FACES OF DIGNITY

Seven stories of girls & women with fistula

Women's Dignity Project • Utu Mwanamke
Women’s Dignity Project extends its deep appreciation to the girls and women who opened their lives to us and shared their stories. Without them, this booklet would not have been possible.

A number of these stories were collected during field research conducted in 2003. Interviews were conducted by: Atuswege Mwangomale, Catherine Kamugumya, Barnabas Solo, Yusta Ntibashima, Mary Zablon, Francis Donko, Marieta Mtumbuka and Barnabas Chipeta.

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All names, photographs and identifying details of these stories have been changed to protect the privacy of the women involved.

In 2003, US $1 was roughly equivalent to 1,000/- Tanzanian Shillings.
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Introduction

Faces of Dignity recounts the experiences of seven girls and women in Tanzania who have overcome the tremendous challenges posed by “obstetric fistula.” This booklet is about their determination to maintain dignity in the face of social and political arrangements that fail poor people.

Fistula is a devastating childbirth injury that leaves girls and women leaking urine and/or feces continuously from the vagina. It is preventable and occurs almost entirely in Africa and South Asia. Currently, at least two million girls and women live with fistula.

This booklet paints a portrait of girls and women who live with fistula and illustrates their resilience and strength. It shows how despite enormous stigma, they continue to work and care for their families. The booklet also seeks to leverage the attention and resources necessary to address fistula at community, national and international levels. This includes action to prevent fistula from occurring, and funds to ensure that every girl and woman living with fistula gets the medical treatment she needs.
But fistula is more than a women’s health problem. Its roots are deeply embedded in political, economic and social determinants that underlie poverty and vulnerability. These include limited expenditure on priority social sectors that benefit the poor, absence of governance structures that bring the voices of marginalized people into policy setting, lack of transparency in the use of public funds for basic services, and the exclusion of women and girls from family and community decision-making.

Fistula provides a lens onto these determinants of inequity. It also serves to gauge whether or not policy objectives to reduce poverty are creating meaningful change for the poorest and most marginalized members of society.
About “fistula”

Obstetric fistula is caused by prolonged and obstructed labor. The constant pressure of the baby’s head in the birth canal causes a hole to form between the bladder and the vagina (vesico-vaginal fistula or “VVF”) or between the rectum and the vagina (recto-vaginal fistula or “RVF”). As a result, urine and/or feces leak continuously and uncontrollably from the mother’s vagina. In nearly every case of fistula, the baby dies.

Some girls and women with fistula are entirely abandoned, while some are forced to live and work in isolation. Others have supportive families, but struggle to be accepted within their communities and to find medical treatment.

Despite these challenges, girls and women with fistula are typically strong and resourceful. They continue to support their families and themselves. They manage the significant responsibilities that poor women typically shoulder that include finding water, hauling firewood, cooking, caring for family members and working in the fields. They may spend years saving money to pay for medical care and transportation to a facility providing treatment.

Urgent action is needed to ensure that every girl and woman with fistula gets treatment and reclaims her dignity. Prevention efforts must be strengthened so that in the future fistula does not occur. Girls and women deserve no less.
Stela

Stela is 20 years old; her mother died when she was ten. When her father remarried, the new step-mother treated Stela so cruelly that she ran away from home at age eleven. She traveled alone by train and bus to live with her grandmother and brother in a far away village.

When Stela was fourteen she got pregnant. Her grandmother and brother chased her out of their home, and she looked for work as a maid. She moved from one friend’s home to another, until eventually, her boyfriend’s parents realized that their son had gotten Stela pregnant. They encouraged the couple to marry, and Stela went to live with her new husband.

When Stela’s labor began she traveled with her husband and sister-in-law to the local dispensary, and waited for three hours before she was seen. Since the labor was not progressing, they went to a hospital where Stela waited for nearly two days to get a cesarean section. She says her operation was delayed because other patients paid the providers to get care more quickly. Stela had no money to offer them, so she stayed in the hospital in labor through the whole next day. She finally got a cesarean section the second night in the hospital.

“I got fistula because I had no money. Women who came to the hospital with money for the doctors and nurses were able to get care more quickly.”

Stela’s relatives, husband, and grandmother came to visit her in the hospital, until her grandmother wouldn’t allow anyone to see her—including her husband. Stela remained alone in the hospital with nothing to eat or drink, and had to ask for food from other patients. One week after the operation, Stela realized she was leaking. She also had foot drop and was confined to a wheelchair, so other patients’ relatives had to help her wash herself.

