BANGLADESH and DEMOCRATIC REPUBLIC OF THE CONGO

Living with Obstetric Fistula: Qualitative Research Findings from Bangladesh and the Democratic Republic of Congo

WHAT IS FISTULA?

Obstetric fistula is a childbirth injury, usually occurring when a woman is in labor too long or when delivery is obstructed, and she has no access to a cesarean section. She endures internal injuries that leave her incontinent, trickling urine and sometimes feces through her vagina.

Fistula Care works to prevent fistula from occurring, treats and cares for women with fistula, and assists in their rehabilitation and reintegration. For more information about fistula and the Fistula Care project, visit www.fistulacare.org.

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Introduction

Obstetric fistula is a condition that most frequently affects women living in resource-poor countries where, for a variety of reasons, access to emergency obstetric care (EmOC) is difficult. In such settings, women living in rural areas and those from low socioeconomic households have fewer opportunities to obtain EmOC (specifically, a cesarean section) and are therefore more vulnerable to fistula. When not repaired, vaginal fistula causes incontinence, and for some women it can result in an inability to carry and bear children. Because of the physical consequences, fistula stigmatizes women, often forcing them to isolate themselves and remain silent about their condition (Women's Dignity Project & EngenderHealth, 2006). Due to the nature of the condition, the prevalence of fistula in particular countries is difficult to assess.

Few studies have examined what the social consequences are for women with fistula or how the broader social structure in which these women live affects the way they are treated. In this regard, qualitative research was carried out in the countries of Bangladesh and the Democratic Republic of Congo (DRC) to examine the lives of women suffering from fistula, including the physical and social consequences associated with the condition and attempts to obtain care. This brief describes the experiences of these women living in two very different sociocultural contexts.

Bangladesh

Located in South Asia, Bangladesh is a densely populated country with more than 140 million inhabitants (BBS, 2011). The country is experiencing rapid economic growth and social changes, particularly in urban settings. However, nearly two-thirds of the population works in the agricultural sector, and the majority of inhabitants are very poor.

Most residents of Bangladesh are Muslim, with a minority Hindu population. The sociocultural system enforces a hierarchical organization of gender relations, which contributes to the continuing unequal status of women. Female educational attainment is still low, with more than one-third of women of reproductive health age never having attended school. Cultural norms enforce arranged marriages of females at a young age; the median age at marriage is 15.3 years (NIPORT, Mitra and Associates, & Macro International, 2009; Rozario, 2001).

Newly married women typically move into their in-laws' home, where they are absorbed into the social framework of maintaining the household and are judged by their ability to fulfill their primary roles—bearing children and providing care for family members. Marriage marks the point at which it is socially acceptable to have children, and there is tremendous pressure on newly married women to demonstrate their fertility. The median age at first birth among women of reproductive age is about 18 years, with women having, on average, 2.7 lifetime births.

Poverty and oppression, often inflicted by household members, combined with low literacy and restrictions on female mobility, limit women's access to information on maternal health, particularly in rural areas. The vast majority of Bangladeshi women

are unemployed; those who are employed mostly either are engaged in agricultural work that produces limited income or are paid in kind. Women are socialized to be obedient to their husbands, and divorce and separation are socially unacceptable and uncommon.

In an effort to reduce maternal mortality, the Government of Bangladesh implemented a program in 1994 to upgrade health facilities to make EmOC available to all women, resulting in a marked expansion of EmOC services. Considerable investments have also been made in the country's infrastructure; at present, road systems are extensive, and a variety of types of transport are generally available 24 hours a day, even in rural areas. These factors have likely contributed to the substantial decline in the maternal mortality ratio, which has fallen from around 600 maternal deaths per 100,000 live births in the 1970s to 194 per 100,000 in 2010 (NIPORT, 2010). Despite this, only 27% of births are assisted by qualified health providers (NIPORT, 2010).

In the public sector, fistula repair services are offered at 11 Medical College Hospitals, with more complicated cases referred to the National Fistula Center located at Dhaka Medical College Hospital in the capital city. Since 2005, the U.S. Agency for International Development (USAID) has supported fistula services at four private hospitals, through the Fistula Care project. This work has focused on fistula prevention and repair, as well as on efforts to link women who have undergone repair to rehabilitation and reintegration activities.

