



**United Nations Population Fund** 

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# Mending Torn Lives:

A series of open conversations with women suffering from obstetric fistula in Eritrea

UNFPA in collaboration with the Ministry of Health

May, 2003 Ellen Krijgh Bruce Campbell and Tigisti Abraha

## UNFPA's involvement with the problem of fistula worldwide

In recognition of the urgent need for such repairs, of the concomitant need to raise public awareness on the issue, and of the need to reach out to the appropriate target population in this respect, one of the many UNFPA priorities and commitment to protect the health of women in 2002, was to support the "initiative against fistula". Recently, UNFPA joined the International Federation of International Obstetrics and Gynecology (FIGO) and Columbia University's Averting Maternal

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#### Background of the medical problem of obstetric fistula

Pregnancy and childbirth should be a special time in the lives of women and families.

Unfortunately, it can also be a time of great danger. Throughout the world, half a million women die from complications of pregnancy and childbirth every year. Others remain alive, but are often scarred by permanent disabilities. Throughout Africa and other developing regions millions of women suffer from one of the most severe of the pregnancy-related disabilities: obstetric fistula.

An obstetric fistula is a hole that develops between the vagina and either the bladder or the rectum, usually as a result of trauma during childbirth. If a woman's baby will not fit through her birth canal

because her pelvis is too small or the baby is too big or badly positioned, the labor is said to be obstructed.

The baby's head becomes wedged in the mother's pelvis, cutting off the blood supply to the soft tissues of her bladder, rectum and vagina. Where there is inadequate obstetric care, a woman may be in obstructed labor for 3 or 4 days without relief. The baby usually dies. If the mother survives, her injured pelvic tissue rots away, creating a fistula.

Besides the above-mentioned main cause of prolonged obstructed labor, a number of concomitant factors are contributing to the occurrence of obstetric fistula: early marriage and childbearing; lack of skilled or timely assistance during pregnancy, labor and delivery; and harmful cultural practices related to marriage, reproduction and childbirth are some of these. Poor access to obstetric care and an absence of education and health education are other underlying causes.

Fistula's may also result from ritual genital cutting, unsafe abortion attempts, and in some cases from pelvic fractures or other injury.

#### The consequences of obstetric fistula are severe

A woman may have bladder (vesico-vaginal) fistulas, or rectal (recto-vaginal) fistulas. In both

After enduring the agony of unrelieved labour and the death of an unborn child, these women face the prospect of lifelong incontinence, infertility, shame, social isolation and poor health.

cases she is left without control over either her urine, or over her bowel movements, and most often suffers great physical discomfort. Constant wetness causes genital ulcerations, frequent infections and a terrible odor: a condition bringing shame and social stigma, if not abandonment: she faces increasing poverty and malnutrition.

Additionally, the poverty and lack of access to obstetric care that often lead to fistula also prevent affected women and girls from having the fistula repaired.

wound caused by protracted labour. Its victims are mostly very young and very poor - girls or women without access to emergency obstetric care.

Obstetric fistula is a

Death and Disability program (AMDD) to offer support to survivors of fistulas and to prevent further cases. Their working group seeks to mobilize the international community on the need for urgent action, and to create a Fistula Fund to support treatment and prevention work in the multiple locations where it is most needed.

#### UNFPA's mandate in relation to Obstetric Fistula

UNFPA in Eritrea has focused its Reproductive Health Sub-programme on a number of related issues including:

- Alerting communities of the dangers of early marriage, and the need for timely medical interventions when complications of pregnancy arise.
- Advocating for emergency obstetric care for all who need it.
- Increasing the capacity of existing fistula repair centers.
- Training specialized medical teams.
- Raising funds to subsidize the cost of surgeries and transportation to fistula hospitals.
- Raising awareness about the condition, its prevention and treatment.
- Partnering with other groups working on this issue.

#### Identification of the problem of obstetric fistula in Eritrea

In many places where the problem of fistula has been reported, reliable or scientific data on the prevalence and incidence of fistula are rare. In Eritrea it is not different.

However, through the Demographic and Health Surveys as well as the routine health information system, it is known that Maternal Mortality and Morbidity are both high, and skilled attendance at delivery is still below 30%. And anywhere where maternal morbidity and mortality are high, the prevalence of other pregnancy, labor and birth related complications are expected to be very high as well.

In Eritrea, many socio-economic and cultural factors, which contribute to the development of an obstetric fistula, are reinforcing each other:

- Women commonly have very heavy workloads, but lack control over resources.
- Despite literacy campaigns and increase in building of primary schools during the liberation struggle and after independence of the country, women's access to education and information is still very low; traditionally, low status is being accorded to girl children and therefore to the need for their education.
- In some contexts, nutritional intake of girls and women may be less than that for boys and men, and micronutrient deficiencies (particularly anemia) are common amongst women of childbearing age.
- For almost 90% of women, the age at first marriage is below the age of 20, and often their marriages will be arranged according to tradition. An approximate 78% of women will be between 16 and 20 during the time of their first pregnancy.
- Unplanned pregnancy is common, and women typically have large families with the children closely spaced (average of 4.8 children: EDHS 2002).
- At the same time women have little or no access to information about their own health, nor to health services:

Most Eritrean families live at least 20 km from the nearest health station. Only about 28% of pregnant women deliver with the assistance of a trained health worker (EDHS 2002). The other 72% deliver their babies at home without trained assistance. The most accessible health care provider for many women and communities still is the traditional healer.

• Most often, men are the decision makers when it comes to opinions about the use of family income, or the utilization of antenatal, delivery and postnatal care.

- The cutting of female genitals is a near universal practice among all Eritrean ethnic and religious groups, in various forms of severity, yet limited knowledge appears to exist amongst women regarding the process and the health problems that occur as a result of the practice.
- The increasing prevalence of HIV/STI, unsafe abortion practices, as well as morbidities such as severe anemia have been found to present common risks to health for Eritrean women in childbearing age as well.