When she was discharged from the hospital Stela went to live with her grandmother. After two weeks, the grandmother complained that she was tired of the smell of urine and asked Stela to leave. Stela moved back into her husband’s home but didn’t stay there for long. He complained that his mattress was rotting because of her urine, and he took all of her things and threw them out of their home.
Finally, Stela went to live with her grandmother’s sister, who treated her with kindness. Stela worked from home plaiting hair for 50 cents per client and did odd jobs such as washing and collecting water for $1-$2 per task. She used her small earnings to help buy sugar, soap and other necessities.

Stela learned to hide her condition extremely well, especially the smell of urine. She received a marriage proposal from a man who gave her $50 to find a repair. He told her there was a hospital in another district that could do the surgery, but when she went there she found that they did not treat fistula. She was referred instead to another hospital, but she couldn’t afford to get there. She had already spent most of the money on transportation to and from the first hospital.

Stela lived with her grandmother’s sister until another man proposed to her. At first she refused the offer because of her leaking, even though she had learned to conceal the smell. The man persisted and told her he wanted to be with her in spite of her condition, and she finally agreed to marry him. To prevent the marital problems she had experienced with her first husband, Stela used plastic, nylon and clothes to prevent the mattress from rotting.

Stela never gave up hope of being repaired. She earned the money to get to the hospital by doing odd jobs around town, and by selling her purse and a small piece of furniture. Her husband remained supportive and collected money to help pay for his wife’s surgery. Thanks to their combined efforts, Stela finally got her fistula repair. She healed and returned home to her husband, freed from the worry of how to keep her bed dry at night.

\[1 \text{In some cases of prolonged labor there is extensive nerve damage to the lower limbs, making it difficult or impossible for a woman to walk.}\]
Rehema

Rehema got fistula at the time of her third pregnancy. She delivered at home and had a breach birth: the baby’s legs came out first, and by the time its head was out the baby was dead. Rehema stayed in bed for a week recovering from the difficult labor and delivery, and when she got up and started walking, she discovered that she was leaking urine.

Rehema went to the local hospital three times seeking treatment for her condition, but there were never doctors present for her scheduled appointments. Next she went to a larger hospital, but she received only medicine, which offered no relief. After her fourth unsuccessful attempt to find repair services, she returned home and decided to stay there.

One year later Rehema conceived again and gave birth to a baby boy. Her husband, who did nothing to help his wife or the baby, eventually died. Rehema’s friends began to treat her unkindly and rarely visited her. Her depression mounted, until one day she decided to commit suicide. She looked at her baby, began to cry and was on the verge of hanging herself, when a friend found her and asked, “Why do you want to die and leave this baby?”

Rehema’s son grew up to be supportive and caring. When he married and had children the whole family treated Rehema with kindness and gave her all the help she needed. They were especially kind when she grew older and found it harder to stop the leaking. She was grateful that she didn’t suffer any harassment from her family.

“Why do you want to die and leave this baby?”

Rehema went to traditional healers to try to cure the fistula, paying them in cereal grains because she had no cash. Then Rehema heard that she could be repaired at a major hospital but had no money to pay for the transportation or the operation. She had a few goats which she decided to sell, but before she had a chance to sell them they were eaten by a wild animal, destroying her only means of income.

After the goats were eaten, Rehema’s son bought a cow. He told his mother that when it had calves, he would sell one of them to pay for Rehema’s transportation to the hospital. They waited until they
had amassed three cows, but when they were ready to sell, all of the cows were stolen.

Eventually, Rehema’s son heard on the radio that people over the age of 60 would be able to get medical treatment for free. They waited several years until Rehema turned 60, but the procedures for getting free treatment were never made clear to them. So Rehema continued to wait for treatment, indefinitely.

A few years later, visiting researchers met Rehema and offered to take her to the hospital and get her a repair completely free of charge. After so many failed attempts, and then so many years more of waiting for affordable treatment, Rehema was reluctant to accept the offer. She feared another disappointment even more than she feared living with fistula for the rest of her life. Only after urging by the researchers and the village leader did she agree to go to the hospital.

True to Rehema’s fears, her first operation failed, and she continued leaking even after the surgery. Yet the health providers did not give up, and they succeeded in their second attempt to repair the fistula. Now, after over 30 years of leaking, Rehema is finally dry.
Neema

Neema is 17 years old. She never went to school and cannot read or write. When she was 15, she was walking home alone from church one day and came upon a man who asked to escort her home. He took her to his sister’s house, where he locked her in a room for three days and raped her repeatedly.

