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Living with fistula: An examination of the social and cultural consequences and careseeking behavior in DR Congo

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I have lived through very difficult times. I must wear diapers all the time like a baby. These cloths cause sores. I release odors which prevent me from being with other people. It is difficult because my life has been dramatically reduced and the flow of urine increases. I cannot engage in any activities. This condition has taken away all of my value as a woman or mother. I cannot even do anything for my three children. I must stay in one place to avoid offending other people. This condition makes everybody uncomfortable. (Woman with fistula from Lodja)

INTRODUCTION

While more than half a million women die each year in pregnancy and childbirth, the number of women and girls who survive obstetric complications and subsequently live with maternal morbidities extends far beyond pregnancy-related deaths (AbouZahr 2003; Gulmezoglu et al. 2004). The World Health Organization (WHO) estimates that maternal disabilities resulting from severe obstetric complications affect 15-20 million women worldwide each year. These disabilities include severe anemia, Pelvic Inflammatory Disease, genital prolapse, incontinence, nerve damage, pituitary failure, depression, infertility and fistula.

The global prevalence of fistula is not known because the condition mostly affects young women and girls of low socioeconomic status living in rural areas; moreover, the shame associated with fistula stigmatizes women and forces them to isolate themselves and to maintain silent about their condition (EngenderHealth 2006). Vaginal fistula is a severe injury consisting of an abnormal opening between the woman's bladder and vagina (vesico-vaginal fistula) or between the vagina and rectum (recto-vaginal fistula), allowing urine or faeces to leak continuously and uncontrollably. The condition most frequently occurs during prolonged, obstructed labour and affects women living in resource-poor countries where access to emergency obstetric services is difficult. In these settings, fistula repair is rare. When not repaired the condition causes incontinence and can result in an inability to carry and bear children, often leading to devastating consequences on the social, economic and psychological status and health of women affected (EngenderHealth 2006; Lister 1977; Murphy 1981; Wall 1988). This is particularly true in societies where the value of women is closely linked to their role as child bearers and childcare providers (Wall 1988). Their productivity and ability to carry out routine household chores may also be affected, causing them to be viewed as a burden to the family. An inability to work and interact with community members due to fear and public humiliation further plunges them into poverty and social vulnerability. Moreover, a wife and mother suffering from a chronic disability is likely to affect a broad range of family members in a variety of ways. For example, studies examining the impact of other adult illnesses and debilitating conditions have found that reduced productivity of a female household member results in reallocation of labour (National Research Council 2000). Older children, particularly girls, are reported to have dropped out of school to assume their mother's responsibilities. Financial costs involved in seeking care also place economic burdens on family systems, adding to the economic strains a family may have already experienced from losing the woman's work productivity.

There are three sets of causes of fistula, including obstetric, traumatic, and iatrogenic. While obstetric fistula is by far the most common cause, it can be prevented if a woman experiencing prolonged or obstructed labor has timely access to emergency obstetrical care, specifically a Caesarean (c-section). Traumatic fistula is most common in war-torn countries and is generally caused by gang rape or the insertion of foreign objects into the woman's vaginal canal. Iatrogenic fistulae are caused unintentionally by errors made by health care providers during surgery such as c-sections or other surgeries unrelated to childbirth. Recent data suggest that

iatrogenic fistulae are more common than previously suspected, with information gathered from women seeking fistula repair suggesting that 10-15 percent of cases have iatrogenic fistula (DHS 2008).

Recently, much attention has been given to fistula in the war ravaged eastern region of the Democratic Republic of Congo (DRC), where gender-based violence involving gang rape and mutilation of women with probing objects has been widely documented (Longombe 2008). This extreme form of gender-based violence, which appears to be mainly perpetrated by military groups, constitutes a weapon of war and is reported primarily in the conflict zones of Eastern DRC. However, even in the war-torn East, the most common cause of fistula is obstetrical, which was reported in 82 percent of the cases treated in the Panzi Hospital in Bukavu, one of two fistula treatment centres in the East, between 2006 and 2007. Given the poor state of the health infrastructure, the long distances women must travel to access emergency obstetrical care, and insecurity in the region, this is not at all surprising. Moreover, poor access to emergency obstetrical care and long distances to facilities exist throughout DR Congo. Despite this, little attention has been given to obstetric fistula in other regions of the country.

Funded by USAID, AXxes is one of several projects within the SANRU program. A major emphasis of the Project AXxes involves access to curative health care, which has included providing treatment to women with fistula. In this regard, at the outset of the project several physicians were trained in fistula repair, with the goal of placing the trained doctors in different hospital settings where women with fistula could obtain their services. However, once trained, many of the physicians opted to seek work elsewhere and the numbers of women accessing care was fewer than expected. With the goal of making services more accessible and sustainable, the project decided to create a mobile unit, which could visit different health zones over a 4-6 week period and provide treatment to women with fistula in surrounding areas. These sessions have been extremely well-attended, with the number of women in need of fistula repair typically exceeding the number of available beds and the time available to surgeons to repair fistula cases. It is now important to understand how the mobile unit approach compares to treatment provided in fixed health facilities, in terms of accessibility and quality of treatment.

Using a mix of quantitative and qualitative methods, the study was carried out in three sites in non-conflict regions of DR Congo. This included one urban site in Kinshasa offering fistula repair at the hospital level and two rural sites in Lodja, Kasai Orientale Province and Kabango, Katanga where mobile fistula repair services were offered. The study aimed to describe the lives of girls and women before and after having developed fistula, including the prenatal period and childbirth, as well as the physical and social consequences associated with the condition and attempts at obtaining care. The results are meant to guide policy makers in establishing recommendations for prevention of fistula and appropriate treatment approaches.

STUDY OBJECTIVES

Primary objective:

To examine the social consequences and careseeking behaviors of girls and women who develop fistula in urban and rural settings in DR Congo

Specific objectives:

- 1) Describe the socioeconomic characteristics of girls and women with fistula
- 2) Examine the physical and social consequences associated with their condition and how this changes over time
- 3) Examine the local understanding of the condition, including causal explanations
- 4) Delineate health seeking practices and identify obstacles to accessing treatment involving fistula repair
- 5) Compare programmatic approaches available to treat women with fistula.

RESEARCH METHODS

The study employed a mix of quantitative and qualitative methods carried out between March and June 2010 in three sites, including Kinshasa (St. Joseph Hospital), Lodja (mobile clinic) in Kasai Orientale Province, and Kabongo (mobile clinic) in Katanga Province. Inclusion of the three sites allowed us to make comparisons between urban versus rural settings, and fixed versus mobile services, as well as other assessments related to obstacles to seeking treatment, socioeconomic profiles of the women, and cultural differences.

Study Design and Sampling

Quantitative

A closed-ended questionnaire was administered to all of the women obtaining vesico-vaginal and recto-vaginal fistula treatment in these three locations. Socioeconomic and demographic information on the woman was collected, as well as information specific to her condition. Information collected included:

When the condition was detected:

- her age, educational level, economic situation, marital status, parity, province of origin, the cause of the fistula, and treatment subsequently sought

At present:

- her age and years living with the condition, economic situation, marital status, parity, living children, place of current residence, treatment sought

Qualitative

Qualitative data collection involved key informant and in-depth interviews and group discussions. The purpose of these interviews was to gain a greater understanding of women's lives since the onset of the condition, including the social, psychological and physical consequences attached to the condition. We also examined what women experienced at the onset of the condition, including the environment in which she delivered, her initial reaction and understanding of her condition, and how she has been treated by family and community members over time. In addition, we examined what treatment options had been sought since the onset of the fistula and obstacles women faced in seeking care. Table 1 presents the data collection in each site.

Key informant interviews—were carried out with experts in fistula and fistula repair including policy makers, physicians, trained midwives, traditional birthing attendants and community leaders. Key informants were interviewed on several occasions with the aim of gaining a broader understanding from different perspectives of the problem, including the perceived cause,

means of prevention and ways to improve access to treatment. Key informants also helped to interpret data as it was collected through in-depth interviews and group discussions.

In-depth interviews—were administered to women with vesico-vaginal and recto-vaginal fistula who accessed treatment services in the research sites. These interviews were open-ended in nature with all of the women suffering from obstetric or iatrogenic fistula. Topics for data collection included prenatal care, family planning, birth planning, childbirth at the time the fistula occurred, women’s understanding of the condition, social, psychological and physical consequences attached to the condition, careseeking behaviours, the way the woman learned about fistula repair, and barriers to seeking treatment.

Focus Group Discussions—were conducted with four types of respondents, including three groups of women (women suffering from fistula, women who accompanied women with fistula to health care facilities, and local community women) and one group of men in each location. Information generated through the group discussions was used to validate data collected during the in-depth interviews and explore both preventative and treatment approaches.

Table 1. Data collection in each site

Site/Methods	Lodja	Kinshasa	Kabongo
Key Informant interviews	5	5	5
Semi-structured interviews	14	9	10
Group discussions	5	3	5

Data Collection and Management

Quantitative

Close-ended questionnaires were administered by clinicians to women with fistula seeking fistula repair. Interviews were carried out in the hospital environment in a private setting and lasted about 15 minutes. Subsequent to the interview, a physician carried out a physical examination to understand the type of fistula the woman experienced and its size and location.

Qualitative

Two researchers with backgrounds in anthropology and vast experience carrying out qualitative studies led the field work. Both researchers have received extensive training on qualitative data collection, including approaches used when interacting with respondents, conducting open-ended questioning with an emphasis on probing, note-taking, and writing up and expanding upon field notes and ethical issues related to carrying out research.

In Lodja and Kabongo women were recruited to translate questions from French into the local language and responses from the local language into French. The researchers were responsible for training the female translators. Criteria for selection of these women included the ability to

speak French and the predominant local languages of the area, a minimum of a high school education, and good interpersonal skills, with a preference for women who had already carried out research.