Against this background, available, information, it can only be guessed at this stage how many Eritrean women are suffering in silence and ignorance because of this debilitating, yet preventable, and if not so, repairable condition.

And the small percentage of women that have learned that there may be a solution for their problem, may have been inhibited from seeking further help because of:

- Lack of personal financial resources;
- Lack of trained surgeons in Eritrea to perform such an operation;
- And the difficulties associated with obtaining access to treatment and repair abroad.



In this context a medical mission consisting of a team of 4 gynecologists from Stanford and Johns Hopkins universities in the USA, with subspecialties in neurology, stayed in the Mekane Hiwet hospital between September 24<sup>th</sup> and October 2<sup>nd</sup> 2002 for an operating period of about 3 weeks. These specialists volunteered to perform a number of fistula repair operations and share their skills with Eritrean physicians. In the light of their mandate, UNFPA in collaboration with the Ministry of Health supported this important initiative. Efforts were made to promote awareness about the problem and the possibility of a solution for it by means of radio messages prepared by the Ministry of Health. Via these broadcasted messages women were also invited to come to the Mekane Hiwet Maternity hospital for a pre-operative assessment and possibly, a repair operation.

In this way, through medical personnel in other hospitals, and via word-of-mouth, many women were reached.

Thirty-seven of these women actually managed to come to the hospital, most of whom were in desperation about their problem, and were hoping to find a long sought after solution.

Out of these 37, thirteen women shared their personal stories as a testimony of an important Eritrean health problem needing urgent attention.

#### **Objective of the case studies**

The overall purpose of this assessment was to gain more insight in the problem of obstetric fistula in Eritrea.



The more specific aim was to supplement the medical/health care, and operational information available to the Ministry of Health with "real life" experiences, by describing a number of simple case studies, based on open-ended questions, and derived from person-to-person interactions with Eritrean women suffering the humiliating and devastating consequences of fistula.

These "case studies" do not pretend to be an anthropological study, but are rather designed to connect all of us interested in improving the lives and living conditions of women in Eritrea with a number of truly stirring, case studies of a number of Eritrean women of child bearing age. At the same time it is believed that a continuous shedding light on personal experiences of this important target population will provide valuable guidance for future action plans in the area of women's reproductive and emotional health.

#### **Background of the women**

All women spoken with were admitted at the maternity hospital in Asmara after learning about the fistula repair mission, either via promotion messages by the ministry of health via the radio, through medical personnel at other hospitals, or in some cases via word of mouth.

Out of 37 patients coming for fistula repair, 21 women belonged to the Tigrynia, 2 to the Hedarb, 9 to the Tigre, 4 to the Saho, and 1 to the Belen ethnic group.

The following 13 case studies are representing these ethnic groups in the modest sense that conversations took place with 1 or more women belonging to each ethnic group, and that participating women were chosen randomly from amongst the 37 patients.

All conversations took place in the hospital setting, before and/or after the fistula repair operation. In order to protect the identity of each woman, their original names were omitted. Similarly, names of health staff and in some cases health facilities have been left out in order to maintain anonymity.

#### Type of interview

General information was gathered about each woman, such as: origin, ethnic group, age, marital status and educational status. After that a number of simple, open-ended questions were asked to guide or stimulate conversation, e.g. about extended family, means of living, and arrangements of marriage. It proved to be very easy to gain some insight in the more personal aspects of each woman's life from there; virtually everyone was very willing to share details, and beyond that showed much appreciation for an interest in their own life story.

The case studies that follow are mostly literal accounts of what the participating women told. In the case of other than Tigrinya ethnic group origins, either a nurse, or in one case a fellow patient, acted as direct translator of the ethnic language spoken.

**CASE STUDY 1:** 31-year-old woman Ethnic group: Tigrinya 8<sup>th</sup> grade education

Four years ago I became pregnant for the first time. I had been working as a house servant for some years in Addis Abeba. There I got to know a man, and I got pregnant on purpose because I really wanted to have a baby, but the man I was seeing then did not want me anymore.

During the 4<sup>th</sup> month of pregnancy I had a chance to return to my village in Eritrea – it was before the war started-, so I went to live with my mother again. My sister helped me to return home. My father had long since died, but my two brothers were also there. I never had a check-up during my pregnancy: the health center was not close enough, and when the time of labor came, there was no transportation to the clinic either, so I stayed at home. The contractions lasted for 4 whole days and nights, and it was very, very difficult. Finally some people from the village managed to get a car and they took me to the health center. There everything went wrong, it was so horrible. When they pulled the baby out, it hurt so much, and my baby was dead. It had already died in my womb, and there was nothing anybody could do, and I did not know either what to do. I was so afraid and so sad, and I lost consciousness. I do not even know how they took my baby from me, but I never saw it again.

Then they kept me for 3 weeks in the health center, because my condition was very, very bad. And when I finally returned home, my problems never ended.

Since that delivery I have been so sick: I know that then the big damage was done: right away I could never hold my urine anymore, and since then the problem only got worse.

Two years ago I came back to the hospital in Adequala, and again some time ago because I still was so sick, but every time the doctor checked me down there, it hurt so much. Then my uncle, who lives in Asmara, came to visit me in the hospital because they kept me there for one whole week. He told me that sometimes you can be operated and he then helped me to write a letter to the hospital in Asmara to ask me for such an operation. We therefore heard of this mission of doctors coming to do operations, and they sent me a letter on September 8 that I could come. So I came to Asmara right away, and again my uncle helped me to fill out the papers in the hospital. I am very thankful to him.