According to Neema’s culture, because she spent the night alone with a man who was not her husband, she could never return home. When her family learned where she was, Neema’s father and brother arranged for the man to take Neema as his wife, in exchange for six of his cows. Neema’s new husband then took her by train to the capital city, and the couple made their living by selling vegetables.

When Neema got pregnant she sought antenatal care at a local maternity clinic. The providers reported no problems with the fetus and advised her to deliver at a hospital. She worked long into her pregnancy, first selling vegetables and then charcoal, because her husband refused to give her money to buy the supplies required for a hospital delivery.

When she was nine months pregnant, Neema moved into her mother-in-law’s house. When her labor began and grew very painful, her mother-in-law told her, “You are a woman, you have to be strong, you have to tolerate the pain.” Because no one would take her to the hospital, Neema stayed at her mother-in-law’s home, in labor, for nearly a full day.

“You are a woman, you have to be strong, you have to tolerate the pain.”

Finally the husband’s family gave her money for the bus and accompanied her to the hospital. They left Neema alone that night. The next morning—still in labor—she was told to go to another hospital. She got up from her bed to leave and could barely walk because she had already developed foot drop in one of her legs.

At the second hospital, after more attempts to push the baby out, Neema finally received a cesarean section. After the operation, one nurse told Neema that her baby had died, while another said it would be brought to her later. To this day, Neema does not know what really happened to her baby.
Neema found that she was leaking urine and told the doctors and nurses about her problem, but they told her it would correct itself. She spent the next two months alone at the hospital depending on other patients’ relatives for food and water. She was visited only twice: once by her brother-in-law, and once by her brother, who lived in the same city.

When Neema returned home her husband said he no longer needed her because he had a new wife who wasn’t leaking. Neema continued living with him since she had nowhere else to go. Her brother provided Neema with transportation money to go for fistula repair, but her husband pocketed the cash and refused to take Neema to the hospital.

Neema’s brother later brought her to the hospital, and her repair was partially successful. She continued to urinate through a catheter, but she was no longer leaking. When Neema returned home, her husband was angry that her problems were not fully cured. Sometimes he would beat her because she had to wait three months after the surgery to have sexual relations. He refused to give her money for food, so Neema borrowed money to begin selling vegetables. Neema’s husband began to steal her supply of vegetables, and finally one day he threw her clothes out of the house and said he didn’t want to see her anymore.

Neema left her home and began working as a maid, and earned $10 in the first month. She used $6 to rent a room for two months and purchased buckets and pots with the remaining $4. She found a new job that paid her 40 cents per day and she invested half of her daily salary into a women’s rotating credit fund. Neema used the balance of her wages, plus income from the credit fund, to purchase a mattress.

Neema’s employer fell ill, and she lost her job as a maid. She secured support from a local organization to establish a small business selling vegetables, but even this opportunity presents challenges for a young girl who works alone and lives alone. 17-year-old Neema must sleep overnight in an open marketplace in order to sell vegetables in the early morning, making her vulnerable to robbery and physical and sexual assault.
Pendo

Pendo has lived with fistula for over 30 years. When she was asked to talk about how and when her problem began, she stood up, and as urine poured out of her she asked, “Can you imagine living with this condition for 32 years?”

Pendo went to school until her father forced her to get married at age twelve. To this day, she laments not being allowed to finish her studies. According to local custom, Pendo lived with her husband’s parents for two years, during which time she learned how to be a good wife. At age 14 she had her first menses and moved into her husband’s home.

Pendo worked hard during her first pregnancy, collecting firewood and water, and doing all other domestic chores. Her labor was terribly difficult, painful and long. After three days spent at home without delivering, her family took her to a hospital 20 kilometers away. The doctors delivered the baby by forceps.

The baby survived, but Pendo developed fistula as a result of the prolonged labor. She tried several times to have the fistula repaired, but every time she went to the hospital the visiting surgeon had already left.

“Can you imagine living with this condition for 32 years?”

Pendo’s brother said the problem could not be cured and she should give up on her attempts to get treatment. A brother-in-law advised Pendo’s husband to abandon her and marry another woman, but the husband ignored that advice. Pendo’s husband remained very supportive and after 32 years the couple is still very much in love. After Pendo got fistula, she went on to have eleven more children, all of whom treated her with respect and kindness. The sons and daughters helped with the household chores and washed Pendo’s urine-soaked clothes.
Pendo continued to work and support her family for all those years, yet she also faced significant social challenges. Given the enormous shame of leaking urine uncontrollably, Pendo avoided situations where people might find out about her problem. Whenever she came across other people while walking along the road, she would cross to the other side to prevent them from smelling the urine.