Interviews and group discussions were only carried out in a private setting; if privacy could not be adequately maintained, the researchers changed the location of the interview or rescheduled the interview for a later time. In-depth interviews took anywhere from 1 to 1 1/2 hours; if additional time was needed to complete the interviews, more than one session was held. For the interviews, the researchers took detailed notes during the interview and expanded upon their notes shortly after the interview was completed. Researchers paired up to lead group discussions, with one acting as a moderator and a second taking notes; discussions were tape recorded and transcribed subsequent to their completion.

Data Analysis

Analysis of the quantitative data was carried out on SPSS. As qualitative data was collected, a coding system based on the initial research questions and objectives, theoretical concepts, as well as emergent themes generated through the data, was developed by the investigators for the qualitative data analyses. Content analysis was used to identify and compare trends of key concepts in the coded data. Data triangulation was employed to identify only those concepts that could be validated through a combination of data sources, such as multiple interviews and group discussions.

Ethical Review

Informed consent was obtained from all research participants. The study was approved by the institutional review board of the Kinshasa School of Public Health Ethical Review Committee which follows international ethical standards to ensure confidentiality, anonymity, and informed consent.

Dissemination and Use of Findings

The research findings were disseminated at the conclusion of the study during a workshop in September in Kinshasa. Participants included government representatives working in maternal health, such as officials in the MOH and the Reproductive Health Program, as well as national and international NGOs working in maternal health and other relevant stakeholders such as WHO and USAID. The workshop was designed to elicit feedback and recommendations from participants.

RESULTS

Background Information

The socioeconomic data presented in Table 2 suggests that women developed the condition at a very young age, with the median age in all three sites under 20 years, and that they lived with the fistula between 8-12 years before getting it repaired. The information also shows that many of the women were uneducated, particularly in Lodja. In each site, there were respondents (Kinshasa 4, Lodja 2, Kabongo 5) who got pregnant while they were in secondary school. The vast majority of women developed the fistula during their first pregnancy, and there were women from each site who already had a history of intrauterine demise.

Table 2. Socioeconomic background and reproductive history of women from the three sites experiencing fistula

Socioeconomic Variables	Kinshasa	Lodja	Kabongo
Median age developed fistula	19	17	16
Median number of years living with the condition	8	8	12
No formal education	44%	71%	30%
Reproductive History	Kinshasa	Lodja	Kabongo
Pregnancy			
- First	6	5	9
- 2-3	2	5	0
- 4-5	0	0	1
- More than five	1	4	0
Former stillbirths			
- 0	5	8	9
- 1-2	2	1	1
- More than 2	2	5	0

Pregnancy and Childbirth

Prenatal Care

In Kinshasa and Kabongo, the vast majority of women attended prenatal care (ANC) visits regularly throughout the pregnancy. The one respondent from Kabongo who did not participate was a girl who apparently did not understand the importance of attending the ANC and was ashamed to be present due to her young age. In contrast, only 6 of the 14 women in Lodja participated in antenatal visits, with most indicating that the distance to the health center and the time the sessions take prohibited them from participating. Fewer indicated they did not have money or did not see the benefit, with one specifying her reliance on the traditional birth attendant.

In general, the antenatal care visits seemed to be something women enjoyed, with many suggesting that it was helpful to share experiences with other pregnant women. Descriptions of the sessions were vague, entailing being weighed and touched by the nurse on the stomach and asked questions. Many women added that attendants confirmed that the pregnancy was progressing well. Discussions around birth planning were absent or minimal, with a few women indicating that the nurses suggested delivery at the center where the antenatal visit took place. The vast majority of respondents suggested that they did not experience any problems or complications during pregnancy. Those few who did have problems described conditions typical of pregnancy including vomiting, back pain and swelling of lower extremities.

Planning of Pregnancy

In each site, about half of the pregnancies were planned, with women adding that it brought them pride and happiness to conceive a child. Respondents from both Kinshasa and Lodja highlighted that having a baby was a way to strengthen or formalize their unions with men, particularly those from Lodja, indicating that because they were involved in a new relationship it was important to confirm their fertility. This Lodja woman explained,

Yes, the baby was planned. As it was a new relationship, we had to have a baby to strengthen the “marriage.” My husband wanted a new baby in the family at all costs. Especially since my two other children were fathered by another man from my first marriage, he wanted also to show his strength. That pregnancy was meant to solidify our union. In a marriage, if a baby does not arrive quickly, the union risks to deteriorate.

In Kabongo, more women were already formally married and proud to conceive a child as a married couple. One woman stated,

My husband followed the official way to give the dowry to my parents. When I conceived, it was a great joy for our young union. My husband and I planned this baby. At that time I was 15 years of age.

Those who hadn't planned the pregnancy indicated that it was a surprise or accident, with some realizing that they were pregnant when other women detected it or were gossiping about the woman's changed body shape. In all sites, several of these unplanned pregnancies occurred amongst school girls who were having casual sex with fellow students. This respondent from Lodja said,

I was surprised by the pregnancy. I didn't expect it. I was 14 years of age and I was only having fun with the young boys who were making advances on me without knowing that this could lead to a pregnancy. For this reason I did not realize it when I got pregnant. It was a neighbor who first noticed. Even my mother didn't know.

Knowledge of Family Planning

Strikingly, the vast majority of women in all sites were not familiar with family planning, with most women confirming that they had never heard about family planning before the subject was introduced by our researchers. Those who had heard of family planning emphasized that it was almost taboo to talk about, with some explaining that conceiving children was regarded as a gift from God and that they desired many children

This Lodja respondent said,

I know nothing about family planning, my husband also does not know about family planning. In the village, it is difficult to talk about family planning, we want a lot of children and don't calculate how many children to have because they come from God. It is God who gives children. If you talk about family planning, your partner might suspect you.

Many other women suggested that introducing the subject of family planning could raise doubts and jeopardize their relationship. The following two quotes from Lodja respondents explain why women find it risky to discuss family planning with their partner.

I do not know what family planning is. It is the first time that I have heard about it. The way we live, it is difficult to talk about family planning with your husband. He will find it strange and it risks to weaken the marriage. The man can talk about it first, but not me the woman because he can chase me from his home.

I know no family planning methods, men do not even want to talk about family planning. The woman who talks about family planning to her husband can even provoke divorce. It is a topic that does not work in our community.

Women also explained that the nature of relationships makes it hard for women to use contraceptives. This woman in the Kinshasa sample stated:

The way that we live in the village, it is difficult to use these methods. A man who finds that you use these methods, which he doesn't know about, will consider you a witch. If a man gives you some things or buys you a *pagne* (traditional cloth), and then after if he has intercourse using a condom, he will feel that he did nothing. He can even reclaim everything that he has given you.

Other women explained that they were trying to get pregnant or that pregnancy and delivery is a mystery that is not discussed. Several respondents suggested that even health workers do not talk about family planning. It was not clear whether women do not value attending the educational sessions that precede the ANC and therefore arrive late to the ANC, or whether family planning is simply not a topic included in the sessions given. This woman from Kabongo explained,

I don't know about family planning. I cannot remember ever hearing about that. If they talk about it during ANC sessions, I have never participated in a session when the nurse talks about family planning. Usually, I arrive late when they are weighing the babies. Given the distance between the health center and my village, it is difficult to arrive before the start of the ANC session.

We also learned from adolescent respondents that, due to their youth, it was considered inappropriate to introduce the concept of family planning to them.

The few women who knew about or had ever used methods mentioned condoms, the calendar method, having the man ejaculate outside the vagina, and sleeping separately from their husbands, which was the most commonly mentioned method. Women explained this is done in order to create child spacing. When those women familiar with family planning were asked whether they had ever used methods before developing the fistula, few had. We received some intriguing responses regarding why they could not use family planning methods. These included: they were too young, family planning is for city women, they wanted to get pregnant because it was the first pregnancy or other pregnancies resulted in miscarriages, men want to have many children, and it causes suspicion and is risky to a relationship. This woman from Lodja said,

Nobody talks about family planning. I don't use these methods; often the woman doesn't have the power to talk about family planning to the man. As the men in our community have more than one partner, you risk being left alone.

Another woman from Kabongo explained,

In the village we do not talk about this. Even if we spoke about it, our men like to have children—you cannot dare talk about family planning. It will cause you a big problem because men like very much to have children. When women find a reason not to have children, the man will suspect she is unfaithful.

Birth Planning

The vast majority of women from Kinshasa (7/9) and Kabongo (9/10) had planned to deliver either in a health center or maternity with trained birthing attendants, with one woman from Kinshasa planning on delivering in a hospital where doctors are available. Some emphasized that women who attend the ANC are expected to deliver in the health center. In general, women felt that delivering in the health center was safer, with some stipulating that safety was particularly important because the woman was young or it was the first pregnancy. Interestingly, many respondents also indicated that money had been set aside for the delivery and transport, and in Kabongo particularly couples placed great emphasis on preparing the 'maternité,' which requires that the male partner buy a new outfit and shoes for the woman and prepare the necessities for the newborn. When the woman leaves the center with her newborn, it

is considered prestigious for her to have delivered in the health center, and she takes great pride in displaying her new outfit while carrying the newborn. If the 'maternité' is not prepared, it is considered a humiliation, forcing the woman to deliver at home. The few women who planned to deliver in the village stated that they had confidence in the TBAs, the distance to the health center was too great, the husband was absent and nobody was available to accompany the woman, and she had not attended the ANC and therefore would not be welcome to deliver in the health center. One respondent from Kinshasa added that TBAs are recognized by the government and women take pride in delivering in the village.

In contrast, most women from Lodja had planned to deliver in the village with traditional attendants or had not planned the delivery and had simply assumed they would deliver in the village. Reasons for planning to give birth in the village included that it is customary and prestigious, the woman had had previous bad experiences delivering in the health center where her babies had died during childbirth, family members advised the woman to deliver with local midwives, the woman's mother-in-law was a traditional attendant, the woman had already had several successful deliveries at home, the woman wanted to avoid a c-section, and the respondent was too young to deliver in the health center. Prevailing belief systems and local understandings of the services offered in the health centers clearly influenced decision making. For instance, one woman explained that witchcraft is the cause of complicated deliveries and there is no point in delivering elsewhere because, once they are after you, the malevolent tactics of the spirits cannot be avoided. After her delivery, this Lodja woman explained,

The traditional midwife said that the vaccine that they give to mothers during the ANC diminishes the intelligence of babies. The best way to avoid those vaccines is to not go to the ANC. Later I discovered that that midwife only wanted to have women deliver with her so that she would receive chickens. Since I arrived at the hospital in Lodja, I understood that a lot of women come to the ANC and the counseling they give them is not to deliver in the village and those who suffer from fistula should have delivered in the hospital where it was possible to do a c-section.