Now I am here, waiting for the operation. I do not know when they will do it. Nobody came to tell me that, and nobody explained what they are going to do. I have never seen a picture of as woman's body on the inside, but I think that they will do the operation in the lower part of the abdomen, perhaps on the place where the urine comes from, but not on my vagina. The nurse has not explained anything; she just comes in to give us towels and these paper cloths.

But you know, my greatest hope is that after the operation, whatever they do, I can meet people and be married again, and do some work on the land, and perhaps have a child. I just so wish to improve my life's condition. As it is now, I do not have any social life. I have to stay with my mother, and in the house the whole time. I cannot work at all. I have a small piece of land given to me by the village leaders, because of this situation, and my 2 brothers who are ex-fighters, give me some of their money. From the land I get a little bit of grain. That's all. My mother is fortunately still healthy and works on her own piece of land, because my father died 12 years ago during independence.

Everything is so hard right now, but if God wants, my menstrual cycle will come back. Because I haven't had any cycle since these problems started, and I worry about that. Do you think I can have a baby if I have no cycle?? And do you think I will be able to have a baby after this operation? Can you explain it all to me?

My uncle is very good and brought me food yesterday, and my mother will also come to visit me later, so I am not alone. Really, I am not too afraid of this operation, because it is my only hope to get a better life.

#### CASE STUDY 2:

28-year-old woman Ethnic group: Tigrinya Illiterate

This is my story:

I never went to school, and I never got married. I had sex just for play. During Independence, in 1990, I did it many times with a civilian man. I knew him for a year already, and had sex with him many times. He already had a wife and children.

He first always came to our home. Then I got pregnant, and when that happened, he brought me gold, a necklace and earrings, to compensate.

During the pregnancy he still saw me, but when the problems started, he never wanted to see me again.

I never had check-ups during pregnancy, because the health center was much too far. And when the time of contractions started, I came with a taxi to the hospital with my mother. From that moment

onward, I do not want to remember anything of the delivery. It was so very, very terrible. It was the worst time I ever experienced.

First I had labored in the home of a traditional midwife for 4 whole days. They kept me in a separate room, and the women smoked incense for me. They also killed chickens and spread the blood on the floor around me. The midwife pushed very hard on my stomach. After a long, long time my mother went to the health station and brought a health worker back to where I was kept. When the health worker saw me he said: you will kill this lady if you don't take her to the hospital right now.

My mother then had to pay 400 nakfa to take me to the hospital by car.

When I arrived in the hospital, they told me there were two babies, and immediately after arriving, the first baby already came out, then the second one, because the nurse pulled them very hard. But they had already died, and it was worse than worst.

The Doctor was there at the time too, but she did not do anything, just the nurse. When the doctor saw me she just said: the damage has been done, I cannot do a thing now. She has to go to Asmara. I felt so, so horrible.

They did not do anything anymore, and I just had to go to Asmara. In Asmara, the doctor sewed all around my anus and everywhere, 3 days after the delivery. I had to stay in the hospital for a month, because I was very weak by then and needed glucose. But right away the problem with the urine started: I could not hold it at all. I think everything down there had burst open.

The Doctor told me to go to Addis for this problem, because he said there is a special hospital there, but unfortunately the war started, and nothing could happen.

Now it has been 12 years, and my problem has always remained the same: I have a lot of pain, like contractions, when my urine comes, but then I cannot hold it.

My mother told us before that my sister and I have been circumcised, but we don't know what that means. I don't know what part is cut. My mother tells us that we need to circumcise our babies, but we don't know. Is circumcision bad? What do you think?

I remember that the first night of intercourse was terrible though. I was a virgin, and I was bleeding so badly, but people say that you always bleed like that when you are a virgin.

You know, in the village it is said that we women got this problem because of men. If that is true, I hate men for that.

Before my life changed so much, I was working in the grain mills. My mother prepared food for weddings, and I helped her with that too. Now I have not been able to do anything at all for all those years. I live off what the village government gives me. That is mostly wheat. My mother is still very active. She is a trader and goes to Gash Barka to sell shiro, but I have to stay in the house. The villagers know I have this problem, so sometimes they give me 5 or 10 nakfa. And sometimes people who have been abroad give me some clothes. I cannot do anything myself, and it makes me very sad.

Fortunately I have 1 married sister and 1 married brother, and to save rental money, we all live together. My father I have never known: he died while I was a child.

Everything is very hard, but I am so happy to be here now. Some time ago the doctor from the health center sent a person to tell me to come here to Asmara. And then I also heard on the radio about these operations that can be done. So then I came here right away with my mother, last Saturday, and I was accepted. I do not really understand what is going to happen, but I think they are going to stitch my kidney, so the urine does not run away anymore. I heard something like that. So now I feel that maybe I can have a solution to my problem here. It feels like finally after 12 years of waiting, I am getting the services I needed.

If God gives, I so hope to give birth to even one child, whether I am married or not. And if that is not granted to me, I hope so much to be healthy once again and to be able to do some work. That's all.

CASE STUDY 3: 20-year-old woman Ethnic group: Tigrinya Illiterate

My husband is a fighter. I have been married with him since 5 years. My parents arranged our marriage because of money reasons, and I got pregnant right away, during our first days of staying together. My husband came and went, and while I was pregnant I never had any check-ups, because we are living quite far from the health center. I was staying in my mother's house when the time of labor started. She and the neighboring women kept me at home for 3 days while I was having labor pains. All the neighboring women attended around me, but the labor pains became so very bad, that my mother finally decided that I should go to hospital. Some men then took me to the health center on a stretcher, and it was quite a long walk. From the health center they took me to the hospital by car. I arrived in the hospital at 8 o'clock in the morning and the labor pains went on and on. I gave birth at 4 o'clock in the afternoon. In the end they just pulled the baby out, but it had already died. It was really horrible.