In 2003 Pendo learned that her fistula could be cured, and immediately went for repair. The surgery was successful, and Pendo finally stopped leaking. When she had fully healed and was ready to return to her family, providers reminded her that she must wait three months after the surgery to resume sexual relations with her husband. Pendo happily told the providers, “Three months of waiting after 32 years of leaking is nothing!”
Asha lives in a small village. Her husband works as a guard at the village government office and earns very little money.

Before she developed fistula, Asha delivered one daughter without any problems. She became pregnant again and endured a very difficult labor. When Asha realized that she could not deliver at home, her husband borrowed $6 from the village leaders to rent a wheelbarrow pulled by a cow. The wheelbarrow carried Asha to the main road and her husband found a car to drive them to the hospital for $60. Because he had no money, he hired the vehicle on credit.

At the hospital Asha got a cesarean section, but the baby died. Asha developed fistula as a result of the prolonged labor. To pay the $40 bill for his wife’s operation, Asha’s husband had to request more money from the village government. The terms of the loan required him to work for free, until his meager salary had paid off the $40 in full. This left the family of three without any income.

The family struggled to get water to help Asha stay clean. The closest well is a six-hour walk away and because Asha was constantly leaking, she needed to bathe and clean her clothes with greater frequency. But each time she used extra water to wash the urine from her clothes and her body, she depleted the supply of water for her husband and her daughter, and for the cooking and cleaning.

The water situation was particularly problematic after Asha’s cesarean section, when she was too weak to make the journey to collect water. Her husband had to pay 10 cents per day to get one bucket delivered by wheelbarrow, making it extremely expensive for Asha to wash herself and her clothes. Each extra bucket of water to cleanse her urine added to the huge debt that the family had already accumulated.
Meanwhile, the pressure of the unpaid debts continued to mount. All of Asha’s husband’s salary was being used to repay the loan for the wheelbarrow and medical treatment, leaving him unable to pay back the $60 he owed for the car to the hospital. The vehicle owner came to the house frequently to harass the couple for the money due, until Asha’s husband finally sold a plot of land for $20. Because this sum paid off only a third of the car debt, Asha’s husband contemplated selling another plot. Ultimately, he sold one of his five cows instead, because the land was his most valuable asset.

Friends gathered together $15 to help pay off the transportation debt, and took Asha to a hospital where her fistula was successfully repaired. When Asha returned home she was no longer leaking but her family’s financial situation remained grave. Her husband owes a remaining $25 for the transportation and is still working for free to repay the $40 hospital loan. It is uncertain how long Asha, her husband, and her daughter can survive without any salary, with one less plot of land, one less cow than before, and two outstanding debts.
Habiba

Habiba, a 17-year-old girl, was raised by her grandmother after her parents divorced and moved to separate villages. She went to school until age 11 and married when she was 16.

Habiba attended a local health center for antenatal care during her pregnancy. The providers told her she should deliver at the local hospital since she was young and short, and this was her first pregnancy. Habiba shared this advice with her husband, but he told her that he had no money to take her to the hospital.

On the morning that Habiba went into labor, her mother was summoned from her village. They waited for several hours hoping that Habiba would deliver at home because they did not have the money to go to the hospital. The baby would not come out. Finally, late that afternoon, Habiba went to the local health center, accompanied by her mother, mother-in-law and husband.

The providers at the health center turned Habiba away since they felt they could not help her and had told her to go to the hospital. The medical officer intervened and told the other providers that they could not refuse to give her care, and so the nurses checked her dilation. When Habiba was fully dilated the nurses told her to push, but still there was no progress.

To get to the hospital, Habiba would have to walk 11 kilometers to catch a pickup truck that was often too full to fit any more passengers.

The providers insisted that Habiba needed to be cared for at a hospital, but there was no transport available. She would have to walk 11 kilometers to the main road to catch the pickup truck that could take her there. Even then, she might not be able to board because the vehicle was often already full by the time it reached that stop. So Habiba stayed at the health center, unable to deliver, for three days.
On the third day of Habiba’s labor the medical officer went to a local leader for help. The leader was hosting visitors, and they offered to transport Habiba, her mother and her mother-in-law to the hospital in their vehicle. It took them two hours to drive 80 kilometers along the rough roads to the hospital. There was no room in the vehicle for Habiba’s husband, so he traveled six hours by bicycle to visit her.

