

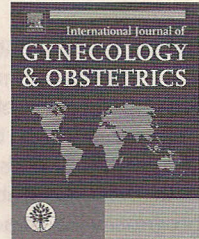


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CRITICAL ISSUES

Social and economic consequences of obstetric fistula: Life changed forever?

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KEYWORDS

Meta-analysis;
Obstetric fistula;
Social consequences;
Rehabilitation

Abstract

Objectives: To summarize the social, economic, emotional, and psychological consequences incurred by women with obstetric fistula; present the results of a meta-analysis for 2 major consequences, divorce/separation and perinatal loss; and report on improvements in health and self-esteem and on the possibility of social reintegration following successful fistula repair. **Methods:** We conducted a review of the literature published between 1985 and 2005 on fistula in developing countries. We then performed a meta-analysis for 2 of the major consequences of having a fistula, divorce/separation and perinatal child loss. **Results:** Studies suggest that surgical treatment usually closes the fistula and improves the physical and mental health of affected women. **Conclusion:** With additional social support and counseling, women may be able to successfully reintegrate socially following fistula repair.

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1. Introduction

Among all the morbid conditions that can affect women following labor, having an obstetric fistula is considered the most debilitating and devastating [1]. The result of prolonged obstructed labor, an obstetric fistula is an abnormal communication between the vagina and the genito-urinary system and/or the rectum, and is characterized by continuous urinary and/or fecal incontinence. The continuous urinary dribbling excoriates the adjacent genital areas,

produces painful rashes, and emits offensive odor. Describing the devastating effect of the condition, Harrison [2] writes, "In the case of the girls with an obstetric fistula, the baby is usually stillborn and...together with the fact that her odor is offensive....[soon] her incontinence becomes confused with venereal disease, and the affected family feels a deep sense of shame. The consequences are devastating: the girl is initially kept hidden; subsequently, she finds it difficult to maintain decent standards of personal hygiene because water for washing is generally scarce; divorce becomes inevitable and destitution follows, the girl being forced to beg for her livelihood."

Fistulas are preventable and treatable, but estimates suggest that millions of women in developing countries are affected by this dreadful condition [3]. According to Browning and Patel [4], "At the world's current capacity to repair fistula, it would take at least 400 years to clear the

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backlog of patients, provided that there are no more new cases"; and by this estimate, the unmet need for surgical treatment could be as high as 99%.

The World Health Organization's Global Burden of Disease study estimated that 21.9% of the disability-adjusted life years lost by women aged 15 through 44 years were attributable to reproductive ill health, and that 14.5 years per woman were lost to adverse maternity-related causes [5]. According to that study obstructed labor—the immediate effect of which is fistula—accounted for 22% of all morbid maternal conditions. Not only does the problem of fistula affect the productivity of a country, community, and household, it also changes the life of the affected women forever. Women with fistulas are no longer able to successfully fulfill their societal role of wife and mother, and are often deserted by husbands and family and stigmatized by society. This article summarizes the social, economic, emotional, and psychological consequences of having a fistula as well as the improvements in health and self-esteem, and the possibility of social reintegration, following surgical repair.

2. Methods

2.1. Literature review

We identified the fistula-related articles published between 1985 and 2005 in the electronic databases PubMed and Medline. The keywords used were *obstetric fistula*, *vesico-vaginal fistula*, and *recto-vaginal fistula*. We also searched Web-based documents on fistula using the Google search engine. In addition, we used search facilities at the Web sites of international health and donor organizations, including the following organizations dedicated to the care of women with fistulas: United Nations Population Fund, World Health Organization, US Agency for International Development, UK Department for International Development, EngenderHealth agency, World Fistula Fund, Women's Dignity Project. We then read the reference lists of these documents and located additional articles. We also used references to earlier important studies when relevant.

A summary of this literature review is available on request in a matrix format, along with the study description and key findings covering the following areas: study objectives, sample description, patient characteristics (age, parity, education, marital status, and anthropometric measures such as weight and height), presence or absence of genital cutting, age at marriage, age at first pregnancy, mode and location of delivery, comorbid conditions, reported etiology, type of fistula, whether maternal and/or fetal death occurred for the index delivery, results of surgical repair, and postoperative morbidity.