I stayed in the hospital for a day, but they did not sew me up again, even when there seemed to be a big hole. Then after a week the problem started, with my urine running. I did not even have pain anymore, nor contractions. But up to this day I still cannot do anything.

I do not know if I am circumcised or not. But I have once seen the circumcision of a boy. Otherwise I do not know anything about it.

My husband has been good to me. Soon after my problem started, he wanted to take me to Addis, because he had heard there is a special hospital there. But the war broke out and he had to join the army. Now, for almost 3 years, I have not heard from him. I live with my mother and father. I also have 2 sisters and 2 brothers, but they live elsewhere, although close as well. Only 1 brother lives with us. My family members are farmers, so I do not have a problem with food, but I cannot do anything myself.

Some people come to visit me at home, but that's all. Sometimes I feel very alone. In January I felt so bad, I came to this hospital for a check-up. They then asked for a contact number of a relative. This relative sent a person to the village to tell me about the possibility of an operation. The hospital contacted me after that: I heard on Wednesday, and arrived here on Thursday. My father brought me and went back to the country. Now I am here alone. I do not know when they will do the operation. I do not know what they will do either. Perhaps something in my abdomen.

But I hope that when my problem gets fixed, my husband will come back to me, and that then we can live together and have a child together.

I still have a lot of fear, because I do not know what will happen with me afterwards, but my biggest hope is that I would still be able to have a baby. And therefore, I am happy to be here now, because it is my only chance.

#### **CASE STUDY 4:**

39-year-old woman, Ethnic group: Saho/Tigre 11<sup>th</sup> grade education

Perhaps my experience is different than that of most women here:

I live in Asmara, by myself, and I am working in a clinic for disabled ex-fighters as a health worker. I earn 1300 nakfa per month, so my living conditions are all right. Unlike many women here, my pregnancies were normal; I went for regular check-ups during my pregnancies, and there were no

special problems related to childbirth. I have a 21-year-old son, who is in technical school, and a 13-year-old daughter in 8<sup>th</sup> grade.

But I still have a fistula problem. It all started in 1988, at first not so seriously, but it worsened over time. I have had 3 fistula operations already. First I just had problems around my anus, but now the problem has expanded to my vagina. After being sick for long stretches at the time with diarrhea, I got fistula. I do not have a problem with running urine, but having to cope with frequent diarrhea with sour faeces caused me to have more and more fistula. The operations did not help – my condition remained the same, but after the  $3^{rd}$  operation it all became much worse.

I expect they will take the entire fistula away now. I know my problem is unrelated to childbearing. But in 1988 I went to Massawa every week to help my mother build a house; the weekly journey in the bus, all the walking, the hard physical labor, and also being a fighter became a cause of my problem. It is very terrible, because now I have to use sanitary towels all the time, because of the discharge from the fistula. I have a lot of pain too, but I continue working to earn our living. My husband was a fighter as well and died during the war.

The doctor who operated me before, told me about the mission of specialist doctors coming to Asmara, and recently I heard it on the radio as well, so I came yesterday and was admitted. While being a fighter, I got training as a health worker. That was a good opportunity, so now I can continue the same work. Because of that I have also done my nursing exams.

I feel good about being here, because there may be a better solution to my problem now, and that will make life much, much easier for me.

#### CASE STUDY 5:

20-year-old woman Ethnic group: Tigrinya 7<sup>th</sup> grade education

My problems started two years ago. I had a normal pregnancy, and went for monthly check-ups because I had learned that that was a good thing to do. Even the delivery went normally, but there was a nurse, who was just in training, and after my baby was born, he pulled the placenta out by force. It was like he was pulling a rope with a lot of strength, I do not know why, but it hurt terribly. Because normally they only press the stomach hard. But when he pulled, another nurse shouted at him: don't do that!

I was torn badly down there, so they had to stitch it all up, but everything got infected, and that infection never seems to have gone away. Since that time I always have terrible pains in my abdomen. And since that time, my menstrual cycle stopped completely. Do you think that is normal?

I am still breastfeeding my baby quite often, but while I am here in the hospital, my baby is with my mother, and my breasts hurt a lot. I do not know what to do, because the baby is not allowed to be here.

Since the delivery of my baby I continued to have a lot of pain, and I think that is because that infection never cleared away. They gave me tablets a few times, but they did not help. I went for several check-ups because the problem got worse all the time, but they also did not help. Then I heard via the radio that more women have this problem, and that it is possible to have an operation. So I came as soon as I could, because as it is I cannot do anything at all.

I live with my father and mother. My husband is with the defense force. I have not seen him for 7 months now. And before that, when we tried to have sexual intercourse, it hurt much too much because of my problem, so I could not do it anymore.

My father and mother got separated before. I now live with my mother and the baby, and my husband sends a small amount of money, like 200 nakfa sometimes, which he gets from the government. We live off that money, we just don't have more; my mother has very bad eyes, and cannot work. I myself was a waitress before, but because of my problem, I cannot do such work at

all anymore. My only brother is married so he does not have money left to give us. My husband's parents cannot spare anything at all. And I don't know when my husband will return, or if he will return. I did get married to him because of friendship, not because it was arranged. Fortunately the baby has stayed healthy up to now.

I really, really hope that after this operation will be done, I can work again. If I get healthy again, I will take up any type of work at all to earn us a bit more to survive.

I would also like to have more children, if God so wills, and if I can be together with my husband again.

Sometimes I don't know; I want to be with him again, but at the same time I hate him for having sex with me the way it was, and then causing me this problem. And now I cannot even have sex with him anyway anymore. Only when my problem gets fixed, I can be with him again, because like it is now, sex gives me too much pain and suffering. Before I did not have any problems with having sex.

I have not been circumcised, because my mother does not like that at all. She says 3 of her babies died because she herself was circumcised, but I do not really know what she means, or what it means to be circumcised.