Another woman from Lodja described the prestige attached to delivering in the village,

I always wanted to try the experience, delivering a child in the village brings with it a lot of acclaim. People will say here is that strong woman, she pushed one time and the baby came out. At that moment you are widely admired.

Explanations for not planning the delivery included information that the woman's partner had abandoned her and her natal family rejected the pregnancy; she thought she would deliver like all other village women; the woman was not certain if the pregnancy would come to term; the girl was too young to make a plan; and her first baby had died and she was unsure whether the second baby would survive.

Women who delivered in the village also suggested that the cost involved in home births was relatively minimal. In these cases, a small symbolic gift (e.g. chicken or *pagne*) or sum of money may be given to the traditional attendant. Money is also needed to buy new clothes for the newborn and mother, and beverages (like palm wine) distributed to family and friends in celebration of the birth.

Delivery

Virtually all of the women went into labor when they were in their perspective villages. While Table 3 shows that the majority of women eventually delivered with trained attendants, most women from Lodja and Kabongo spent on average about two days in their villages trying to give birth with traditional attendants before seeking care in a health facility. Fewer women from Kinshasa were assisted by a traditional attendant, and these women also spent less time (on average 17 hours) in the village, with all obtaining care from a trained provider. Choice of the health center was related to where they attended the ANC, distance to the center from their homes and the reputation of care offered. Six women from Lodja and two from Kabongo did not go anywhere for additional care, delivering at home on a matt with traditional attendants or a charlatan claiming to be a trained attendant.

Table 3 illustrates that women typically spent hours traveling long distances to reach the health centers or hospital, with the average computed time in Kabongo being by far the longest, including one respondent who took three days to travel 160 km. to obtain trained care. Women from Kinshasa and Lodja in particular gave vivid descriptions of the difficulties they faced reaching the health centers or hospitals due to the distance or environment in which they lived. For instance, several women from both sites described being transported on a chair for five hours or about 30 kilometers, with one woman from Kinshasa indicating that she was transported on a chair for hours after the head of the baby had breached. Another respondent had to wait three days before she was able to catch a canoe to take her to the health center. In addition to the pain, some women suggested that traveling caused them extreme anxiety, explaining that they wanted to avoid gaining attention when going to the maternity in fear that their condition would attract witchcraft or evil spirits.

Across the three sites, many women were transferred to a hospital typically after spending several days in the health center trying to deliver. Two women in Lodja who were transferred from the health center to a reference hospital had to travel long distances by foot, with one walking five hours and the other 50 km. after already having been in labor for several days. In all three sites we estimate that women took between two and three days on average from the onset of labor to the delivery of the baby; however, this is likely to be an underestimate, as the time spent, particularly in health centers, was difficult to obtain.

Table 3. Description of the birthing experience at the time the fistula developed

Birthing Experience	Kinshasa	Lodja	Kabongo
Assisted by a traditional attendant			
- Yes	3	11	6
- No	6	3	4
Average number of hours in village before seeking care	17.3	51.4	48
Where went for delivery care			
- Health center	4	6	3
- Health center with a maternity	2	0	0
- Hospital	3	2	5
- Nowhere/delivered at home	0	6	2
Average number of hours to get to the health center	2.30	5.69	12.5 (one took 3 days)
Kilometers traveled to get to health center			
- Average	20	46	31
- Minimum	1	1	1
- Maximum	40	150	160
Transferred to hospital			
- Once	3	5	7
- Twice	0	2	0
C-section	8	4	7
Time took to deliver	2 days, 9 hours	2 days, 14 hours	2 days, 8 hours
- Minimum	6 hours	1 hour	6 hours
- Maximum	7 days	7 days	5 ½ days

In addition to distance and lack of transport, other delays or obstacles to reaching the health center included cost, the fact that the birthing attendant was a family member and therefore the delivery had to be with her, or the traditional attendant discouraged the woman from going to the health center. Women, especially those from Kinshasa, described barriers they confronted after reaching the health facility, where health workers delayed transferring them to a higher level facility offering emergency care. Overall, attendants in the health center were described as negligent, uncaring and slow in transferring women to emergency facilities. For instance, in one case, the health personnel refused even to touch the woman because she lacked adequate funds for payment, and it was only after several days that the woman was transferred to a hospital without first having received any care. During this time, the condition got progressively worse, and the child eventually died.

Women commonly described potentially harmful and abusive practices employed both by birthing attendants in the health centers and traditional practitioners at home. In both settings, women indicated that the attendant introduced his or her unprotected hands on many occasions, and in the health center forceps were also used. It was also common to apply pressure to the abdomen to force the delivery, and in the home setting men were sometimes recruited to assist. Foreign and often sharp objects such as a young palm branch were also sometimes introduced at

the village level to open the cervix. This woman from Kinshasa explained the physical abuse inflicted on her by trained attendants,

In the health center in my village, I felt like the nurse used a sharp object, but before using that object the nurses hit me. They were mean because they made fun of me. After hitting me they again asked me to stand up and walk.... There were two nurses who hit me, they pushed on my stomach in an effort to apply pressure so that the baby would come out. When the trained midwife arrived in the center it was too late; she asked who made a hole in the bladder and the nurses said we did. Everything was bad, nothing went well.

Another woman from Kabongo described her experience in the health center,

The doctor asked the birth attendants to assist me. There was one attendant named Dede and another named Josephine who pushed on my stomach so that the baby would be delivered. They introduced their hands, but the baby would not come out. They said that the baby was too big. The doctor then used forceps to deliver the baby who died after one hour.

This woman from Lodja who delivered at home explained,

The birth attendant introduced her hands the first and the second day, but as the child was not delivered, the third and fourth days the mother-in-law requested for two young and strong men to get on top of me and push the baby out. Because that did not work, somebody came with a medicinal product in a cup. It was after I took the liquid in the cup that the child was delivered dead.

A woman from Kabongo who gave birth in the village said,

The child was dead in my stomach. The attendant said that it was my fault and that I was scared to push.

In addition to the rude or brutal behavior of the attendants, common complaints about the quality of birthing care were that the attendants sometimes refused to provide care, the long wait before women were referred to a health center or an emergency center, and infections that occurred where the incision for the c-section had been made.

The majority of women in Kinshasa and Kabongo eventually received c-sections in an emergency facility, with many of these women indicating that the medical intervention saved their lives. Many women who delivered in health facilities were unconscious after the delivery; others indicated that they were “half dead” from fatigue or in a life-threatening condition, with some woman experiencing complications such as severe hemorrhaging. In contrast, caesarians in Lodja were fewer in part because more women delivered at home.

Condition of Baby

All of the babies born to women in the fistula study in Kinshasa and Kabongo died before or just after the birth, with some of the fetuses already decomposed and having to be removed piece by piece. While the vast majority of babies in Lodja were also stillbirths, one baby survived up to a month after the delivery and two babies lived. In retrospect, many women concluded that the calamity they experienced during childbirth and the extreme sadness they suffered in losing their babies was only the beginning of their nightmare. This woman from Kinshasa said,

When I think about it today, I tell myself if I could have died with my baby, that would have been better than suffering forever like this, today I have become a part of the hospital.

Many were profoundly saddened that they never even saw the face of their child.

Onset of Fistula

Discovering the Condition

Women indicated that within a few days, they realized that they were urinating uncontrollably, with one woman from Lodja and one from Kinshasa also suffering from recto-vaginal fistula. Women who delivered in a facility said that they noticed that they were incontinent after the catheter was removed, when they gained consciousness, when they recovered from other complications (e.g. hemorrhage) or shortly after a c-section. Interestingly, in the two rural sites most women recognized the condition, indicating that there are local terms (see Table 4) in both Otetela and Kiluba describing fistula. In contrast, most of the women at St. Joseph suggested that they were unfamiliar with the condition, expressing tremendous uncertainties and fear, not understanding what they had.

Table 4. Local terms used to describe fistula in Lodja (Otetela) and Kabongo (Kiluba)

Lodja/Otetela		Kabongo/Kiluba	
Local term	English	Local term	English
Kuthsu ya wani kambo tondo	Bursting of the bladder	Meema antamba	Water that flows
Kutshu ya wanyi ya mbole	Hole in the bladder	Mulalue ne mwana	Destroyed by the force of the baby
Kutshu ya wanyi	Sickness of the bladder	Kutambua ne mema	Water that you drink passes directly
Kutshu ya wanyi ambole	Sickness of the urine pocket	Mwana ba musakula	The baby did not follow the normal path

Women were devastated when they realized that the problem was chronic and that they were unable to control the flow of urine. Several indicated that they cried inconsolably, asking why

this had to happen to them, and they were greatly troubled about the condition and fearful of their future. One woman from Kinshasa said,

Put yourself in my situation, if you had a health problem, and not any health problem, but one attached to the sex. I started to cry, asking God if I could die so that my suffering could be over. I even thought about committing suicide. Imagine that I had to wear a cloth that must be changed every moment.

Another Kinshasa respondent said,

I felt abandoned at that instant, I felt very sad, I could no longer feel comfortable. It was the beginning of this nightmare.... When I realized that the urine leaks without stopping I said to myself that my life is destroyed, that I stopped being a real woman.

Causal Explanations

Table 5 shows that most women attributed the cause of the fistula to birthing practices employed both by trained personnel and traditional birth attendants. Women stated that nurses in health facilities caused the problem by pushing on their stomach and entering their bare hands multiple times, with some indicating they went to any lengths to deliver the baby. C-sections were another explanation, with some women speculating that the sharp instruments used by physicians may have created a hole. Particularly in Lodja, women believed that the traditional birthing attendant created a hole with their long finger nails or fingers when entering their bare hands in the birth canal. Women from Lodja and Kabongo also attributed the cause to witchcraft or to an enemy with whom they were in conflict, such as a stepmother or member of the in-law's family who had cast a spell. One Kabongo woman believed that witchcraft prevented her husband from making a quick decision to take her to the hospital.