2.2. Meta-analysis

We performed a meta-analysis for 2 of the major consequences of fistula, divorce/separation and fetal/perinatal loss. Studies consistently show that high fetal and perinatal death rates are commonly associated with obstetric fistula. The loss of a child resulting from obstructed labor and the formation of a fistula—a condition often leading to childlessness—adversely affects the social status of women and may lead to divorce and separation. Without family support, a woman with a fistula who becomes divorced or separated from her husband experiences the

greatest economic hardship. Because of significant variations in the reported rates of fetal/perinatal deaths and divorce/separation in the literature on fistula, a meta-analysis was performed to estimate an overall rate with 95% confidence intervals (CIs). Owing to the very limited number of studies that examined the adverse social, psychological, and economic consequences of having an obstetric fistula, a meta-analysis could not be carried out for other adverse outcomes such as depression or unemployment.

3. Results

3.1. Physical consequences

Arrowsmith and colleagues [6] coined the phrase "obstructed labor injury complex" to encompass the extent of physical and social injury caused by fistulas. Almost 80% of women will develop chronic excoriation of the skin from the direct irritation caused by urine; in addition, they may develop amenorrhea, vaginal stenosis, infertility, bladder calculi, infection, and footdrop (due to neurological injury).

Evoh and Akila [7] reported that 41% of the women with vesico-vaginal fistulas (VVF) admitted to Lagos University Hospital for surgical repair had secondary amenorrhea, which the authors attributed to severe malnutrition and anemia. A much higher rate of amenorrhea (84%) was reported at Benin Teaching Hospital, Nigeria. Wall [8] suggested that nearly two-thirds of women with obstetric fistulas may develop amenorrhea because of hypothalamic dysfunction, panhypopituitarism (Sheehan syndrome), and intrauterine scarring. Psychological stress may also lead to amenorrhea. Several studies reported that a large proportions of women with fistulas also experienced amenorrhea at the time they were evaluated for care [6,9–11]. No study we reviewed attempted to differentiate between postpartum amenorrhea and secondary amenorrhea. However, because of the high rate of fetal and perinatal deaths associated with obstructed labor, postpartum amenorrhea is likely to be shortened, and is most likely due to the adverse effects of the incurred fistula.

Several studies state that women with VVFs are malnourished and underweight [6,12–14]. Nutritional deficiency contributes to prolonged labor in 2 ways. It may arrest or slow the normal development of the pelvis during childhood and adolescence, resulting in a contracted pelvis and an increased risk of cephalopelvic disproportion and obstructed labor. It also causes fatigue during pregnancy, and uterine muscle inertia can develop in women too weak to expel the fetus.

Nutritional deficiency is not only a cause but also a consequence of fistula. Kelly and Kwast [15] noted that after a long and difficult labor a woman is too exhausted to move and can lie on the floor for a very long time; and that, as a result, she is prone not only to fistula formation but also to pressure sores and infection. As soon as a woman sustains a fistula the physical and mental trauma she experiences, coupled with the anguish caused by sudden social isolation and economic hardship, greatly increase the likelihood of her developing nutritional deficiency. In the Kelly and Kwast [15] series, marked weight loss and malnutrition were evident in 36.6% of the women with fistulas and limb contractures were present in 8.5%. Fistula repair could be hazardous and postoperative healing delayed in the presence of severe malnutrition, and the malnourished women received special