Now I am not afraid of this operation. Instead I am happy that I have decided to come, because it is the only thing that may at least change my future a little bit.

#### **CASE STUDY 6:**

20-year-old woman, Ethnic group: Tigrinya 6<sup>th</sup> grade education

I got married in 1999, when I was 17 years old. My husband is an ex-fighter, and he lives with me. He lost one arm in the war and cannot work anymore, but the government gives us some money. I do not know how much we get, because only my husband knows. My husband is 32 years old, I think.

After we married, I got pregnant immediately. While I was pregnant I went for monthly check-ups at the health center. There they told me everything was normal.

When the labor pains started, I immediately went to the health center by ambulance, because that was the only transport. I stayed in labor in the clinic, 3 days long. The baby finally came out with too much force, and everything down there tore open. It hurt terribly. But they sowed me up right away.

My baby only lived for 7 days. I was at home with her, but she got a cold and it was very bad, and then she suddenly died within a day. It's so very sad.

But I did not have any problems from the stitches or from the delivery. I also could resume having sexual intercourse with my husband. During those days he was not there all the time, he was coming and going, and it seemed to go all right.

I got pregnant again in October 2000, and delivered in July 2001. This time I also went for checkups. The pregnancy went allright, but the problem began with the labor. I went to the nearby clinic when the contractions started. For 3 whole days I labored. Only sometimes the contractions would stop. There was no doctor. At last the nurse decided it lasted too long, so they took me to the health center by ambulance.

There they saw there was a problem out of their control, but only after one night they took me to the hospital. There they prepared to take the baby out by operation. They did the operation for one-and-a-half hours. That is what the nurse told me later. But when the baby came out, he had already died. And they took it away from me...

Later the doctor told me that I was very anemic, and that they had to do a blood transfusion. They took blood from my husband for that. I had to stay in the hospital for one month. But there was a problem right away, because there was a very big tear from the long labor, and since that time I could not hold my urine anymore.

The doctors in the hospital got to know me well, and still now they say: it is amazing that you have survived this all.

It has been more than a year now. My husband and I have tried sexual intercourse, and that seems to not give too many problems, but if I do not drink enough water there is too little urine and then I get a lot of irritation and pain right away by my anus and my vagina.

I don't know what it looks like down below now. My mother told me I have been circumcised, but I do not know what that means.

I still hope so much to have a baby, even only one, if God so permits. I am not able at all to work right now, and I live only with my husband. He is Muslim and I am Christian. We were neighbors and so got to know each other. My family has accepted that I became a Moslem. I do have 3 brothers in the military service, and 1 younger sister of 14, but they all live in Agordat.

I am so glad that I heard about this mission of doctors coming here on the radio. I heard it while I was in the hospital last year. In June I was in the hospital in Keren again for a check-up, and then they told me to come here at his time. So I came alone from Gash Barka. Nobody came with me. I did not even know this hospital. I first slept in Halibet hospital for one night, then found this place only the next day. I only have 150 nakfa with me, but that is for transport back to Gash Barka. We have so many problems, and do not have anything. But we still thank God and as for only one thing: health.

I am here now with big hopes. I do not know when or how they will do this operation, perhaps on the organ for the urine? Because I have normal menstrual periods, so I think those parts are all right. But I think that I will feel like being born again, because now I am like a baby. I do not even have these sanitary towels at home. I just tear old pieces of cloth and wash them all the time. If my urine problem can get fixed, I will feel like a whole person again.

#### CASE STUDY 7:

26-year-old woman Ethnic group: Bilen  $2^{nd}$  grade education

I belong to the Bilen ethnic group, but my father was Italian. When I was 5 years old I went to Sudan with my family, and stayed there for almost 21 years. I married there, but my husband died of severe asthma 4 years ago. My father came to Eritrea during independence, and remarried another woman in Keren. In 93 my mother went to Australia as a refugee. She was 45 then. She took 4 children with her; I have 4 brothers, but from a different father: an Ethiopian man whom my mother met in Sudan after my father left her.

I myself married an Eritrean man in Sudan, and got pregnant 3 times from him. But only 2 of our children survived. I got married when I was 14, but I only got pregnant for the first time after 5 years, I don't know why.

I did go for monthly check-ups. The pregnancy went normal. Also the baby came out normally. When the contractions started, I went to the hospital in Sudan, called the Abraham Malik hospital, immediately. The baby was born and was healthy, and still is up to now.

It took long before I got pregnant again, even though I never used anything to prevent babies from coming: 4 years. With this pregnancy again I went for check-ups all the time. The delivery went normal again, in the same hospital. My son who was born then, is now 6 years old.

Then I got pregnant again after 1 year, and again everything seemed to go allright. But God did not let me keep this baby: my little girl died from pneumonia after 9 months.

And with that sorrow it did not end: a month after the last delivery my problems had already started. With all 3 deliveries I had very big tears, but they stitched me right away. I am not sure what went wrong, but since 1988 my faeces just comes out by itself, I cannot control it. Therefore I cannot do anything anymore. I lived by myself, with my 2 children in Khartoum. My mother sends me some of the money that she gets in the refugee camp in Australia, because I still have to pay house rent and the children go to school now. Life is very, very hard for us. When this problem started, I immediately went to the hospital. I already became aware of a problem after they sewed me up after the last delivery. The stitches were not done well I think, because very soon after I felt a big hole, and then faeces passed through that hole. One year later I went to the clinic. The doctors told me that there was no problem with the stitches and that everything was healed. Then I went to a private doctor as the hole became bigger, and my legs really started to hurt, and also my abdomen. This doctor then advised me to have an operation. So I went back to the hospital in Khartoum and there they re-stitched everything again. But just after the operation I went to another room, and had to vomit so badly, then everything burst open again. They left me like that in the hospital, all open, and then sent me home. I was shivering with the pain all the time, and had to wash the hole with salt water, otherwise it would get too infected. Three months later I again had an operation; they tried to join the two loose pieces of skin and make it straight, and sowed it all up again. But some parts of the skin were very rough by now and they did not do it well. So the problem only continued, but much worse.