Democratic Republic of Congo

The DRC, a vast country located in central Africa, has a population of more than 70 million. Potentially one of the richest countries in Africa, economic indicators place the DRC at the bottom of the global continuum of poverty. Inhabitants of the DRC are predominantly Christian, with literacy rates among women estimated at 60% (Ministère du Plan & Macro International, 2008). Women report having had their first sexual relations by a median age of 16.8 years, and the median age at first marriage is 18.6 years. (In the DRC, the term "marriage" often means that a couple cohabits but may not have been formally married in a religious or civil ceremony.)

Once in a relationship or married, women encounter much social pressure to conceive and produce a first child, which helps to formalize and secure the union. In addition, it demonstrates the woman's fertility and thus gives her some power in the relationship and some status in society. Given this context, it is not surprising that 24% of women begin childbearing during their adolescent years. Societal norms, which encourage women to have many children, combined with limited access to contraceptive methods lead to high fertility rates, with women having on average more than six births during their childbearing years (Ministère du Plan & Macro International, 2008). Women often engage in work outside the household, either in agricultural or in petty commerce, thus allowing them to generate income that they control. Women are generally free to travel in and around their village settings, including to health facilities to seek treatment or attend consultations.

The government of DRC has invested little in the health infrastructure, which is a fragmented system managed by nongovernmental organizations (NGOs), religious groups, the private sector, and the government. The combination of the poor economic state, a failing health infrastructure, and limited road systems has led to elevated mortality rates in DRC, particularly in the most marginalized populations (Coghlan et al., 2008). Estimates of maternal mortality are very high, at 549 maternal deaths for every 100,000 live births (Ministère du Plan & Macro International, 2008). More than two-thirds of women are reported to deliver in health facilities, with 74% of births assisted by trained professionals.

Much attention has been given to traumatic fistula caused by gender-based violence in the war-ravaged eastern region of the DRC (Longombe, Claude, & Ruminjo, 2008), where fistula repair services are offered in several cities. Even in the war-torn East, however, the most common cause of fistula is obstetric, reported among 82% of women receiving fistula treatment at Panzi Hospital in Bukavu between 2006 and 2007. Given the poor state of the health infrastructure, the long distances that women must travel to access EmOC, and the insecurity in the region, this is not surprising. However, limited access to EmOC and long distances to care exist throughout DRC, and recently more attention has been given to ensuring that quality fistula repair services are available in regions of the country other than the East. At present, a major treatment center is operating in the capital city of Kinshasa. To make repair services more accessible in Kasai Orientale and Katanga provinces, Project AXxes, a USAID-funded health project managed by Interchurch Medical Assistance (IMA), developed mobile medical teams to provide treatment to women with fistula.

Research Methods

Research Sites

The first study was carried out in Matlab, Bangladesh, between November 2006 and July 2008. Located 45 km southeast of the capital of Dhaka, Matlab has a generally poor population, with farming and business the primary sources of income (HDSS, 2007). The International Centre for Diarrhoeal Disease Research, Bangladesh (icddr,b) maintains a hospital and four subcenters in Matlab that provide free child and maternal health care services, along with general health services for a population of 110,000. Other health services include government hospitals and private facilities offering EmOC, as well as an array of informal health providers. Outreach services for identifying women with fistula and referring them to appropriate repair facilities are available in Matlab.

The second study was implemented between March and June 2010 in three regions of the DRC, including Kinshasa in the west, Lodja in Kasai Orientale Province in the central region, and Kabongo in Katanga Province in the southeast of the country. In Kinshasa, the study was carried out at St. Joseph Hospital, where fistula repair has been available since 2003. The clinic at St. Joseph has used television and radio broadcasts and "ambassadors" (denoting women who have successfully had a fistula repaired) to inform women in Kinshasa and surrounding areas about

Fistula clients await care at a facility in DRC.

fistula and about repair services. The other two sites are large village centers; trained mobile teams traveled to these areas to set up temporary fistula repair services for women living in surrounding rural areas. Starting one month prior to offering the services, radio messages were disseminated to inform women that fistula repair would be available.

Methods and Study Population

Both studies employed qualitative data collection methods, which allowed us to gather descriptive information illuminating the stories of women suffering from fistula and the social consequences they have endured. Qualitative methods are particularly appropriate when investigating a sensitive topic such as this one, which could not be explored in detail through structured, quantitative methods.

