learn from Medius's story?

- Why did Medius's sisters need to care for her at the hospital?
- How can having a fistula affect the social interactions of a woman and her family?
- How might these social interactions change once a woman is no longer leaking?

How can we use what we have learned to:

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?



KEY MESSAGES

Antenatal care is essential for all pregnant women, and developing a birth plan should be part of antenatal care.

A woman should seek out skilled care as soon as she begins labor.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

Increasing the minimum age at marriage and delaying childbearing through the use of family planning can reduce the risk of obstetric fistula.

Due to limited resources and staff at health facilities, patients must often bring family members to care for their basic needs while they are at the facility.

Even close family members may shun and abandon a woman with fistula. Many are unaware of obstetric fistula or might harbor myths and/or misconceptions about its causes and treatment.

Especially in rural settings, there is generally no easy way to soak up

leaking urine. Women are left to their own devices to find hygienic and effective ways to soak up the urine, thereby reducing discomfort and odor. Medius resorted to lying on the floor to avoid spoiling the bed.

When a woman living with fistula lives in a small home, often with just one room, the odor can pervade the entire home, thus making social visits difficult.

Outreach efforts to find women with fistula and to bring them in for treatment are important. Without these, Medius might not have become aware that surgery could repair her fistula.

Even after multiple surgical attempts to repair a fistula, surgery can still work. Medius's fistula was closed after multiple surgeries.

After a woman's fistula is repaired and she is dry, in some cases she may be welcomed back in her village. Medius has remarried and is happy in her village.

Women who have fistula should seek treatment at a health facility.



I'm called Silvia Nankanda. I'm from Rakai District.

I will not forget the day I went into labor. I pushed and pushed until morning. I tried my best to give birth, but around 3PM that day a nurse came from the nearby clinic. She tried her best but failed and sent me to a hospital. We reached the hospital around midnight, and they took me for an operation. They tried to save the baby, but it died.

My stitches did not heal well, even after two months. Then I started seeing black liquid coming out, and I also started passing urine all the time. My mother and the nurses tried to help me, but I did not get completely well.

They sent me home still leaking urine and with unhealed stitches. I thought they wanted me to die at home.

I was always in wet clothes.

After some time, my brother took me to a nearby clinic to have the wound cleaned.

The stitches on my belly burst again. When my brother saw that, he hired a car to take me back to the hospital. They operated on me, and I recovered well. But the urine kept leaking. I thought the problem couldn't be fixed.

My father had taken my brother to a different hospital when he had a problem, so he took me there too so I could get better. The doctor examined me and said I had three holes in my bladder. They fixed two of the holes, but one kept leaking urine.

When I went home, I got pregnant again and miscarried at seven months. Then the urine came back.

Though I am still in pain, it's not as bad as it was. I can pad myself and be

around other people without fear.

Note on Silvia's story: Silvia explains that of three holes in her bladder, two were fixed, but one kept leaking urine. She then goes on to say that after a miscarriage, the urine "came back." A plausible explanation

is that the one hole that was not fixed did not leak much urine, but that after her miscarriage (and subsequent delivery) the hole became larger or one of the two other holes opened up again, thus causing her leaking to become worse.

DISCUSSION QUESTIONS What is Silvia's story about?

- What happened to Silvia when she went into labor?
- What happened to her when her stitches did not heal?
- How did she finally get the help she needed?

How did you feel as you heard Silvia's story? Can you relate to parts of it?

- How do you think Silvia felt when she thought her fistula problem could not be "fixed"?
- How do you think Silvia felt when her brother took care of her and helped her?
- How might Silvia feel about the fact that she has to live with fistula?

What can we learn from Silvia's story?

- Why might Silvia have waited to have a nurse come and attend to her labor and delivery?
- Why would Silvia think that the people at the hospital wanted her to die at home? Why might she have been sent home with unhealed stitches?
- Can a woman lead a productive life even if her fistula cannot be repaired to the point of being dry?

- Ensure family and community support for women with fistula?
- Help prevent other women in the community from developing fistula during labor?
- Provide better care for women with fistula?

A woman should seek out skilled care as soon as she begins labor.

An African proverb states that "The sun should not rise or set twice on a woman in labor." This is true regardless of whether the woman is laboring at home or at a facility.

Health care workers should communicate with their patients and keep them informed of their condition. Silvia thought that she was being sent home from the hospital to die.

Men have an important role to play in ensuring access to skilled care for labor and delivery, support for women with fistula, and access to treatment. Therefore, it is crucial that men have accurate information about prevention and treatment of this condition.

Community awareness about the causes of fistula and possible treatment for fistula can reduce stigma, increase support for women with fistula, and also strengthen prevention efforts. Silvia did not realize that her condition was treatable.

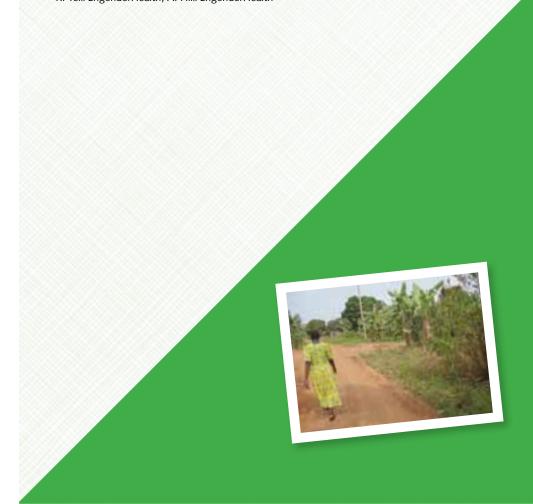
If a woman leaks urine, she should go to a health facility to determine what is wrong.

Even if a woman's fistula cannot be repaired, she can lead a productive life. Silvia can pad herself and feels comfortable around others.

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