Then I left my 2 children with my deceased husband's brother, and came to Eritrea, in October 2001, to see my father in Keren. Soon after I came here, I had such bad pains in my chest, and I was losing weight. So I went to the hospital for a check-up for everything. There they told me I have TB now too, and they gave me medicines for that. When I went for that TB. check-up, I still had a bad infection down below. I told the doctor, and he said: " there will be a mission of doctors arriving in Asmara soon who may be able to help you. You cannot return to Sudan now, wait for this mission." So I waited and meanwhile lived alone in a tiny rental place in Keren. Then I came to Asmara already on the 11<sup>th</sup> of September, and I will be operated today they say. I am not so afraid of the operation, but very much of the pain afterwards, because I know my hole is very big.

Even, I was circumcised too, but my circumcision was small. Not like the Bilen women usually do, which is to take all the female parts away and then sew the hole shut. I never had problems with sexual intercourse, because mine was not so big.

But in the future I do not need another man, and I never ever want sexual contacts anymore. I am only thinking about how I can possibly raise my children. Because my little baby girl died, I would love to have a little girl once more, but yet I would never want to give birth again. The only thing that I am sometimes thinking about is that if I have an opportunity, and if I get more healthy again, I could perhaps adopt a little girl.

#### **CASE STUDY 8:**

25-year-old woman Ethnic group: Saho Illiterate

I have never gone to school. I just helped at home. My parents arranged my marriage so when I was 17 years old, I got married. For 7 years I lived together with my husband, but God never gave me a baby for all those years. I only got pregnant 1 year and 1 month ago, and have been living with my parents from the time of the birth. I shall tell you why.

While I was pregnant, I never went for check-ups, because the health station was too far away from our area, and there are no vehicles to reach there. When the time of contractions started, 4 men carried me on a stretcher from Oubel (in the southern region) to the health station. But then, my mother and the neighbor woman first kept me in the house for 2 days. It seemed to last so long, and only when the labor pains were getting too bad, they took me to the health station. It took more than half a day walking to get there. In the health station the nurse listened to the baby, and said it was not possible to do anything there. They sent me by ambulance to the health center. The same happened in the health center, and from there they sent me to the hospital. By that time I had lost consciousness. It still took 2 days for the baby to come out, but then it had already died. It was so terrible, and I had a big, big tear, and they sewed it together. I went home, and after 3 days the stitches healed, but I could not urinate. I always had to stand up and push hard on my belly to make the urine flow out.

When that problem started, I went back to the hospital, but the nurse there told me to go to Asmara. So in July of this year I came for a check-up here, and the doctors told me that this mission of special doctors would come, and that I would have an opportunity. We do not have a radio at home, but my neighbors told me about it too, because they have a radio, and they heard about it that way. I came last Monday, with my mother. She is now staying with a relative in the town now.

You see, I still live with my parents and my 4 sisters, and 1 brother now, because of my problem. We have a piece of land on which we farm. And we sell some wood to get some money. I do not want to live with my husband now, because I have this problem, and I cannot have sexual contact. I sent him a letter, because he is far away now, but he never came to see me after the delivery when he heard everything. Before that, we could have normal sex.

I was circumcised, but they did not cut away any parts. They just closed the hole and left a tiny part open. But there was no problem with sex because of this. I do not think so anyway, and we just could do it normally. But that is over. Now, I can only try to help my mother in the house to make coffee and enjera, but I cannot go out, and I cannot even do laundry.

But I am here now, and maybe things will get better. I do not know at all on which parts they will operate. Nobody told me that yet. I also do not know when they will do it, but I am not fearful, because I hope so much that my problem will be solved now. Because if I get better, I want to go back to my husband and have a child with him. I really, really hope that will be possible.

#### **CASE STUDY 9:**

21-year-old woman Ethnic group: Tigre Illiterate:

If my mother had been alive, I would never have had the problem that I have today. My mother died 12 years ago while she was giving birth. She stayed in labor for 2 whole days. Then she died, and her baby too. But I needed her when I got pregnant myself...

I got married in '97, with a Christian man. Before that I was serving in teashops, and got to know my husband that way. When we got married, I was a virgin, but my husband never managed to penetrate and "de-virgin" me. But somehow I got pregnant anyway. I think he was sick, because he could never "do it" and it made me dissatisfied. So after 3 months I went to live with my father again, even when I was pregnant. During the pregnancy I went for check-ups in the clinic nearby. There they told me everything went as expected. When the labor started my father brought an Eritrean midwife and I asked her at that time: "I am a virgin, how can I deliver my baby?!" I have not been opened up. Please take me to the hospital so they can get the baby out by operation."

So I went to the maternity hospital. There the nurse put in her hands by force, because my opening was too small, and I had enormous pains. After 2 hours the contractions started. The doctor came

and said: "her opening is much too narrow; her parents must have arranged her marriage when she was too young. " And it is true: I got married when I was 16, because my father arranged it so. When the labor pains started to get worse and worse, the doctor pulled the baby out by force, but she was alive. I had a big, big tear and they sewed it together. But right away I had a big problem: I could not control my faeces anymore. The doctor did an operation after 6 months to fix it, but one month after that operation the same problem returned, although it was a little better than before. Before I could not hold any faeces, but now I can sometimes.