In Bangladesh, the research was part of a larger community-based study of maternal morbidity. Qualitative research was conducted to examine chronic morbidities, including fistula, associated with childbirth and their consequences on women's lives. To identify women with fistula, community health workers (CHWs) administered a screening tool during routine household visits; probable cases were examined by a female medical doctor. Women confirmed to have fistula were invited to participate in the study, and in-depth interviews involving narrative histories were collected from these women. All women were offered fistula repair.

In the DRC, several methods were employed:

- *Key informant interviews* were carried out with formal and informal leaders involved in maternal health, including policymakers, physicians, trained midwives, traditional birth attendants (TBAs), and community leaders. The aim was to gain different perspectives on maternal health services and understand what respondents knew about fistula and fistula treatment.
- *In-depth, open-ended interviews* were administered to women suffering from obstetric or iatrogenic fistula who accessed treatment services offered at the clinic in Kinshasa or by the mobile teams in Lodja and Kabongo.
- *Focus group discussions* were conducted with four types of respondents, including groups of women suffering from fistula who participated in in-depth interviews, women who accompanied women with fistula to the repair centers, and local community women, as well as one group of men at each location. This information was used to validate the in-depth interview data and to explore preventive and treatment approaches.

In both countries, the purpose of the in-depth narrative interviews was to examine what has transpired in women's lives since the onset of fistula, including the social, psychological, and physical consequences of the condition. Topics explored included causal explanations, associated physical consequences, treatment-seeking, reactions of family and community members, and coping strategies.

Data collection procedures

Data for both studies were collected by researchers with training in anthropology and with experience carrying out qualitative research. Prior to the study, researchers participated in classroom and field-level training on administering the study instruments. All efforts were made to administer interviews in a private location; if privacy could not be maintained, the researchers changed the location or rescheduled the interview for a later time. Verbal informed consent was administered to all respondents before they participated in the study. International ethical standards were followed to ensure the confidentiality of the information collected and the anonymity of the respondents.

Findings

Bangladesh

Background information

Four women screened at the community level were identified as having fistula. These women were on average 48 years old and had lived with the condition for a mean of 15 years. All were housewives, and three of the four women had not received formal education; two women were Muslim, and two women were Hindu. Two of the women were well under five feet tall. All four women were married, and their mean age at the time they developed fistula was 32. All of the women had a stillbirth when the fistula occurred; three had previously

experienced a stillbirth, and the fourth had had a perinatal death. Three women had one living child, and the other woman was childless.

Causal explanations

All respondents, who had experienced prolonged labor and severe delivery complications, attributed their condition to procedures employed during childbirth. Two women, who had delivered at a medical facility, believed that the surgical instruments used for a cesarean section had made a hole in the bladder. The other two women, who had delivered at home, claimed that a hole in the "packet" that holds the urine was caused by the TBAs (who, they explained, had long fingernails and repeatedly inserted their hands inside the birth canal) or by a village doctor who was called to assist when the TBA was unable to deliver the baby and who used an instrument to force the delivery.

Coping with the condition

During the day, women wore a cloth made of material from *saris*, the traditional dress Bangladeshi women wear, which would get saturated with urine quickly and therefore had to be changed and washed several times a day. Women attempted to wash the swabs of cloth in private, to avoid drawing attention to their condition. It was difficult to find a hidden location to dry the napkins, particularly during the rainy season. Women explained that they were always preoccupied with hiding their condition. As a result, they had to think about their every movement; when sitting, for instance, they had to consider whether they had enough protection to avoid wetting the bed or chair. They also restricted intake of liquids and foods considered high in water content, to decrease the flow of urine, and they used powders and perfumes to try to cover the smell of urine. The two Muslim respondents reduced their daily prayers because they were unable to follow religious tenets regarding cleanliness. One woman explained:

> *If I say prayer once or twice a day, then I do not the other times. I feel tired doing all the things needed before prayer. Anybody would get frustrated, changing outfits and napkins and washing before each prayer. Other women just do the ablution and say the prayer.*

Physical consequences

Women complained of an array of physical consequences associated with the fistula, including rashes, boils, and ulcers that developed around the vulva and thighs, causing itching and severe burning and leading to vaginal infections. Their skin became particularly sensitive during the hot and rainy seasons due to the rubbing of the protective cloth, and the only relief was to change the cloth frequently, or when intolerable, not to wear it. Removing the napkin further restricted their movement and interactions, as they could not leave the house or spend time with visitors. Other common complaints included interrupted sleep caused by the wet bedcover, anxiety, lack of confidence, and weakness, with women suggesting that passing urine drained their insides. Women also indicated that they always emanated an offensive odor.