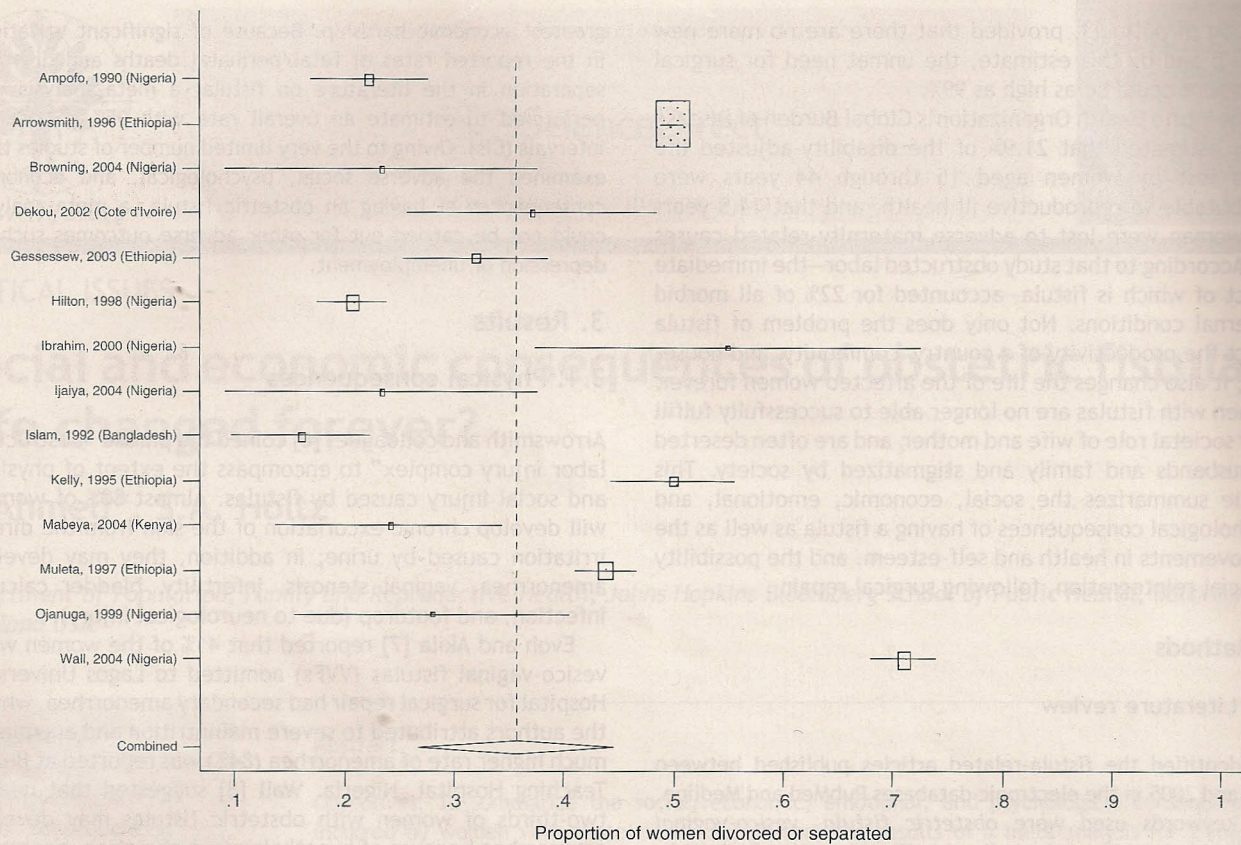


Figure 1 Results of a meta-analysis assessing the proportion of women with fistulas who were divorced or separated from their husbands between 1985 and 2005 in different developing countries because they became affected with a fistula.

feeding preoperatively to correct their clinical protein deficiency.

3.2. Social and economic consequences

Fistula is considered a "social calamity" [2] and women with VVFs are often ostracized by their husbands, families, and communities. The condition is often considered a sexually transmitted disease and viewed as a punishment from God. Most women with fistulas report disturbed socio-psychosexual lives and are usually deserted by their husbands. A study in Africa reported that immediately after the fistula occurred, 14% of new patients were divorced by their husbands and only 42% continued to live with their husbands; and if the condition persisted, 28% of the women were divorced and only 11% were allowed to stay [16]. And among women affected with fistulas in Niger, 63% were divorced [17]. Often, until they are cured, married women with fistulas are sent back to their parents' home where they are not allowed to cook food, participate in social events, or to perform religious rituals [16,18]. A study of how women with fistulas perceive the societal reaction toward them in Nigeria found that most (53%) consider themselves rejected [19]. Our meta-analysis for the estimation of the mean percentage of women who are divorced or abandoned because of a fistula is shown in Fig. 1. A random-effect estimate shows that about 36% of the women (95% CI, 27%–46%) (47% with fixed-effect estimate) were divorced or separated. As shown in Fig. 1, there is substantial heterogeneity in the observed rates.

Whether the presence of children was associated with the risk of divorce or separation was examined only in 1 study conducted in Zaria, Nigeria. The findings suggest that the presence of living children may reduce the risk of separation or divorce unless the mother has long been affected with a fistula [16].

A study in Addis Ababa found that without support from their husbands and without the means of earning their livelihood, 39% of the women with fistulas were dependent on relatives for food and 22% begged or lived on donations [20]. Kelly [21] gave a vivid glimpse on their social isolation. When suggested treating a blind woman with a fistula for her blindness first, she replied, "Cure my fistula first. If I am blind people will sit with me and talk to me, but no one will come near me because I'm wet and I smell." The reduction of stigma remains a major challenge for public health programs involved with the problem of fistula [22].