Table 5. Women's perceptions of the cause of the fistula

Perceived Causes	Kinshasa	Lodja	Kabongo
Medical intervention			
Nurses/medical personnel	3	5	2
Doctors performing a C-section	2	1	2
Traditional Birth Attendants	1	4	1
Way baby was delivered	-	1	-
Witchcraft, somebody cast a spell	-	1	4
Catheter	1	-	-
Prolonged labor	1	-	-
Something in stomach created hole	1	-	-
Multiple births	-	1	-
Didn't know	-	1	1

Coping strategies

Managing the Condition

Over time, women became resigned to using a variety of approaches to manage the condition, the most common being to wear a protective piece of cloth or several layers of cloth to absorb the leaking urine. The cloth had to be changed several times a day to avoid wetting their clothes and emitting a bad odor and to prevent irritation on the upper thighs and vaginal area. Managing the cloth was an ongoing preoccupation which involved washing the cloths with soap and water and ensuring that they were properly dried, all of which required tremendous time. Many women also covered the cloth with a plastic bag to ensure that the urine did not drip, and in Lodja women also used sawdust to absorb the urine and prevent it from leaking through their clothing. In Kabongo, during the day many women wore loose skirts that provided more comfort when urine was dripping and made the leaking urine less noticeable.

Even if they changed the cloth regularly, women often were unable to manage the flow of urine, with many admitting to having no control and persistently wetting their clothes. They emphasized how shamed they felt that others could see traces of urine on their clothes, causing them to feel disgraced and forcing them into hiding. Some stated that this was the most humiliating of all the consequences attached to the fistula and the main reason for refusing to socialize. Some women explained that the leaking of urine was more likely to occur when they had a lot of sores and could not tolerate wearing a cloth. While wearing a plastic cover could help prevent the leaking of urine, lack of exposure to air and the heat created by the bag also caused skin irritation and led to sores. Women explained that the flow of urine varied from day to day and therefore it was hard to predict how best to control the condition.

Women also admitted to urinating in bed at night, often wetting the bed or their clothes. Some added that they produced more urine at night, and others simply stated that it was impossible to control their urine in their sleep and inevitable that they got wet, indicating that it was too challenging to interrupt their sleep to change the cloth periodically. Some highlighted the fact that their condition was less embarrassing at night because others were not aware of the leaking urine. Women in relationships suggested that intercourse caused them to produce larger quantities of urine at night. Solutions used to protect their clothes and mattress included leaving plastic over the mattress or a cover to absorb the urine, wearing a plastic bag over their cloth, or using more protective cloths at night. One woman from Kabongo stated,

I prefer sleeping naked because I already suffer a lot during the day with my bottom always wrapped with cloth like a baby. Nighttime is when I can choose to allow more air between my legs. Despite the plastic I put between the pagne (local wrap) and bed, the plastic always moves allowing the urine to get on the bed.

The vast majority admitted that they always smell of urine, with several suggesting that they were offended by their own body odor. Many women applied scented powders, perfume or

perfumed soap to cover the offensive odor. However, despite these efforts, the stench was impossible to conceal. Due to their odor, they attempted to stay apart from other people and often refused to participate in public gatherings, with some isolating themselves in their homes. Many of the respondents at St. Joseph indicated that the odor was impossible to control because they lived in villages where water was frequently unavailable. This woman from Kabongo said,

In this condition producing odors is inevitable, you become like a male goat that emits an odor everywhere he goes. No perfume is capable of covering up these odors.. I give off a lot of smell. In spite of the perfume I use, urine has an odor capable of overpowering any perfume I use. In addition, when urine is mixed with perfume, it creates an odor that is intolerable. I use perfume before going out. If the clothes are already wet, I do not dare put on any perfume.

Mobility

Some women were restricted to the home setting, while most limited their movement to the village and their immediate surroundings, indicating that it was extremely difficult and painful to travel. They described the challenges in managing the leaking urine which, whether travelling by vehicle or walking, required that they wear many cloths. Movement caused the wet cloth to rub and further irritate the sores and rashes that had already developed on their upper thighs and around their vagina, creating new wounds. Some indicated that it was also painful to remain seated for long periods of time. Women suggested that they only traveled when it was necessary, such as the times when they were in search of treatment, had to visit another market to sell or buy goods, or to participate in special ceremonies such as a family marriage or funeral. Due to the shame and harassment they faced in their own villages, several Kinshasa women were forced to travel long distances to move to another location where they were unknown.

Careseeking

Initially, our respondents were generally unaware that fistula treatment was possible, with many believing there was no treatment and they would therefore have to live with the condition. Nonetheless, most women did seek care at least one time, with many going through unsuccessful operations before eventually receiving fistula repair. For example, four women from the sample in Kinshasa went through unsuccessful fistula surgery before arriving at St. Joseph. In one case, the woman went through three operations, another two women went through two surgeries, and a final woman went through one operation. Seven women from Lodja underwent fistula repair once, with one other having two operations before finally being repaired through services offered by the AXxes mobile clinic. Three women from Kabongo had gone through surgery prior to obtaining services provided by the mobile clinic, with one woman being operated on two occasions unsuccessfully.

Table 6 shows that most of the careseeking for fistula treatment was with trained attendants in hospital settings. Several women from Kinshasa and Lodja did not seek any care until they

heard about repair offered by AXxes or St. Joseph. Reasons for not seeking care were that they believed there was no treatment or that it was too costly. Overall, the number of careseeking episodes was few, mostly because initial treatment was unsuccessful and women subsequently got discouraged, concluding their condition was not treatable, or as was the case in Kabongo, women subsequently sought treatment with traditional practitioners. Women expressed extreme worries about their condition, with some thinking they would die and others considering ending their lives in order to stop the condition and end their suffering.

Table 6. Careseeking behaviors of women seeking treatment for fistula

Careseeking episode	Heath center	Hospital	Traditional healer	Religious healer	Croix Rouge
Kinshasa					
1 st		4	1	1	
2 nd		4	1		
3 rd		2			
4 th		1			
5 th		1			
Lodja					
1 st	3	5	2	1	
2 nd	-	3	1	-	
Kabongo					
1 st	2	6	1	1	-
2 nd	-	-	4	1	1

Reaction to the Condition

Partner

Table 7 presents information on the status of relationships between women and their male partners during pregnancy and after the fistula developed. The data show that more respondents in Kinshasa, several of whom were students, were initially involved in casual relationships that dissolved even before the fistula developed. In Lodja and Kabongo, many women separated from their partners shortly after the fistula was detected. Several of these women were clearly abandoned by their partners, who indicated they could not tolerate being with a woman who leaked urine and manifested an offensive odor, suggesting that the woman had lost all sexual appeal and value. This woman from Kabongo said,

With my first husband, we had no sexual interactions because he said that he felt nausea due to the urine abundant in my vagina. I became doubtful about the relationship. I could no longer ask him to have intercourse and he also did not want it anymore.

In another instance, a man from Kinshasa told the woman several days after she developed the condition that she was “no longer good for the bed” and he didn’t want to smell her anymore. Interestingly, some Lodja women left their partners of their own accord, stating they were no longer fit to be in the relationship or were concerned that continuing sexual relations might further aggravate their condition.

Particularly in Kabongo and Lodja, several women remained with their original partners, who they generally indicated treated them with respect. In one of these instances, a Lodja man took a second wife, with the fistula respondent speculating that her repeated miscarriages forced him to marry again. Another woman from Kabongo explained how the condition dramatically changed their relationship.

To live with this situation and be next to a man is a big problem. The man gets involved in other relationships. He starts to say things that are impossible. The woman is more preoccupied with her own situation. Me, I have another job on top of what I must do and that is washing my cloths all the time. I must always apply powder and beauty cream with a strong perfume. I must iron the cloth all the time with a charcoal iron.

The two women from Kinshasa who remained married lived separately from their partners; in both cases the men had established new relationships, with one man succumbing to family pressure that he should not stay with a woman who leaked urine. Interestingly, three women from Lodja and one from Kabongo who had been rejected by their original partners later established new relationships with other men who accepted their condition.

Table 7. Status of relationships between women with fistula and their male partners during pregnancy and after the fistula developed

Status of relationship	Kinshasa (9)	Lodja (14)	Kabongo (10)
Casual relationship/Abandoned during pregnancy	4	1	-
Abandoned/separated shortly after the condition developed	2	8	5
Abandoned years after onset of condition	1	-	-
Remained with partner	2	4	5
Husband died	-	1 (during pregnancy)	-
Established new relationship	-	3	1

Sexual Life

Sexual activity reported by the women varied significantly according to the site and was clearly influenced by women's marital status. In Kinshasa, where most women were single and resided in the hospital, the vast majority no longer had sexual relations. Reasons given included the following: they were following the doctor's instructions, they wanted first to get better and did not want to risk worsening their condition, they were too embarrassed in their present state to have sex, they had been abandoned by their partners due to the fistula and no longer had interest in men, they had lost physical desire and feared that the pain would be too difficult to tolerate, urine interfered with their pleasure, and their body was destroyed and didn't function properly. One woman said,

I cannot suffer again for the pleasure of men who after (having sex) forget that it is because of that pleasure that the condition started. I decided only to be with a man once God cures me.

Another woman from Kinshasa explained,

As the first man mistreated me, I no longer have interest in men. Moreover, my situation does not permit that a man be with me. I am embarrassed to sleep with a man with my urine (problems).

In the other sites, those women still involved in relationships were obligated to have sexual relations, with some having to endure many consequences in order to satisfy their husbands. This woman from Lodja stated,

This condition causes sores around the vagina and thighs, sometimes when I have intercourse I am in pain, but I sacrifice myself to satisfy my husband.

A woman from Kabongo said,

Despite the sores, I accept what my husband wants in order not to be forced out of the household. This would be another subject for mockery.