Attempts to get treatment

Women made repeated attempts to obtain care, with initial care-seeking occurring between several days to three months after the incontinence started. Two women first sought care with medicine shopkeepers, who prescribed drugs and, in one case, inserted a catheter; one woman consulted a trained physician, and the fourth woman was referred to a hospital by a CHW. Subsequent care-seeking was mostly from medicine shopkeepers or in large hospitals.

While three women attempted surgery, they were misinformed about where quality fistula repair services were available, ultimately spending large sums of money in fruitless attempts to obtain treatment, with one woman undergoing three unsuccessful surgeries over three years. The last woman only sought care with medicine shopkeepers and employed home remedies, such as applying hot water, ointment, and kerosene on growths around her vaginal area to reduce the burning sensation.

Eventually, all four women resorted to home remedies, also obtaining remedies from medicine shopkeepers for accompanying physical consequences, such as weakness or sores and burning around the vagina. One woman took antibiotics regularly over a period of 10–12 years to treat the sores and infections. Due to the shame associated with the condition, women often sent family members to consult informal health care providers; however, family members frequently failed to provide details on the woman's condition, including the fact that she was incontinent.

All women with fistula refused surgical treatment offered by the study. The three women who had already gone through unsuccessful surgical procedures were convinced that their condition could not be repaired.

Social consequences

Two women were divorced subsequent to the onset of the condition, with one husband indicating that he was disgusted by her condition and her inability to have children. Divorce in this society is extremely shameful; thus, unskilled women rejected by their spouses often return to their natal homes. However, one of these women was also rejected by family members and had to live alone. The other two remained married, and despite extreme discomfort, they did whatever was needed to perform household chores and ensure that their husbands could not find major fault with their role. These women continued to have sexual relations but felt embarrassed when they leaked urine during intercourse. Three women received emotional and financial assistance from their natal family members.

Outside of the household, women were victims of harassment and name-calling, such as "person who urinates all day" or "person who has to wear a napkin," or people spat when detecting their odor. They were often labeled as "bad" and told that Allah wanted to punish them. Their condition also affected the family image, potentially damaging life events such as siblings' marriage eligibility.

A coping strategy to avoid humiliation was to limit social interactions, with two women rarely leaving their homes. In particular, they avoided events that required long stretches outside the homestead, due to concerns that they

would be unable to manage the flow of urine. Whether with family or non-kin, they always kept a distance to avoid the detection of urine on their clothes or an odor. The constant apprehension over exposing their condition and being shamed prohibited women from enjoying basic pleasures, such as gossiping with other women. Most women did continue to receive visitors in the household, with the exception of the woman who was ostracized by family members.

DRC

Background information

Thirty-three women with fistula were interviewed in the DRC; at all three sites, the median age at which they developed the condition was under 20 years. Women from the three sites lived with the fistula for 8–12 years before getting it repaired. Educational levels varied, with 44% of women from Kinshasa, 71% from Lodja, and 30% from Kabongo having received no formal education. Many women, particularly at the site in Kinshasa, were shorter than five feet. While 25 of the 33 women had a facility-based delivery, the majority had also been assisted by TBAs during earlier stages of labor. Several respondents had become pregnant and developed the fistula while in secondary school. Twenty of the 33 women developed the fistula during their first pregnancy, and 11 of the 33 had already had at least one stillbirth before developing fistula. Most women traveled long distances—sometimes over several hundred kilometers to obtain fistula repair services.