Still I cannot work or do anything at all, and when my baby was 1 year and 3 months old, I gave her to the father because I could not financially support her. Before I only got some money from the work in the teashops. My husband from before then lived in Keren and that is where my child went. I never heard anything about her afterwards, but when she was 2 years old they sent me a message saying that she had died, and they did not even tell me how or why....

My second husband I have now known for 3 years: because I do not have the faeces problem continuously, we can have a normal sex life. But I have been living together with him for only 1 year. Two years and 6 months ago I even got pregnant again. I went for check-ups and delivered while living with some relatives. During this time of labor and delivery, the labor pains started on Friday, but the baby only came out at midnight on Saturday, in the maternity hospital. I again had a very big tear and they had to sew it al shut again. This time the outside stitches healed, but the inside ones did not, and the faeces started to come out by itself, and that never changed after that. Still it does not affect my life with my husband so much, because he accepts my condition. And he supports me with money. He is a tailor so we can survive as is. And I can also move around a bit, because my problem only has to do with faeces, so it does not happen all day long.

But while going for a check-up I heard that there was the possibility of an operation for such a problem, and then I also heard about the mission of doctors coming. So I came here on Monday and was admitted. Nobody at all told me what they will actually do now, so I feel indifferent about this operation, because what can I feel if I don't know?

But my big hope for the future is now that my problem gets fixed, and that my husband and I can have 2 more children.

#### **CASE STUDY 10:**

30-year-old woman Ethnic group: Bilen Illiterate Post-operative interview:

It took me 3 days of traveling to reach here. I really wanted to come because it is so important to me; for 5 months now I have had such big problems. I will tell you how it all happened: I don't really know when I got married, but I think it is about 10 years ago. My parents arranged my marriage. After 4 years of marriage, I got pregnant for the first time; my husband was moving all the time, for the farming seasons. His land is in different places, but when the harvest time arrives, he comes back home.

While I was pregnant, I never went for check-ups, but my baby was born normally after 12 hours of labor pains. I was with my mother at home, and my baby was a little girl. Something had burst open, so my mother sewed my vagina together again with thorns of a bush, like my people always do. My baby girl fortunately stayed healthy and is 5 years old now.

When I was pregnant again after 2 years, I got vaccinations and I went for check-ups: there is a clinic nearby, and when I felt sick during the beginning of the pregnancy I went there, and there they told me to come a number of times during pregnancy. So I did.

When the labor pains started, the neighboring women came to help. I was staying with my mother, because my husband was not there. I stayed in labor for 2 whole days and 2 whole nights. Then, because it took so long for the baby to come, my mother opened the parts of my vagina that were

sewn together the last time. But still the head of the baby stayed there for a long time without being able to come out. Finally the baby did come out, but it had died already. I was torn badly, but my mother and the neighbor sewed the lips of my vagina with thorns together again, very tightly, very narrowly. After 7 days they took the thorns out. I know that when I was very little, they did the same. And now they had to do it again.

Two weeks after the delivery, I got very bad headaches and fevers. I went to the clinic, and they gave me some medicine.

After 10 weeks I could not hold my urine up anymore. Again I went to the clinic and they referred me to the hospital. They told me I was anemic, and that I had to drink milk and eat meat and feed myself well. I stayed in the hospital for 5 days, and then they told me to return after 40 days. When I returned at that time, they referred me to Asmara. So I came here and here I was told of the mission coming.

From the time I was 5 months pregnant, I had no relation with husband anymore. He did not want me anymore. He does not even come to visit his baby girl. But I know he is doing the same work: traveling and farming.

Now I hope that if my problem will finish, I will still find another man and get married again. Do you think that I can ever get married again? Who wants you with such a problem? (she points at her urine bag and catheter) It is just after my operation now, and I cannot know how it will be later. But it is my biggest wish to have some more children. And if it would be possible to marry again, I would arrange my OWN marriage. I would not listen to my mother and father again for sure. But first I have to get healthy. I still am anemic the doctor says, but we do have some goats at home, so I do get some milk to drink and bread to eat. And the parents of my former husband have brought me some food and a goat after the 2<sup>nd</sup> delivery. But he himself does not come back...The money that I need to survive; I get from my father and mother.

Now, after the operation, I feel more or less allright, except for some severe headaches. But I hope that those will pass and that everything will be fine.

#### **CASE STUDY 11:**

18 years old woman Ethnic group: Hedarb Illiterate Post-operative interview.

I think that I am 18 or 17 years old. I was a fighter. I got married 3 years ago, because my father arranged it so. We always accept when our fathers arrange a marriage for us.

But you should not judge me by my physical appearance: I may look older than you think, but I am only very young, yet married.

Immediately after getting married, my husband went to national service. Because he left, I stayed to live with my parents. When he returned after one year, I got pregnant.

When I was 6 months pregnant I went to the nearest clinic. Because I know that pregnant women have to go for check-ups I went there by myself. I never ever went to school, but I learned that because the clinic is nearby, and I had heard it there before. That's why I also got vaccinations then. And I went for a check-up again the next month.

I had my labor and delivery at home. The village birth attendant came. I stayed in labor for a whole night, a whole day, and a whole night. When the fluid came, the midwife cut me open with a traditional knife, such as midwives always use. That was in the morning. Still then the baby only came in the evening. It was a girl, and she was alive. She even is here in the hospital with me! (As she talks about the baby, her mother enters with the baby girl and sits down to listen).

My mother and the midwife had only cut half of my opening to let the baby pass and the rest broke open during delivery. My mother was planning to sew it all shut again in our traditional way some

time later, but then I got a big problem. And my husband had already been complaining that they had sewn me up so tightly. He always had a problem with entering me during sexual intercourse, so he told my mother: "don't sew her up like that again!''

(At this point the little baby girl is put on the bed by her grandmother, and the mother and grandmother show the baby's vagina, while the mother comments): Now look at my baby girl here. She will NOT be circumcised because look at me and see what big, big problems that brings! (Upon which comment, grandmother nods vigorously).