Another woman from Lodja explained,

I do not have the same sexual desire as before, but if my husband expresses a sexual need, I cannot refuse. It is the man who is the head of the household and it is he who can say that he does want to have sexual intercourse with me. If he finds no fault in having sex with me, I cannot refuse.

Some women described the inconvenience of getting wet, with some avoiding liquid intake before having sex to accommodate and satisfy their husbands. Others suggested that it was not a problem for their partners to get wet during intercourse. Fewer women indicated that they still

had the same sexual desire as before the onset of the condition. One married woman from Kabongo explained,

I was always available when my husband wanted to have intercourse. I always had the desire and as soon as my husband wanted to have sex, I had no objection. I also wanted us to have sex regularly.

Those who were not in relationships expressed disinterest in engaging in new sexual relations and responding to the multitude of questions the condition inevitably provoked.

Violence

One woman from Kinshasa and four from Lodja indicated that they were victims of physical violence after they developed the fistula and before they separated from their partners. This Kinshasa respondent explained,

During the five months that we remained together, he treated me with extreme violence. He wanted me to return to my parents, but I could not because I did not develop the condition there. It was in his home that I got pregnant which caused the condition and therefore I could not return to my parent's home. For this reason he decided to leave the village so that I could no longer stay with him.

Family

Many women who were forced to leave their partners returned to their natal homes. Most women indicated that they were cared for and protected in the refuge of their immediate family members, with some emphasizing only family could accept such a condition and without family support they would not have survived. Some respondents suggested that their mothers, in particular, protected and gave them hope; when the woman's mother was absent, we found that the woman was more likely to be rejected or subject to abuse. For instance, a couple of respondents from Kinshasa were forced to live on their own because extended family members would not accept their presence in the household. In one case, the young respondent left her village to join her uncle; his wife could not support her presence, and she was forced to live alone in a house on the periphery of Luanda. Women from Lodja stated that, although they were cared for by family, their role and value changed, illustrated by the fact that they were less able to partake in family discussions and decisions. Some women who were co-wives suggested that their husband's second wife often used the condition to insult or make fun of her.

Of the three women in Kinshasa who had children, two were forced to leave the husband's household. In one case, the children remained with the husband, and in the second case, the children were distributed to other family members. When they were with their children, women indicated that their condition prevented them from caring for them properly and responding to their needs. The third woman was bedridden and could no longer care for her children. Of the

seven Lodja women with children, in two cases the children had been given to other family members. The remaining five women were with their children, with some indicating that while they are not in a position to raise them properly, nobody else was available to provide childcare. The two women from Kabongo with children also indicated that although they were unable to give proper childcare, nobody else was available to care for their children.

Friends

Most women in Lodja and Kabongo indicated that they continue to have friends who visited them, and they also could visit friends in their homes, but for short periods only due to the leaking urine and odor. However, many women added that certain of their former friends insulted or avoided them due to their odor, and in Kabongo some women indicated that after their marital separation, some former friends showed a malicious interest in the cause of the breakup. While most of the respondents from St. Joseph also indicated that they still had friends, many described a life of seclusion as they avoided their friends by isolating themselves in their home environment, suggesting that by exposing their friends to their condition, they would only incite derision and mockery. This respondent explained,

Yes, in my village I had friends but whom I could not go see due to my condition. They could come to see me, but I thought that if we got together, it would end up by them making fun of me, and my condition would always be the main topic of conversation.

Another respondent said,

Before having this condition, I had friends. Since my return I avoid them because if we are together, they are going to ask me a lot of questions about my situation, I will be forced to bathe with them and share my life. That would be dangerous for me, that would jeopardize my situation and expose my secret. Instead of being humiliated, I stay at home.

A couple of respondents explained that if friends visit, the women have to make up reasons for them not to stay too long; they explained that over prolonged visits, they were likely to leak urine and their friends could detect traces of urine on their clothes. One respondent stated she no longer has any friends, explaining, “In this world it is when you are in good health that many friends come to see you, but when you fall sick the majority leave you.”

Community Members

Women described their changed status in their perspective communities, with many indicating that they were made fun of due to the leaking urine and their odor, and as a result, people refused to get near them. Many women were commonly ridiculed and harassed, particularly by female rivals, and they were often the victims of such name-calling as “somebody who leaks urine all the time,” “you wear diapers but we don’t see any children,” “instead of controlling urine, urine

controls you,” and “half woman,” signifying that she could no longer conceive and reproduce children. A Kabongo woman explained that when she gets near other women, they say, “look at Kilulu,” meaning look at the woman with the bad odor. A respondent from Kinshasa stated that young boys with whom she had refused to have relations with prior to her condition, would come near her home at night and say,

Marie, you leak urine. You will no longer marry. It is finished for you.

Women at St. Joseph were also harassed in the hospital by women living in the adjacent pavilion who often accused them of witchcraft. In all of these instances, women with fistula emphasized that their condition rendered them silent, and they did not have the courage to respond.

Mockery also centered on the fact that they were childless, signifying that their position as women in society was reduced, or that they had been abandoned by their partners and were living in their natal households, also symbolizing a loss of honor. Many described an extreme feeling of disgrace and general rejection and a lowering their self-esteem, forcing them into isolation in an attempt to hide the condition and protect themselves from further humiliation. These women from Lodja explained,

Other women consider me a woman, but if I get near them and they smell the odor of urine, they will move away. In order not to offend others, I remain isolated. I do not have any friends who can stay near me when I give off an odor.

The problem is with certain women my age who do not want to get near me. I do not have the right to speak, even if I have reason. It makes me feel weak and diminished.

Some women left their villages for other communities so that they could live clandestine existences. This respondent from Lodja said,

For others my condition is a mockery, particularly in my village. This is why I cannot return without finding a cure. I will stay in Lodja until the next (fistula) campaign. Even if I have to die, I would rather die here instead of returning to my village to live in shame.

Ability to Work

Household Level

Data on participation in household work varied, to some degree reflecting differences in socioeconomic status, living arrangements, and the severity of the women’s condition. Specifically, four respondents from Kinshasa whose conditions were very complicated did not continue partaking in household chores, while the vast majority of women from Lodja and Kabongo indicated they had no other option but to manage the household work. Most of these women suggested that their strength was reduced and they could not work as before, with some explaining that movement increased the leaking of urine and need to change the cloth, slowing

down and interrupting their work. Some women, particularly those who were married, indicated that the condition, along with the fact that they were childless, put additional pressure on them to perform their household chores well, adding that their reputation would be further diminished if they were forced to rely completely on family members, which would make them more vulnerable to criticism and rejection. This woman from Kabongo said, “I do household work to avoid having my husband send me to my parents, where my life would become very difficult.” In general, failing to perform household work gave additional ammunition for their rivals to pass judgment on them.

Agricultural Activities

Most women from Lodja and Kabongo indicated that they engaged in agricultural activities either related to the family cropping or to generate an income from such work as collecting or picking agricultural produce like palm nuts. They lamented that they were unable to work as hard as other women because their strength had been reduced, once again referring to the time required to change their cloth. Some complained that hard work increased the dripping of urine, causing discomfort, with others indicating that the movement involved in walking to and from the fields and working in the fields caused the cloth to rub their skin, increasing the skin rashes and sores and further preventing them from working hard. However, these women once more underscored the fact that they are forced to work both to survive and maintain respect in society. Women indicated that even in the field they were concerned about being subjected to ridicule. This Kabongo woman said, “To go to the fields, I must wait until the other women have already left so that they do not confront me, and for the return, I must come back before or later to avoid being met by other women.”

Those women who no longer worked in the field said it was due to the open sores they developed and the difficulty they had walking long distances and working hard. None of the women from Kinshasa did field work regularly, with some explaining they no longer had the strength, while others lived closer to or in urban centers.

Market Setting

Most women no longer went to the market, either to sell or buy items, both because of their odor and to avoid wetting themselves in front of others and being exposed to insults. Therefore, those women who used to sell foods in the market sent such other family members as their children, sisters or co-wife, indicating that people would not approach and buy foodstuff from anyone with their condition, with some expressing concern that the food item would carry an odor of urine. Other women explained that they themselves only go to the market to buy items, leaving quickly to avoid any embarrassing moments.

In general, women described how difficult it was to complete all of their work, while at the same time trying to control the flow of urine and maintain cleanliness. This woman from Kabongo said,

I have suffered a lot due to the urine. Despite the way I am suffering, there is nobody to help me. I go to the field, I have all of the household work to maintain. It is difficult to live with this condition because it requires additional work which involves controlling the urine.

Participation in Social Events and Religious Activities

Ceremonies

Half of the women from Lodja and Kabongo and the majority of the women from Kinshasa indicated that they no longer participate in ceremonies. Reasons for not attending related to difficulties in managing the leaking urine and the accompanying odor and concerns about offending people by their odor and thus altering the spirit of the occasion. As ceremonies often involve rituals around eating and food, there was also concern that people might refuse to eat in their company. Those who did attend indicated that it was an obligation to participate in certain ceremonies, particularly funerals of family members or friends, and that otherwise they would be criticized for being unwilling to help with the preparations and pay their respects. When women did attend, they had to be well equipped with adequate clothes for changing and to take other precautionary measures such as applying powder, perfume or perfumed soap in an effort to cover the odor of urine and avoid offending others. In the presence of other people they also attempted to create a physical distance, and they explained that other guests generally refused to get near them. They also indicated that their condition did not allow them to spend the night in other people's homes.

Parties

Most women did not attend parties, explaining that they are trying to hide their condition and because of the risk of exposing urine on their clothes, they avoided places where they might have close contact with other people and thus offend them. Some added that when there is drinking, some people lose their inhibitions and then they could become the object of derision and cruelty. Others suggested that they particularly avoid being in places with men.