Causal explanations

Many respondents knew local terms for fistula or recognized the condition. Most women believed that the fistula was caused by harmful birthing practices used by both trained personnel and TBAs. Women who delivered at a health facility stated that health providers created the problem by using sharp instruments that created a hole, by applying pressure on the abdomen, or by entering their bare hands into the birth canal multiple times, with some indicating that health workers went to any length to deliver the baby. One woman explained:

> *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…. There were two nurses who hit me, they pushed on my stomach to apply pressure so that the baby would come out. When the trained midwife arrived, it was too late; she asked who made a hole in the bladder, and the nurses said they did. Everything was bad, nothing went well.*

Of the eight women who delivered at home, most believed that the TBAs made a hole with their fingers and long fingernails while entering their bare hands into the birth canal. TBAs also administered pressure on the stomach to force the delivery, sometimes recruiting young men to assist. A woman who delivered at home said:

> *The birth attendant introduced her hands the first and second day, but as the baby 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. After I took the liquid in the cup, the child was delivered dead.*

Some women linked the cause to witchcraft or an enemy with whom they were in conflict, such as a stepmother or a member of the in-laws' family who had cast a spell.

Coping strategies

Women wore a protective piece of cloth or 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. Some compared the leaking urine to a poison that burns and destroys clothes. Managing the cloth was an ongoing preoccupation that involved washing the cloths with soap and water and ensuring that they were properly dried, all of which required a tremendous amount of time. Many women covered the cloth with a plastic bag to ensure that the urine did not leak through their clothing. Another strategy was to place sawdust in the bag to absorb the urine. Despite these efforts, women often were unable to manage the flow of urine and persistently wet their clothes. They emphasized how ashamed they felt when others could see traces of urine on their clothes, forcing them into hiding.

Many women applied scented powders or perfume to cover the offensive odor; they attempted to stay apart from other people and often refused to participate in public gatherings. Many respondents indicated that the odor was overpowering and impossible to control, particularly in villages where water was frequently unavailable. One woman 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. Urine has an odor capable of overpowering any perfume. In addition, when urine is mixed with perfume, it creates an odor that is intolerable.*

Physical consequences

The most commonly mentioned and serious physical consequences were the sores and rashes that women developed around their upper thighs and vagina as a result of the leaking urine and constant rubbing of the wet cloth on the skin. Women who employed plastic bags to prevent urine from leaking explained that the heat and airlessness the bags created aggravated rashes and sores. These conditions caused extreme discomfort, forcing women 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 to expose the affected area to air. Some women explained that they would discard their underwear and wear flowing skirts, which allowed the urine to drip freely and permitted them to work the fields in relative comfort. One woman said:

> *I have terrible sores on my thighs, which made me decide to remove my underwear and wear a long skirt underneath with a pagne (local cloth) on top. The sores bother me terribly; I feel as though I am in prison all the time. To allow the area between my*

thighs to get air, I must take off all the cloths that can squeeze my thighs. I notice that underwear and other cloth that has direct contact with the skin also increase the odor.

Women also mentioned that the wounds sometimes became infected, due to the perpetual state of being wet and constant rubbing, and they were also susceptible to vaginal infections. Other less frequently mentioned consequences included loss of sexual desire, pain during intercourse, weight loss, fatigue, the termination of the menstrual cycle, and cysts or tumors around the joints.

Attempts to get treatment

Many respondents stated that they were initially unaware that treatment was possible. Nonetheless, most women sought care at least once, with the majority going to trained providers in hospitals. Of the 33 women interviewed, 14 had gone through operations before eventually receiving fistula repair, with several women having been operated on unsuccessfully on more than one occasion. In several instances, women subsequently sought care from traditional practitioners or religious healers. Overall, care-seeking episodes were few, mostly because women got discouraged after unsuccessful treatment, concluding that they would have to live (and die) with the condition. However, women continued to use home remedies, such as applying powder, palm oil, and hot water to treat the wounds and reduce the pain they produced.

Several women did not seek any professional care until they heard about repair services offered by the Project AXxes mobile team or at St. Joseph Hospital, indicating that they were unaware that services were available, were concerned about the quality of care, believed the condition was not treatable due to former bad experiences, or did not have the money needed for treatment costs (including travel and food costs for the woman and accompanying person). Other barriers to care-seeking included the distance to the health facility, their health condition (which prevented them from traveling long distances), and the lack of anyone to accompany them to a facility.

Before receiving care, women admitted that they experienced extreme worries, with some thinking they would die due to the condition and others considering ending their lives in order to stop the suffering.