When Habiba arrived at the hospital the baby, already dead, was delivered by cesarean section. During the operation the surgeons discovered that Habiba’s uterus was ruptured and immediately removed it. Four days after the operation she started leaking urine and feces. She stayed at the hospital to recover from the cesarean section, and at last report she was still healing and awaiting a fistula repair.

The doctors may be able to fix Habiba’s two fistulas, but they cannot replace her uterus. In a society that values a woman’s fertility over so many other attributes, 17-year-old Habiba is already at a decided disadvantage because she will never bear children.
Zakia

Zakia is an 18-year-old girl living in a remote village. She went to school for seven years, but she never learned to read or write more than her own name. She married at age 17, and according to local tradition, her husband paid some money and gave gifts to her family as a dowry.

Zakia moved to her husband’s home in another village, but the marriage lasted only one week. She could not bear to live with him because he treated everyone with disrespect, including elders and Zakia’s relatives. She ran home to her family, and they had to return the dowry, along with an extra $25 because Zakia left without any warning.

When Zakia returned to her family’s home she had already conceived. Her father was suspicious that she had gotten pregnant with a different man and treated her cruelly as a result.

Zakia had no problems during her pregnancy, and when she was six months pregnant she went to the health center for prenatal care. She was told that given her young age and short stature, she should deliver at the hospital. Zakia’s father refused to comply with these instructions and told her mother, “I have seen many other girls here who are shorter than Zakia, and they are delivering at the health center, so I will not take her to the hospital.”

Her parents walked all night to reach their home for the emergency money and go back to the health center. They then waited three more hours to catch a bus to a hospital.

The father went away to work on a farm in another district and left $50 to be used in case of an emergency. Zakia’s labor started one evening while her father was gone, but the initial pains were not severe. Late the next morning she and her mother walked three hours to the health center for the delivery. They stayed there for three hours, after which the health center providers told them to go to the hospital because Zakia needed a cesarean section.

Late that afternoon Zakia’s mother walked four hours to the farm where the father was working. The parents walked all night to reach their home for the emergency money and to get back to the health
center. In the morning, they waited three more hours to catch a bus from the health center to a hospital. Zakia finally underwent a cesarean section later that day.

The baby died, and Zakia developed an infection as a result of the surgery. The wound began to smell, but the nurses blamed it on Zakia’s mother, saying that she simply was not washing her daughter properly. By the time the father arrived Zakia’s condition had gone from bad to worse: huge amounts of pus leaked from the wound.

Zakia’s father immediately decided to take her to a different hospital and paid a taxi $20 for the 25 kilometer trip. By the time they reached the hospital, Zakia was unconscious and was sent immediately to intensive care where she stayed for seven days. After she recovered from the near-fatal infection she discovered that she was leaking urine from her vagina.

After her infection had fully healed, Zakia’s fistula was repaired. Unfortunately, Zakia has “stress incontinence”¹ and now leaks urine from the urethra. As with other women living with incontinence, Zakia is technically “cured” of her fistula but is still often wet and cannot fully control the flow of urine.

¹ Stress incontinence is a different condition than fistula, but can also result from prolonged labor. In these cases, girls and women leak urine from the urethra with limited control. For many of those with severe stress incontinence the effect of the leaking can be the same as having fistula.
Women’s Dignity Project

The Women’s Dignity Project (WDP) was established to prevent and manage obstetric fistula, enhance the dignity and rights of those living with fistula, and promote gender and health equity. We base our work on the understanding that health conditions affecting poor people result from social, economic and political factors that underlie poverty.

WDP’s seeks to:
• Better understand girls’ and women’s vulnerability to fistula
• Strengthen communities and organizations to take action on fistula and the inequities impacting the poor
• Stimulate public debate and action to address these inequities
• Influence programs and policies to promote the dignity and rights of the poor

WDP also assists girls and women to get fistula treatment and begin their lives anew. If you would like to support a girl or woman with fistula or the work of the Women’s Dignity Project please contact us.
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FACES OF DIGNITY tells the stories of seven girls and women living with obstetric fistula, a devastating childbirth injury rooted in poverty.

Fistula is a concrete reminder of failures in health and social systems. It is also a lens onto poverty and inequity. Fistula serves to gauge whether poverty reduction measures are creating meaningful change for the poorest members of society.

This booklet paints a portrait of resilience and strength in spite of tremendous personal loss. It is meant to mobilize action to prevent and manage fistula, and to challenge the fundamental inequities threatening the well-being of the poor.

The Women’s Dignity Project was established to prevent and manage obstetric fistula, enhance the dignity and rights of those living with fistula, and promote gender and health equity.

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