Church

The majority of women continued to attend church. Preparations were made in advance and often included putting on a thick padding of cloth and a plastic bag to cover the cloth and limiting liquid intake several hours before church began; once at church, they separated themselves to avoid exposing other parishioners to their smell. Women suggested that they had to rush home quickly before the cloth got too wet and caused irritation and sores on their thighs. Those women who did not go to church were worried about offending others with their odor and were concerned about the shame if they started to leak urine in public, once again opening themselves to criticism and humiliation. Some women explained that they had previously gone to church but were hurt when nearby people changed pews after they had first sat or gotten near

them; they subsequently decided not to expose themselves to such blatant rejection. One woman from Kinshasa explained,

No, I cannot go to church. This illness has an enemy, it is the public, because in public, especially in front of men you will feel that you are impure, and the soul is not peaceful.

A Kabongo respondent said,

I am embarrassed particularly about the time when one leaves the church because it is necessary to greet people and try to talk about a lot of things. Thus I do not want to disrupt these groups of people. I prefer to stay at home than to go to church where I must flee quickly because I must change (my cloth).

Consequences

Social

The data presented thus far underscore the severe social consequences that women living with fistula experience. Women described the extreme shame they lived with being incontinent and smelling of urine, and how this forced them to remain secluded from other people in an effort to protect themselves from mockery and humiliation. Other women suggested that the stigma attached to the condition fostered blatant rejection by others, resulting in a life of isolation. Whether isolation was self imposed or inflicted by others, virtually all women indicated that their lives and status as women were destroyed, highlighted by the loss of their husbands, partners and prospects for future relations; the loss of any sort of economic viability or social independence; the inability to have children and be a mother; and for girls formerly in school, the inability to attend school and prepare for their future. Many explained they were no longer considered complete, indicating that they had lost all respect in the community and dignity as women, as this woman from Kinshasa explained, “It is a condition that excludes women from society, because a woman in this situation is no longer whole and must not marry.”

The following quotes collected from women in the different sites illuminate common themes of humiliation and suffering that women experienced:

Women from Kinshasa stated,

My life is destroyed; I have become like a crazy woman who must live alone cut off from the world. I live far from my parents, from my village and from my husband in order to escape the noise (insults and questions) of others and to look for a cure.

I have been living an isolated existence for a long time. Isolation happens with this condition. People treat you as though you are already dead and the only thing that awaits is the burial. Others consider you to be a witch.

The mockery, the injuries, the questions about the diapers/cloths are relentless and force me to isolate myself to avoid everything and so that nobody is interested in what I do.

This woman from Kabongo said,

This situation is considered shameful particularly since it has to do with my sexual organ. You cannot share this with others. I was almost erased from the community. You are scared to be with others, and you become a woman who men only consider a burden.

A woman from Lodja explained,

I am often alone; with this condition, others run away from you, I have become like an animal which has a wound and must isolate itself to avoid the flies.

Physical

The most commonly mentioned and serious physical consequence were the sores and rashes that women developed around their upper thighs and vagina as a result of the leaking urine and the constant rubbing of the wet cloth on the skin. Those women who employed plastic bags to prevent urine from leaking explained that the heat and airlessness that the bags created also aggravated rashes and sores. These conditions caused women extreme discomfort, forcing them to change the way they walked and preventing them from going long distances and engaging in rigorous work. Sometimes the sores became so painful that they were unable to walk and had to remove the cloth and open their legs to expose the affected area with air; in Kabongo, women simply did not wear underwear. They explained that discarding their underwear and wearing long flowing skirts, which allowed the urine to drip freely, permitted them to work the fields for longer periods in relative comfort. Women also mentioned that the wounds sometimes became infected, due to the perpetual state of being wet and constant rubbing, and that they were also susceptible to vaginal infections. A woman from Kabongo said,

I have terrible sores on my thighs which made me decide to wear a long skirt underneath with a *pagne* on top. The sores bother me terribly to a point that I feel as though I am in prison all the time. In order to allow the area between my thighs to get air, I must take off all the cloths that can squeeze my thighs. I noticed that underwear and all other cloths that have direct contact with the skin also increase the odor.

Women used different ways to try to treat the wounds including applying powder, palm oil and warm or hot water to reduce the pain and the heat they produced. Some said that it was very important to change the cloth regularly, with some comparing the leaking urine to a poison that burns and destroys clothes and causes other illnesses. Women explained that while the condition affected a specific part of their body, it predisposed them to other infections and rendered their entire body sick. Other less frequently mentioned consequences included loss of sexual desire,

the pain endured during intercourse, weight loss, fatigue, the termination of the menstrual cycle, and cysts or tumors around the joints.

Psychological

Virtually all of the women interviewed indicated that they were suffering from extreme psychological duress, underlining that their health state and the insults it incited perpetually reminded them of their diminished status in society and the stigma they carried. Many suggested that they were in constant worry about their future and what additional hardship the condition might provoke, with some showing signs of depression such as crying for long periods, particularly after being insulted in public, or even contemplating suicide. This woman from Kinshasa said,

Psychologically, I was no longer me, I was sick. I lost all my sense of humanity as a woman.

Another woman from Kabongo explained,

My husband humiliated me every time I didn't come home, he insulted me in the presence of other women. This caused me to become crazy. I could not tolerate such humiliation. I considered committing suicide. My life was turned upside down and my self confidence was gone. Without this treatment program, I would have remained sad throughout my life because I could not see anything that could offer me consolation.

A few women were able to ignore the mockery and insults, stating that they were not responsible for their condition.

Economic

Most women explained that their condition reduced their work production and limited economic activity, forcing greater dependence on their husbands and family members together with curtailing their lack of freedom to engage in their own desires and interests or to make independent decisions, and for those who had children, an inability to provide for their children. Agricultural activities pursued by women in Lodja and Kabongo allowed them to gain some money to pay for household items and basic needs for their children. Many of these women also engaged in small income generating activities involving sales of food or other small items. In contrast, only one woman from Kinshasa was earning money; the others said that they were unable to pursue any economic activities because of their condition and concern about getting wet or offending others with their smell. As a result, they were completely dependent on family members. Some of women unable to work indicated that this perpetuates further seclusion and isolation in an effort to avoid criticism for appearing idle. This woman said,

Life has become difficult for me, it is as though I am attached to a cord and I cannot go far from the household. I can no longer do anything to earn a living.

Overall, women working in the rural areas indicated that, while work was difficult, for social (to avoid rejection or being victim of humiliation) and practical reasons, such as paying for food or the children’s school fees, they must continue.

Obtaining Fistula Repair

Most of the women had developed the condition and had been attempting to get treatment unsuccessfully in other locations from both biomedical and more traditional providers long before learning about the fistula repair offered by St. Joseph and AXxes. After making many attempts to get treatment, many appeared resigned to the fact that they must live (and die) with the condition. Obstacles that impeded women from getting repaired earlier (in order of importance) included lack of information regarding quality services, the money involved (travel and food costs for woman and accompanying person) in getting treatment, distance, their respective health conditions which did not allow them to travel, and the fact that nobody was available to accompany them.

By the time they underwent fistula repair, they seemed to have come to the realization that the only viable treatment was biomedical care offered in a hospital setting.

Information regarding how the women received information about treatment was varied (see Table 8). While women from Kinshasa and Kabongo obtained information about the repair services from a variety of places, most women in Lodja learned about the mobile clinic from the radio. Either they heard the news directly or somebody else such as their husband, a village leader, or a community “relais” received the information on the radio and transmitted it to them. Some indicated that once the information was broadcast on the radio, there was a lot of discussion in communities among villagers about the availability of treatment. Overall, the information presented in Table x. suggests that a broad range of approaches need to be employed to inform women living in remote areas about fistula services.

Table 8. How women with fistula received information about repair services

How received information about treatment	Kinshasa (9)	Lodja (14)	Kabongo (10)
Health providers/hospital setting when seeking treatment	3	1	2
Family members	2	1	2
Church	-	-	3
Women who had had fistula or somebody who knew of a woman who had had fistula	3	1	1
TV/radio	1	11	-
Poster/announcement in the health center	-	-	1
People talking in the village	-	-	1

Most of the women indicated that they did not obtain the treatment offered by St. Joseph or through the mobile clinic earlier because they were not aware that the services were available,

they were concerned about the quality of care due to former bad experiences with trained health providers, or they were unable to get to the campaign organized to give fistula care in time. Four women from Lodja and two from Kabongo had attended previous campaigns but for the following reasons were turned away and/or had to return for treatment: the mobile clinic was unable to accommodate all of the women with fistula who showed up for surgery; the repair was unsuccessful; during the first attempt, the woman was not in a state of health (e.g. recently had an appendicitis, was pregnant) to undergo surgery; and the enrollment forms were lost.

In regard to treatment results, in St. Joseph where many of the cases were extremely complicated and women were interviewed in the middle of their treatment, respondents realized that repair was a long process involving various steps and that their recovery was going to be lengthy. They were very pleased that, at least in part, their condition was being addressed and treated, with some mentioning that they were regaining their lives as women. The women highly appreciated the quality of medical care, the attention they received, and the fact that treatment was free and all their daily needs were provided. Amongst the Lodja women, 13 of 14 had been successfully repaired, two of whom had already undergone surgery during a previous campaign. The final woman had attended the AXxes campaigns three times and each time the surgery was unsuccessful. All of the eight women operated on in Kabongo appeared to be successfully repaired. The other two did not receive treatment because they arrived at the campaign too late. Most women indicated that the quality of the treatment was good, with many specifying that they could now control their urine and were once again “whole” women. Some women were surprised that a payment for the enrollment card was required and several complained that they were not given sufficient drugs and would have to buy medication.

Future Ambitions

Most women expressed extreme joy in recovering their health and “value” as women, indicating that the change in their condition would allow them to regain their position in their perspective communities and live like other people. Aspirations involved working and earning money, and for those women not married, establishing a long-term relationship with a man. This woman at St. Joseph said,

I am still young, if a man comes by the official way to marry me, that will be a great joy for me, because in our villages, if you are without a husband, it is a problem, you are not considered. We often say that if you sleep alone who is going to help you with problems at night. To have a husband is a wish for all women, and with marriage children will come.