Social consequences

Five of the 33 women interviewed, several of whom were students, had been involved in casual relationships that ended when the girl's partner knew she was pregnant. Of the remaining 28 women, 16 were separated or divorced after the onset of the condition. Some of these women were abandoned by their partners, who indicated that they could not tolerate being with a woman who leaked urine and manifested an offensive odor, suggesting she had lost all sexual appeal and value. As one woman explained:

With my first husband, we had no sexual interactions because he said that he felt nausea due to the urine leaking from 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.

Other women left their partners of their own accord, stating they were no longer fit to be in a relationship, were concerned that sexual relations might aggravate their condition, or simply were not interested. One woman said:

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].

Many women returned to their natal homes, where they were generally cared for and protected. Several women remained with their original partners, who they said generally treated them with respect. Interestingly, four women who had been rejected by their original partners later established new relationships with other men who accepted their condition. All women who remained in relationships were obligated to have sexual relations, with many indicating that they had to endure a lot to satisfy their husbands.

Most women limited their movement to the village and their immediate surroundings, indicating that it was difficult and painful to travel and that they only traveled when it was necessary, such as to seek treatment, to visit a market to sell or buy goods, or to participate in special ceremonies, such as a family marriage or funeral, where they felt obligated to pay their respects. In general, most respondents stopped participating in ceremonies.

While rural residents generally continued to engage in agriculture, they were forced to reduce their economic activities, thus becoming more dependent on family members. Women who had small businesses either sent family members or only went to the market for short periods. Most women continued to receive visits from friends, and they could visit friends in their homes, but only for short periods, due to the leaking urine and odor. Some women added that certain former friends insulted or avoided them.

When circulating in the community, many women were commonly ridiculed, particularly by female rivals, and called names such as "somebody who leaks urine all the time," "instead of controlling urine, urine controls you," and "you wear diapers but we don't see any children." Mockery often centered on the fact that they were childless, signifying that their position in society was reduced, or that they had been abandoned by their partner and were living in their natal household, also symbolizing a loss of honor.

Women described the shame they felt due to being incontinent and smelling of urine, forcing them to seclude themselves in their homes in an attempt to hide the condition and avoid the risk of inciting humiliation. Others suggested that the stigma attached to the condition fostered blatant rejection, resulting in a life of isolation. Whether this isolation was self-imposed or inflicted by others, virtually all indicated that their lives and status as women were destroyed. The following quote illuminates common themes of rejection experienced:

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

Comparison of Findings—Does Sociocultural Context Matter?

Study findings highlighted both commonalities among and differences between the two countries. Explanations about the causes of fistula, about the ways in which women coped with the condition, and about the associated physical consequences were remarkably similar. In both countries, most women lived in rural settings where EmOC services are less available or acceptable and where educational levels are generally low. Many women were short in stature[1] and had already had a history of stillbirth. Women from both studies had been living with the condition for a prolonged period and were unaware of where to obtain quality repair services, with many formerly having been operated on unsuccessfully.

Social consequences were also similar, highlighting the tremendous suffering that women with fistula must endure and suggesting that the physical and psychological hardship that the condition manifests outweighs the differing social contexts. Surprisingly, for women from the DRC, who have comparatively more freedom and economic independence, the severe restrictions on their normally active social and economic lives resulting from fistula may have created more dramatic and profound alterations in their lifestyles. This may in part be explained by the fact that respondents in the DRC were significantly younger when the condition occurred. While in both societies the value of women is closely linked to their role as bearers of children and providers of child care, three of the four Bangladeshi women had already had a child when the condition developed, while the majority of Congolese respondents were childless.

Despite the fact that fistula caused major changes in their lives, the Congolese women were freer to move around and appeared better able to maintain social relations than were their Bangladeshi counterparts. They also made adjustments so that they were able to continue moneymaking ventures. Strikingly, several Congolese women established new relationships with men who were willing to accept their condition. In comparison, adult Bangladeshi women typically have restrictions on their mobility, and they are also much less likely to participate in income-generating activities. Therefore, changes in the lifestyles of women with fistula in Bangladesh may be less evident.