Since that delivery, I have never been able to hold my urine anymore.

Twelve days after my problem started I went to the health center nearby. The referred me to the hospital and admitted me for 3 days. They gave me some kind of medicine. They told me that if I could not keep my urine for one month, I should return, and that if I could, I should stay home. But the problem continued, and even got worse. So then they sent me to Asmara: I came one month ago and they told me about the mission of doctors coming for these special operations. And because I came from such a remote area, I was allowed to stay with my baby and mother. They are so kind for us here, we are really thankful to the hospital.

It has been 6 days since my operation now, and I feel more or less allright. I only had a bit of fever. Because my husband has not returned yet, I will go back to my parent's house. But when he comes, we will live by ourselves. You know, I feel lucky, because my husband is of my age. Most of the time that is different.

But while I was having this problem, I could not do anything. My family moves from place to place for their farming. But what can I do? I feel disabled. The only thing I could do in the last months is feed my baby, and every day I cried almost the whole day. If only my problems are resolved now, I so hope to be able to do a little bit of work again. You see, I am the youngest of 4 children. The others are all in national service.

I have a big fear now to have another baby, because the same thing might happen again. I think I shall await the advice of the doctor now to see whether I could have another baby. But I would so much want that.

#### **CASE STUDY 12:**

23-year-old woman, Ethnic group: Saho Illiterate Post-operative interview

My husband and I live by ourselves. We got married 1 year ago, after my father arranged our marriage. After marriage, I got pregnant right away, but I never went for check-ups, because there was no health station anywhere close.

When the time of my labor came, the women around me never touched me, but sent me to the clinic immediately. So I went by Red Cross car to the hospital, after the health station people referred me there. I had first stayed in that health station for 14 days and after I had been having labor pains for a long, long time they said I should go to the hospital. In the hospital they did an operation to get my baby out, but it was so, so terrible that I cannot tell you: my baby had already died. And immediately after the delivery, 5 months ago, my problems started: I could not hold my urine at all. It feels like there is such a big hole down there. Because of that, I went back to the hospital, and there they referred me to Asmara. When I came there, they told me about the mission coming at this time. So I came right away and was admitted.

Now I have had my operation and I can feel my urine running: it hurts very, very much. But before I could not feel anything, it was like being paralyzed. I could not do anything at all.

Of course I have been circumcised. Amongst my people they sew everything almost completely shut, to leave just a small, small space for the urine to come out. When I got married, my husband

tried to enter me, but because it did not work, some neighboring woman tore my parts below open a little, so sexual contact would work.

But before my baby was born, nobody touched me again to open me more.

You see, my husband is a farmer, but he lives far away from me, because he has to follow the goats in the farming area. I now live with my brother-in-law and his wife because I cannot do anything by myself, and because my mother died while I was a little girl. She herself died while having a baby. But my brother-in-law gives me some money. And after the delivery my husband visited me once in the hospital, then he left, and I have not ever seen him again. But I believe he will come back. At least he knows that I am in the hospital. And if my problems will end now, I really very much want to have a baby. That is what I hope most. But if my condition remains the same, I just cannot. Because in the past months I could not even go anywhere. The only thing I could do was help with very little things in the house. I so hope that things will turn for the better now, even when I do not know at all what they have done to me during this operation. Nobody came to tell me about that. But I just hope that it will all turn out to be easier and better.

#### **CASE STUDY 13:**

19-year-old woman Ethnic group: Tigrinya Illiterate

I married when I was 15 years old, and lived with my husband together since then.

I gave birth 3 months ago, for the first time: my husband is in national service and only comes to me sometimes. Most of the time I live alone. My husband has seen our baby, but he was not there for the delivery. But my husband's relatives live nearby.

While I was pregnant I never went for check-ups. I did not know that I had to go. I only went to school up to 3<sup>rd</sup> grade, but I do know how to read and write.

When 1 month was remaining before the delivery, I went to my mother's home on foot. It took me several hours to get there. When the time of contractions started, they put me on a stretcher and 4 men took me to the nearest health clinic. From there, they referred me to hospital immediately. I had then been in labor for a long time. I don't know exactly how long, but long. In the hospital, they made a tear to open me up and then pulled the baby out. And after the delivery they referred me to another hospital, I do not know why. I do not know even if I have been circumcised, I might have been, but how can I know? I sometimes hear people talking about someone being circumcised, but I do not really know what it means.

I never really had a problem with sexual intercourse with my husband either; my opening was big enough. But then during the delivery, there was a problem. In Araza they gave me medicine, because I think I had an infection. I had to stay for 14 days. I could not even move my legs at all. It was like they were paralyzed. While I was there in the hospital, a big problem started with my urine flow. I could not hold my urine anymore. Then I went back to the Zhoba capital, but there they told me they could not do anything for me. So I came with my husband to Asmara, to this hospital, and then they told us here that there was a group of special doctors soon to come here. We went back home, and then I also heard it on the radio. So I came in time, together with my husband, my mother and the baby. My husband is also in Asmara right now, still for the national service. But my money is coming from my father-in-law. He is a farmer and can give me some grain and other foods.

Right after the delivery I stayed with my mother, so she could take care of my baby, because I cannot do much at all.

My husband and I cannot have sexual intercourse anymore either. It just was not possible. But my husband encouraged me to do this operation and says that soon I will be cured.

Now, after the operation, I am not sure that there will be a difference in my life. There still is that tube through which my urine passes, so I cannot feel it. I think they did not do anything in my abdomen, but in my uterus, but I am not sure.

But if it is going to be true that I will be cured, I want to have another baby. Even when I am very afraid that the same problem would happen again. A boy or a girl: I would love either one so much. Just let it be true.