Several respondents, particularly those who were childless, indicated that their biggest desire was to have children, which they signified would give them status as women and confirm their recovery. For those who were married, this would fortify their union. A Lodja woman said,

Yes, this is my greatest wish; to be a woman in our village and remain childless is a sin. Men measure themselves by the number of children they have, if others ask how much money you have, in my community children are among the most precious assets.

However, many worried whether or not they could conceive and support childbirth, with some expressing concern about going through or providing payment for a c-section or that the condition might reoccur. This woman from Kabongo said,

No woman my age can refuse to have children. It is a wealth, an added value, and it is also a way to confirm being a woman. Actually, the concern is related to the advice that we have been given (by the health personnel); we are worried about giving birth by cesarean and also fearful that the condition may reoccur.

This woman from Kinshasa stated,

It is my wish, but I ask myself after all of these medical interventions, can my body still produce/conceive something? But to have a baby, this is the greatest desire to prove that I am cured. A baby will be my savior.

There was also concern that their future husbands would not accept having only one or two children, as was prescribed by health personnel as a means for women who had been repaired to protect their health. Overall, many women who did not have children were concerned that nobody would be available to care for them in old age. Those who already had children aimed to focus on raising their children. Some of the younger respondents who were former students said that they wanted to complete their studies, and those women who had not been successfully repaired were only preoccupied with their recovery.

Comparison of the Different Types of Services

Information collected through the in-depth and key informant interviews and focus group discussions, as well as informal discussions and on-site observations, gave special insights into the services offered through the mobile clinic and in the hospital setting. While some of the information garnered was relatively evident, our prolonged, firsthand experience in the three study sites facilitated an in-depth analysis of a variety of factors involved in providing services, allowing us to have a different understanding of the needs of and ways to enhance the provision of care for women with fistula. The following attempts to highlight some of the advantages and disadvantages of the two different approaches, mobile clinics and fixed services, examined in this study.

Mobile Clinic

- Advantages
 - Can provide services in remote areas and reach women who generally have limited access to specialized care

- Need a specialist in fistula repair only for a short period
- Employ a campaign approach to mobilize people quickly, facilitating
 - Sensitization of a wide range of people about the problem
 - Bringing together large numbers of women to get repaired over a short time period
 - Fewer costs involved
- Disadvantages
 - Difficult to monitor women's conditions after the operation
 - If the repair was not successful, uncertainty about whether the same woman can be identified and operated on at a later time
 - Not possible to set up services for reintegration into the community
 - Not possible to provide long-term, psychological services
 - Difficult to address other complications and co-morbidities that typically accompany a fistula
- Specific problems that we saw in the field
 - Many women arrived late because messages about the campaign were disseminated shortly before the arrival of the mobile team; this highlights the need to publicize way in advance so that women have adequate time to prepare for the operation and their absence from home
 - Dates for the services were changed on several occasions; once publicized, health personnel need to stick to the dates that services will be offered
 - No place to sleep and eat for the women and accompanying person while waiting for surgery
 - No place for the person accompanying to stay after the operation
 - Medical personnel were not always highly sensitive to the needs and conditions of the women
 - Women who were not served were not provided any educational information
 - Insufficient information regarding their condition, appropriate care at the village level, and subsequent surgery was given to those women who were not repaired successfully and to the person accompanying them
 - No mechanism to follow women who went home without being operated
 - Accompanying people were not educated about post operative care and fistula in general
 - No psychological counseling
 - No reintegration services into community offered

Fixed Approach

- Advantages

- Able to establish relationship with woman to understand her broader needs and develop a holistic approach to treatment
- Involve other specialized personnel who can address different needs and provide a packet of services;
 - Complete medical attention for fistula care and co-morbidities
 - Psychological care
 - Reintegration services
- Carry out multiple surgeries if needed
- Address complicated cases
- Inform/sensitize a range of family members
- Establish a relationship with other women with fistula and share their problems and aspirations
- Disadvantages
 - Expensive
 - Unable to provide services to many women at one time
 - Services are difficult to access from remote areas
 - Require a separate building/pavilion that is somewhat distant from other wards
 - Trained doctors leave for better paying jobs

DISCUSSION

This in-depth examination gives special insights into the multiplicity of health, social and economic factors confronted by women living with fistulas in poor, rural settings in DR Congo. The findings highlight commonalities across the three sites included in the study, illustrating the extreme physical hardship and social vulnerability such women face in a social framework where marriage and having children is critical to a woman's status and security. The results show how fistula consistently affect other aspects of women's social foundation and security, including conjugal and family relations, friendships, community acceptance, religious practices, and economic productivity, impacting on women's mental well-being and dignity and often forcing women to live an existence of isolation and shame. Findings related to prenatal care and the childbirth experience highlighted cultural differences across the sites, as well as tremendous weaknesses in the present reproductive health systems that pose risks to women of childbearing age. The results also illuminate an appallingly limited understanding and knowledge of family planning, as well as the extreme pressure women have to conceive and bear children.

The majority of the women came from poor, farming families living in isolated rural areas far from emergency obstetric services. Overall educational levels were low, particularly among women from Lodja. The median age of onset of fistula was alarmingly low, with most of the respondents under 20 when they developed the condition, further demonstrating the young age of sexual activity and the higher risk for young, physically and socially immature girls to develop the condition. Although height was not measured, anecdotal evidence also suggests that women with fistula were short in stature. While most fistulas developed during the first childbirth, in each site many women had also experienced previous fetal loss underlining that they were already at risk for the condition. Most women had lived with the condition for prolonged periods, with a majority of women divorced or abandoned by their partners. More women in Kabongo were officially married before they developed a fistula and these women were more likely to remain with their husbands.

While the majority of women from Kinshasa and Kabongo participated in antenatal care visits, most women from Lodja did not attend, stating that the distance to the clinic and the time involved prohibited them from participating. The findings suggest that cultural factors may also have contributed. Overall, women from Lodja maintained more traditional beliefs about childbirth and placed greater value on the prestige associated with delivering in the home setting and did not appear to hold in esteem the services that trained attendants can offer. In general, the ANC sessions seemed to be ineffective, with minimal information provided related to the women's health status and pregnancy and the importance of birth planning, and no information at all given about family planning postpartum. Moreover, health workers failed to warn young girls, women who were short in stature, or women with a history of stillbirths about potential pregnancy risks and the importance of birth planning. The data also suggest that young, unwed girls, do not understand the importance of attending antenatal care sessions and were also embarrassed to participate with older, married women.

Overall, about half of the pregnancies were planned, with women particularly from Lodja and Kinshasa suggesting that conceiving and having a child was a way to strengthen their relationship, with many of these unions recent and informal. The institution of marriage in DR Congo is precarious, with the term marriage often signifying that a man and woman co-habit. The union becomes more formal when a child is produced, and there is tremendous pressure on women to conceive and produce a first child, thus demonstrating their fertility and giving women power and stability in the relationship and status in society. While more Kabongo respondents had gone through the official marriage rituals and ceremonies, these women faced the same sort of pressure to demonstrate that they could conceive and produce a first child. Many of the unplanned pregnancies occurred among young, school-aged girls, who were having casual sex and did not even seem to realize that they could get pregnant.

Knowledge of family planning and utilization of contraceptive methods was appallingly poor. However, questions about family planning once again underlined the pressure that women in a relationship face to have multiple children, which in this context symbolize wealth and male virility. Failure for women to reproduce or even the suggestion to postpone conception appears to raise suspicions by the male partner regarding the women's faithfulness and commitment to the union, thus jeopardizing her position in the relationship. Economic dependence on the male partner and societal norms related to women's reproductive roles force women to try to adhere to cultural tenets to have many children. While our younger respondents were sexually active at a young age, the findings suggested that their exposure to and understanding of reproductive health and family planning was extremely limited. The data point to the strong need to carry out more in-depth studies to understand better the barriers to utilization of family planning methods from a female and male perspective and identify ways to improve present initiatives. Clearly, the imbalanced power dynamic between men and women limits the ability of women to use family planning and points to the need to develop strategies to empower women so that they have greater independence in relationships. An understanding of male perceptions and an exploration of alternatives to having many children is also critical.

Data collected on birth planning once again illustrate cultural differences related to birthing practices, with women from Kinshasa and Kabongo much more likely to value formal health services and to plan delivery with trained attendants. In contrast, many Lodja respondents appeared to be guided by prevailing traditional belief systems regarding childbirth, with many valuing the prestige attached to delivering in the household with a traditional attendant. In actuality, when labor began, most women were living in remote areas and were unable to follow their birth plans. The stories women recounted of their attempts to deliver in the home setting with a traditional attendant and the subsequent attempts at getting trained care were horrifying, highlighting the multiple risks women face giving birth and why the physical environment and poor health infrastructure in DR Congo make women vulnerable to obstetric fistula. While most women eventually obtained care with trained attendants, with fewer women from Lodja receiving skilled care, the data illuminate extreme delays at various points in reaching skilled

care, all of which prolonged the labor and placed women at greater risk for developing fistula. The delays were either at the household level where many women were initially assisted by a traditional birthing attendant, at places where it was necessary first to find transport and then to travel to the facility, which often entailed going long distances by foot or being carried under arduous circumstances, and finally in the health centers, where attendants sometimes refused to provide care or prolonged the stay before referring the woman to a higher level facility. We also uncovered dangerous birthing practices employed both by traditional and trained birth attendants, which may have contributed to the development of the condition. This powerful combination of unfavorable circumstances for a healthy birth puts into question the current estimates of fistula prevalence reported by the 2007 Demographic and Health Survey at 0.3%. Evidence indicating that respondents, particularly in Kabongo and Lodja, were already familiar with the condition also suggests a much wider prevalence. The findings reveal the poor state of reproductive health services in DR Congo and the need to focus on strengthening the maternal health systems. A short-term goal may be to identify women at risk for complications during antenatal care, to encourage those women to deliver in an emergency care center, and to concentrate on making more maternity waiting rooms available in hospitals for women at risk.