3.3. Emotional and psychological consequences

Very few studies have examined the women's emotional and psychological status. Not only that mourning a dead child is almost inevitable for a woman with a fistula from obstructed labor, but she soon finds herself fighting for her own survival, social position, and value in society. Mentally she is tormented and devastated. The results from our meta-analysis show that, on an average, about 85% of the women incurred fetal loss from the delivery in which the fistula developed (Fig. 2).

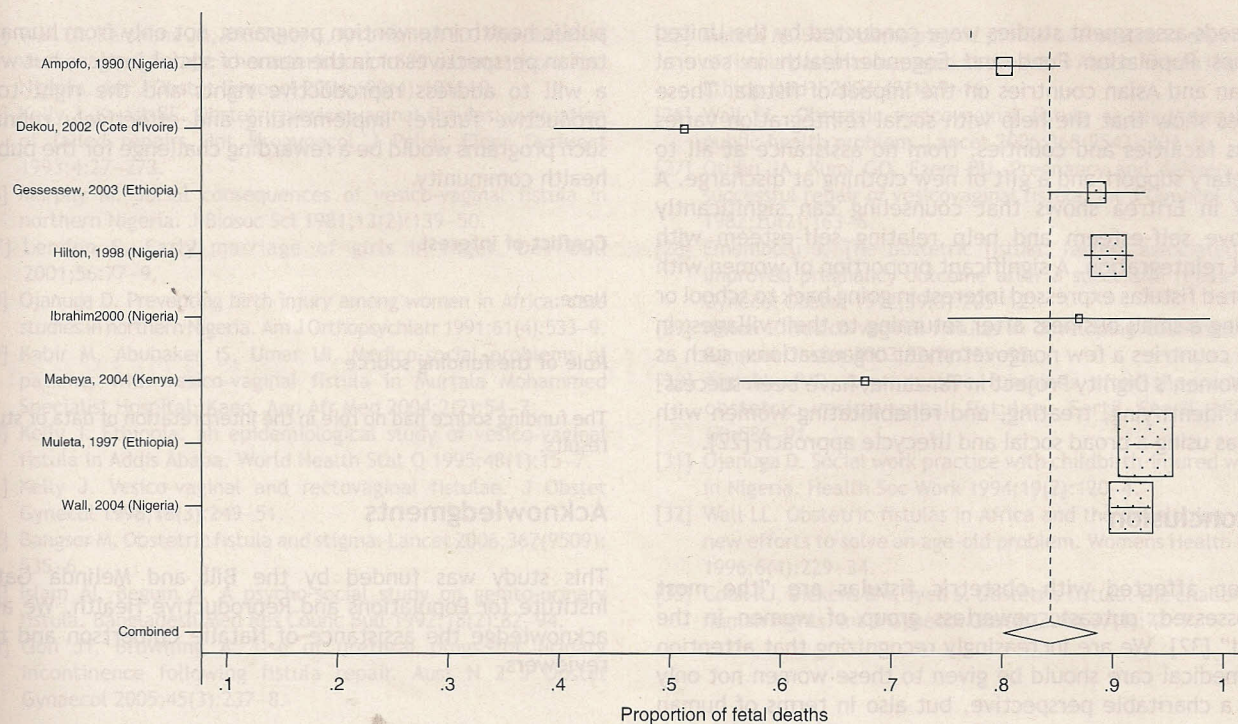


Figure 2 Results of a meta-analysis assessing the proportion of fetal deaths in the index delivery between 1985 and 2005 in developing countries.

In a study conducted in Nigeria about 33% of women with fistulas were psychologically depressed, and an additional 51% were bitter about life [19]. A qualitative case study examined psychological effects of VVF, including anger, depression, and disappointment with life, in 53 women from northern Nigeria. Most reported a loss of self-esteem and experienced stress and anxiety [18]. If emotional support was provided by their husbands, however, the women reported an optimistic view of life.

Islam and Begum [23] conducted an extensive study on the psychosocial consequences of having a fistula in Bangladesh. A majority of women (61.4%) reported embarrassment in their social lives, 39.4% reported feeling constantly ill, and 33.3% reported difficulty in maintaining a sexual relationship. About 50% reported a significant decrease in libido; 59% a reduction in the frequency of coitus; and 45% a delay in experiencing orgasm. Moreover, 52% of the husbands expressed a loss in sexual pleasure with their wives. Regarding their social lives, 87% reported embarrassment; 67.4% an inability to perform their prayers; and 62% unhappiness in their married life. Dyspareunia was reported by 37.9% of the women. Another recent psychosocial study in Bangladesh suggests low self-esteem in women with fistulas, with many reporting depression and anxiety [24].