There are other notable differences. First, many of the Congolese respondents knew a local term for or recognized fistula, thus suggesting that the condition is prevalent where they lived. Maternal mortality is reported to be very high in the DRC, and the number of women who survive obstetric complications and subsequently live with maternal morbidities such as fistula should be even higher (Ronsmans et al., 2006). A high prevalence of maternal mortality and morbidity is likely linked to the poor health infrastructure and difficult access rural women have to EmOC. In addition, fistula repair services have been mostly limited to Kinshasa and the war-torn eastern part of the country. Therefore, until recently, women with fistula living in other areas have had limited access to quality repair services. In addition, the women from Bangladesh were older and had higher parity at the time they developed the fistula than the women from DRC. The fact that these women were in their 30s and that all had had previous births contradicts a common perception that fistula only occurs in young women. These findings coincide with recently published data underscoring the fact that women affected with fistula come from a broad range of ages and parities (Zheng & Anderson, 2009).

Perhaps the most noteworthy difference relates to women's willingness to accept repair procedures. While all of the women from the DRC chose to undergo fistula repair, the Bangladeshi respondents all refused to accept fistula repair, even though it was offered free of cost. Variations in sampling strategies and sample size and the fact that the Bangladeshi women were significantly older are likely to have also influenced these differences.

Study Implications

The findings illuminate a range of social consequences manifested by the condition, highlighting the profound stigma that women with fistula experience. Paradoxically, many of these social ramifications create further barriers to obtaining skilled treatment. The results underscore the importance of identifying women as quickly as possible after the onset of fistula. In this regard, mechanisms should be set up at the community level to screen suspected cases shortly after childbirth, so that the problem can be identified quickly and referrals to facilities offering quality repair services can be made without a long delay. Information must be readily available and disseminated regarding the nature of fistula treatment and where quality care can be obtained.

It is also critical to consider strategies for those women who refuse treatment or whose fistula cannot be repaired. For such women, the study findings highlight the need to establish support systems aimed at decreasing or making more tolerable the negative societal impact of life changes relating to social interactions, religious practices, and economic livelihood.

Results from both studies highlight the need to develop more effective strategies to educate people about fistula, including the nature of the condition and its cause, which women are at risk, and what preventive measures are to be taken, with prevention the focus over the long term. Women, families, and communities need to know that women should not undergo labor in childbirth for more than 12 hours without skilled attendance and that plans should be made prior to the birth for seeking medical care, if needed. Women at high risk for pregnancy complications should be identified during antenatal care consultations and should be encouraged to prepare to give birth at health centers where emergency care is available. Particularly in the DRC, the availability of high-quality EmOC facilities needs to be increased, so that women living in remote areas have easier access to emergency care. Health facilities offering maternal health care must have standard protocols and procedures in place that are rigorously followed when providing treatment to women with prolonged or obstructed labor.

BANGLADESH and DEMOCRATIC REPUBLIC OF THE CONGO

BANGLADESH

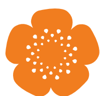
The People's Republic of Bangladesh is one of the most densely populated countries in the world, with more than 142 million people (BBS, 2011). Bangladesh's population growth has slowed in recent decades because of the availability and uptake of family planning services. Despite widespread poverty, the maternal mortality ratio in Bangladesh has dropped by 40% in the past 10 years, from 322 per 100,000 to 194 per 100,000 (Streatfield et al., 2011).

DEMOCRATIC REPUBLIC OF THE CONGO (DRC)

The DRC, while home to rich natural resources and mineral wealth, is one of the poorest countries in the world. Basic social and health services are few and of low quality in many areas. A woman has a one in 13 chance of dying for maternal health reasons over her lifetime (PRB, 2012). Only 5% of married women use modern contraception, and use is lower in rural areas than urban areas (INS & UNFPA, 2011). Among the poorest one-fifth of the population, only 60% are assisted by skilled health personnel at delivery (PRB, 2012). Twenty-eight percent of 15–19-year-olds have given birth or are pregnant (INS & UNFPA, 2011).

Fistula Care at EngenderHealth
440 Ninth Avenue, 13th Floor
New York, NY 10001
Tel: 212-561-8000

www.fistulacare.org



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Note

1. Much research has suggested that short stature may be a predisposing risk factor for fistula (Muleta, 2004; Wall et al., 2004; Meyer et al., 2007; Holme, Breen, & MacArthur, 2007).

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