Respondents employed a myriad of strategies to manage the ongoing flow of urine and odor and to regain some semblance of their former lives. This involved using methods to prevent urine from leaking and covering the offensive odor, maintaining household chores and fieldwork, and attempting to get treatment for their condition. Despite these efforts, living with fistula provoked severe consequences in all aspects of women's existence, including their conjugal, social, economic, physical and psychological lives, causing extreme shame and humiliation and forcing many women into seclusion. The majority of women were rejected by their partners, with some (separated and married) subjected to physical and psychological abuse. In order to preserve their value and maintain their position in the household, those who remained married were forced to engage in household and field work and to satisfy their husbands' physical needs, which often caused women extreme pain. Friendships were also precarious, with women generally choosing to limit or avoid contact with others in order to protect themselves from mockery and ridicule. Especially outside the household in public settings, women were subjected to harassment and were victims of malicious name-calling related to their physical condition and allegations relegating them to the social status of unmarried, childless women. The sense of humiliation and vulnerability these episodes created compelled women to restrict participation in special events and interactions with non-kin. The exception was church where they tried to get solace, but even there they could not escape spiteful reminders of their condition.

Women mentioned a constellation of physical and psychosocial consequences that frequently impacted on their ability to carry out household, agricultural and market activities, and contributed to their overall suffering. The condition and co-morbidities also appeared to interfere with the provision of childcare. Failure to engage in work or work at the same level fostered greater economic and social dependence on family members, further reducing their

sense of self-worth and destroying all dignity, with some contemplating suicide as the best option to end their suffering. The combination of these consequences fostered a vicious and inescapable spiral of ill-health and suffering up to the time they were able to obtain services to repair the fistula.

Most of the women lived with the devastating condition for many years, with many having gone through unsuccessful surgeries and most not even realizing that the condition was treatable until they received information about the services offered through St. Joseph and AXxes. The results demonstrate the effectiveness of using a variety of approaches to inform women about repair services. Data also emphasize the importance of offering a combination of fixed and mobile services in order to reach poor, isolated women most at risk to develop fistula and to offer a broad scope of comprehensive care addressing a variety of physical, psychological and economic needs. This approach will better facilitate a successful reintegration of women into their perspective communities and households. The findings also underscore the tremendous need to focus on preventive measures, which should include standardizing and building the quality of reproductive health services, multiplying emergency obstetric care and strengthening referral systems to prevent the condition and associated suffering of women. The general poor state of reproductive health services and infrastructure also illuminates the need to expand fistula repair services to other regions of the country. An extensive list of recommendations to improve fistula treatment and prevention is presented below.

RECOMMENDATIONS

Fistula Curative Services

- Set-up a system to ensure that mobile services are working in collaboration with fixed services. This will allow medical personnel to:
 - Monitor the woman's condition after surgery and address complications that women may experience after the operation
 - Follow up with women who were not successfully repaired
 - Treat persisting co-morbidities such as infections or sores that the women may have
- Make certain that services are available in every province and that women living in isolated, remote areas are aware of and have access to quality treatment
 - Provide services in provinces of the country such as Bandundu, Equateur, and Orientale where at present no or limited fistula treatment is offered
 - Expand mobile clinic services so that more women in remote areas are reached
- Make certain that when offering fistula repair, a whole package of services needed to ensure a holistic and complete recovery is available for women post-operatively. Services should also be offered to those women who have undergone surgery which was unsuccessful and/or require additional treatment. This package of services should aim to include:
 - Comprehensive psychological counseling
 - Education on sexual behavior and reproductive health, including family planning
 - Education on how the woman should maintain her health and reproductive life post surgery
 - work only after three months of rest
 - refrain from sexual relations for three months
 - plan to delivery any subsequent children in an emergency care facility
 - Education targeting immediate family members on the nature of the woman's condition and what is required for full recovery
 - Preparation for reintegration into the village setting
 - Building skills that can generate income
 - Training in management
- In the hospital setting, educate other patients, people accompanying patients and medical and other staff about the condition and assure that women with fistula are not victims of harassment and insult while obtaining medical treatment
- Establish monitoring systems designed to follow women with fistula who were repaired and those who were not successfully repaired and require additional surgery. This will allow people involved in fistula repair to:
 - Follow women's condition, including their health, reproductive, demographic, and socioeconomic status

- Understand issues women face when returning to the village setting and in the future, better prepare other women who have been repaired for reintegration into their households and the community
- Ensure that women who were not successfully repaired have access to treatment in the future
- Educate health personnel and other community members who have contact with women with fistula about the condition and the places where they can get fistula repair. These people can be involved in identifying cases and ensuring that women get quality and prompt treatment. People who should be targeted include:
 - Health workers in health centers and hospitals
 - Community health workers such as “relais” who have ongoing exposure to community members
 - Religious leaders
 - Traditional practitioners where women may seek treatment
- Engage women who have been successfully repaired as ambassadors in efforts and activities aimed to identify and educate additional cases
- Collect information including demographic and socioeconomic information on women with fistula in health centers and hospitals to:
 - Better understand the prevalence of the problem
 - Describe the characteristics of women with fistula
 - Understand the cause in different regions of the country
- Develop more far reaching ways to educate people about fistula including the nature of the condition and its cause, women at risk, preventive measures and appropriate treatment. Venues that appear to be successful in reaching women include:
 - Radio
 - Health centers and reproductive health activities targeting women
 - Religious places of worship
 - Community groups or meetings where community health workers and ambassadors could convey messages
- Develop approaches to make women with fistula who are waiting to be repaired more comfortable. Issues to focus on to decrease their discomfort and improve their general health could include:
 - Make available a more comfortable protective cloth and plastic cover
 - Treat co-morbidities such as skin rashes, sores and vaginal infection
 - Make medications available to treat the co-morbidities once women return to the village setting

Preventive Approaches

- Provide education on reproductive health to women and girls. Educational efforts should include information on the following:
 - Female reproduction and fertility
 - Male reproduction
 - Risks in getting pregnant at a young age
 - Venues may include:
 - Schools
 - Group sessions at the village level
 - Health centers/ANC
- Develop culturally appropriate, comprehensive strategies that aim to address the lack of knowledge of family planning and the alarmingly low rate of utilization of contraceptives in DR Congo. Strategies should target both men and women and be multifaceted, focusing on:
 - Education of the general public
 - Types of methods that are available including the advantages and disadvantages and side effects of the various methods
 - How the methods should be used to avoid pregnancy
 - Where the methods are available
 - Education of formal and informal health providers
 - Types of methods that are available and the advantages and disadvantages including side effects of the various methods
 - How the methods should be used to avoid pregnancy
 - Administration of methods that need medical assistance
 - Ongoing distribution of contraceptive methods in health centers and other venues (e.g. kiosks, pharmacies) where contraceptives are available
 - Assure that a variety of up-to-date and quality methods are widely distributed
 - Avoid ruptures of stock
 - Assuring that culturally appropriate, opportune venues are used to provide information and family planning services
 - Health centers
 - During ANC
 - Baby weighings
 - Schools
 - Sex education classes
 - Community meetings
 - Women's groups
 - Market settings where men gather
- Standardize and improve the overall quality of prenatal care in health facilities
 - Provide pertinent information to allow women to monitor their health status and understand their condition during pregnancy including the stages of pregnancy, proper nutrition, appropriate workload, signs of complications, etc.
 - Convey information to the pregnant women during the ANC examination regarding their health status and the status of the fetus

- Discuss birth planning and choices of contraceptive methods that can be used postpartum
- Train health personnel on how to identify women at high risk for birthing complications and identify women at high risk during ANC
 - Young pregnant girls
 - Women short in stature
 - Women who already had stillbirths
- Sensitize high risk women during the ANC about complications such as fistula
- Encourage women at high risk for complications to prepare to give birth in a hospital setting where emergency care is available
- Encourage women identified at high risk to go to a hospital in advance of their due date
- Follow-up with women at high risk
- Improve the quality of maternity services/care
 - Train nurses assisting with childbirth on
 - Use of the partogram
 - Identification of severe complications
 - Referring women to a higher level facility
 - Importance of reducing dangerous practices such as
 - Applying pressure on the woman's stomach during labor
 - Entering unprotected hands in the women's vaginal canal
 - Use of forceps
 - Delaying referral to a higher facility
 - Make basic equipment and supplies needed for safe delivery available in health centers and maternities in all health zones, including those not under the umbrella of NGOs. Basic supplies may include:
 - Partogram
 - Gloves
 - Essential drugs
- Multiply the availability of high quality, obstetric emergency care facilities so that women living in remote areas have relative easy access to emergency care
 - Set up waiting rooms for women coming to the hospital prior to their expected due date
 - Set up good referral systems between health centers or maternities and hospital emergency care facilities
- Integrate traditional birthing attendants into efforts to improve reproductive health and delivery services
 - Create an inventory of local birth attendants
 - Educate traditional attendants about signs of complications and when to refer
 - Create incentives to encourage traditional attendants to refer to trained attendants
 - Educate birth attendants on risky practices
 - Prolonged labor/when to refer
 - Putting a lot of pressure on the women's abdomen
 - Calling men to put pressure on the women's stomach

- Putting their unprotected hands in the woman's birth canal to pull out the baby
 - Introducing foreign objects to open the cervix or force childbirth
- Educate traditional attendants about fistula

Proposed Topics for Further Research

- Study examining family planning initiatives and barriers to utilization of contraceptives
 - How family planning has been introduced and why it is not working
 - What are the family planning needs of women and how can they be addressed
 - What are men's perspectives on family planning
- Study on maternity services including
 - Content of ANC
 - Information given to women regarding the pregnancy
 - Educational sessions
 - Discussion of family planning
 - Discussion of birth planning
 - Use of the partogram
 - Availability
 - Providers understanding of the purpose and how to use
 - How the maternity waiting room works; does it help women have better access to quality maternity care
 - Birthing care to identify
 - Health provider knowledge of appropriate care
 - Dangerous birthing practices
 - How to develop an integrated approach including both local/traditional and trained attendants to ensure that more women deliver with trained providers
- Study to explore what happens to women after fistula repair
 - Understand their reproductive health, socioeconomic and demographic status
 - Describe their acceptability in communities
 - Examine factors that help women reintegrate into their communities
 - Understand how their lives evolve
- Study on how to integrate fixed and mobile services

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