3.4. Postsurgical improvement in quality of life

Observed rates of successful fistula repair, defined as closure of the fistula 2 weeks after surgery, range between 85% and 90%. Based on 19 studies, our own meta-analysis suggests a success rate of 86.0% (95% CI, 82.7%–89.3%). These estimates may be misleading, however, as the surgical intervention is frequently performed on prescreened patients. Even with

the successful closure of the fistula, about 5% of the affected women remain incontinent at discharge.

A sizable proportion of the treated women return to their husbands or remarry, but since long-term follow-up is rarely done or reported on, the duration of the reunion with husbands or of the remarriage is unknown. Because of the severity of the damage incurred and subsequent fibrosis, women often report gynaesthesia and dyspareunia after repair [6,25,26]. On the other hand, many of those who were amenorrhoeic report the return of menses [7] and a large number of women become pregnant after fistula repair [7,27–29].

Although a study in Nigeria found that women with unrepaired fistulas have a spontaneous abortion rate of nearly 50%, whereas the rate in those with a repaired fistula drops to 6% [30], a study in Kenya found that almost 60% of women with repaired fistulas report miscarriage [28]. Ebembolu [28] reported a perinatal mortality of 13% among women who underwent repair, compared with 33.9% among those who did not; moreover, the proportion of newborns with low birth weight was lower for the women who underwent repair (20.3% vs. 37.3%).

4. Social reintegration

Several treatment facilities were quick to recognize the importance of rehabilitation and social reintegration, as many women refused to leave after they recovered from the intervention because they had nowhere to go. During the mid-1970s a teaching hospital in Nigeria initiated craft-training programs teaching such skills as embroidery and tie-dyeing, and paid for transportation for the follow-up visits [16]. Social workers were also hired in Nigeria to help women in rehabilitation fight the stigma of having had a fistula [31].

Needs assessment studies were conducted by the United Nations Population Fund and EngenderHealth in several African and Asian countries on the impact of fistula. These studies show that the help with social reintegration varies across facilities and counties, from no assistance at all to monetary support and a gift of new clothing at discharge. A study in Eritrea shows that counseling can significantly improve self-esteem and help relating self-esteem with social reintegration. A significant proportion of women with repaired fistulas expressed interest in going back to school or starting a small business after returning to their villages. In some countries a few nongovernment organizations, such as the Women's Dignity Project in Tanzania, have been successful in identifying, treating, and rehabilitating women with fistulas using a broad social and lifecycle approach [22].

5. Conclusion

Women affected with obstetric fistulas are "the most dispossessed, outcast, powerless group of women in the world" [32]. We are increasingly recognizing that attention and medical care should be given to these women not only from a charitable perspective, but also in terms of human rights and social justice [33]. Having a fistula changes a woman's quality of life forever. Only a few studies have examined the adverse social, economic, and psychological consequences of fistula; nonetheless, these studies provide some empirical evidence that treatment, counseling, social support, and rehabilitation may significantly improve the physical and mental health of affected women, and provide these women with a second chance at participating in family life. However, the vast majority of the women with fistulas do not have access to medical care or to any social services.

Studies suggest that some women commit suicide [6] but nothing has been published on the risk of domestic violence, murder, and "honor killing," especially for young women, considering the long-term burden young women represent for their families and social environments.

Measuring the quality of life (QOL) has frequently been done in the industrialized world to monitor individual health and well-being, but only recently has the world health community begun doing so in developing countries. Defining QOL for women affected with fistulas is challenging, and may need to encompass several dimensions not considered previously in the construction of QOL indices. The public health community has limited experience with rehabilitation and social reintegration programs. Nongovernmental organizations specialized in income-generating activities, such as microcredit social banks, could be involved to better help these women to have a second chance in life.

We identified 4 kinds of adverse consequences of obstetric fistula: physical consequences, social and economic consequences, emotional and psychological consequences, and social displacement. Our literature review suggests that very few studies examined these dimensions systematically. As almost all studies are based on short-term follow-up after surgical repair, knowledge remains limited about long-term prognosis following surgery, and therefore about the long-term contribution of fistula repair to QOL improvement and social reintegration.

We underscore the need to improve the social and economic life of women with fistulas through appropriate

public health intervention programs, not only from humanitarian perspectives or in the name of social justice, but with a will to address reproductive rights and the right to a productive future. Implementing and effectively running such programs would be a rewarding challenge for the public health community.

Conflict of interest

None.

Role of the funding source

The funding source had no role in the interpretation of data or study results.

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