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International Journal of Gynecology and Obstetrics

journal homepage: www.elsevier.com/locate/ijgo

SPECIAL ARTICLE

A bill of rights for patients with obstetric fistula

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ARTICLE INFO

Article history:

Received 12 April 2014

Received in revised form 22 June 2014

Accepted 8 August 2014

Keywords:

Bill of rights

Human rights

Obstetric fistula

Vesicovaginal fistula

Vulnerable populations

Women's rights

ABSTRACT

According to the seven categories of vulnerability proposed by Kipnis (cognitive, juridical, deferential, medical, allocational, social, and infrastructural), and the four generally accepted principles of biomedical ethics (respect, beneficence, non-maleficence, and fairness), women with obstetric fistulas are an exceptionally vulnerable population. Therefore, they merit special consideration in both clinical care and research settings. Adoption of a formal bill of rights for patients with fistula similar to the one proposed in the present report should be encouraged at all facilities where these women are treated. Acknowledgment of their rights would help to improve their care and end the abuses they are exposed to in institutional settings.

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1. Introduction

An obstetric fistula is a condition in which the tissues normally separating the vagina from the bladder and/or the rectum are destroyed during obstructed labor [1]. Obstructed labor occurs when the fetus will not fit through the birth canal, and if labor continues for a long period, the blood supply to the compressed tissues is disrupted. Eventually, the injured tissues will necrose and slough away, creating a fistula [1]. A woman with an obstetric fistula will have urinary and/or fecal incontinence, which is continuous and unremitting. In the worst cases, a woman with a fistula is constantly soaked in urine, shunned by people around her, banished from the family house, divorced by her husband, and forced to the margins of society [2,3].

The unique combination of upright bipedal locomotion and large offspring means that human labor is often prolonged and difficult [4]; obstructed labor occurs in approximately 3%–6% of all births [5]. However, obstetric fistulas do not develop after all obstructed labors because prompt diagnosis and early intervention (usually cesarean delivery) can abort the process which leads to fistula formation. Instead of a still-born child and a mother with devastating genitourinary injuries, early diagnosis and prompt intervention in cases of obstructed labor result in healthy mothers with a live newborn. The women who develop fistulas are those who do not receive competent obstetric care in a timely fashion [6,7].

2. The women of the “bottom billion”

Obstetric fistulas are virtually unknown in resource-rich countries: maternal mortality and severe obstetric morbidity (e.g. fistula) decreased greatly in high-income countries during the 20th century [8,9]. Today, obstetric fistulas are largely confined to the so-called bottom billion—the poorest 15% of the world's population [1,10]. Obstetric fistula, like maternal death, is largely a problem of poverty: it affects poor women in low-income countries where women's rights and social status are also poor, and where, because women's reproductive health is not a top priority, their lifetime chances of dying or being permanently disabled as the result of pregnancy, labor, and delivery are much higher than are those of women in high-income nations. For example, according to WHO estimates for 2005 [11], a woman in Niger had a lifetime risk of dying as a result of a pregnancy-related condition of one in seven, whereas a woman living in France (Niger's former colonial ruler) had a lifetime risk of maternal death of only one in 6900 [11]. Unsurprisingly, obstetric fistulas are common in Niger [12].

By definition, the people in the bottom billion are marginalized. Within that bottom 15%, women themselves are marginalized compared with men. When such women develop a fistula, they are marginalized still further. They are truly at the bottom of the bottom billion.

3. Fistula treatment

Small obstetric fistulas can sometimes heal with prolonged catheter drainage [13], but the vast majority will not be cured without surgery. The fistula was caused by a healthcare system that could not provide adequate and timely surgical services (i.e. cesarean delivery) for the

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patient in obstructed labor, and once the injury develops, the woman is again trapped by a healthcare system that cannot help her in a timely fashion. Surgical services in countries where fistulas are prevalent are generally overwhelmed by emergencies and, unlike obstructed labor or uterine rupture, a fistula is not a surgical emergency. In the bottom billion, women with fistulas are generally near-destitute and cannot afford to pay for surgery privately. They are at the mercy of socioeconomic forces beyond their control.

4. Fistula campaigns and vulnerable patients

Recently, obstetric fistula has risen higher in the public consciousness [1]. Campaigns to recruit patients for mass treatment are common [14]. Foreign aid donors—both governmental and non-governmental—have funded programs for fistula repair and prevention, and new private and public fistula centers have been created. It is imperative to ensure that the best interests of patients—and not another agenda—are driving these activities.

Patients with fistula are a vulnerable group deserving special attention, because they are mostly at the bottom of the bottom billion. The Council for Organizations of Medical Sciences defines vulnerable patients as individuals “who are relatively (or absolutely) incapable of protecting their own interests” [15]. Kottow [16] suggested that vulnerable patient groups exist in a “determined state of destitution” that “can only be reduced or neutralized by measures that are (a) specifically designed against the destitution in question, and (b) actively applied.” Patients with fistula need special programs to repair their injuries (set within a broader range of reforms to combat the structural violence that leads to obstetric fistula in the first place).

5. A taxonomy of patient vulnerability

Kenneth Kipnis proposed seven specific categories of patient vulnerability [17]: cognitive, juridical, deferential, medical, allocational, social, and infrastructural. Although his taxonomy of vulnerability was originally developed within the context of medical research, it is valuable for evaluating patients who cannot look after their own medical interests [18]. Each of the vulnerabilities is common among women in the bottom billion who have an obstetric fistula.

5.1. Cognitive vulnerability

Cognitive vulnerability refers to whether the patient is able to deliberate about whether or not to receive the proposed care [17]. Patients with fistula usually come from rural villages. Many are illiterate. Often they do not understand the nature or causes of their injuries, and may attribute them to supernatural punishment for moral failure. Affected women are at the mercy of individuals who propose to treat them. Typically, they are also desperate for relief and might not understand the surgery or its implications for their lives, particularly if something like urinary diversion is proposed. Misunderstandings are particularly likely to occur in mass surgical camps, where time is short and pressure is high.

5.2. Juridical vulnerability

Patients are thought to have juridical vulnerability when they are subject to the authority of others who might have an independent interest in their care [17]. Throughout Africa, women are usually subordinate to men—their fathers, husbands, uncles, or brothers. Decisions regarding medical care might not be theirs to make. When problems arise in labor, the permission of a male authority can be required before help can be sought. If that person is absent, uninterested, or unwilling to give permission, the woman in labor must wait for treatment, often with disastrous consequences. She is at the mercy of indigenous structures of authority which compromise (or negate) her personal autonomy.

5.3. Deferential vulnerability

Deferential behavior could mask an underlying unwillingness to participate [17]. Cultural patterns of female deference to male authority figures could prevent accurate communication of the patient's needs and desires, particularly when the authority figure is a male from another culture. Language barriers can complicate things even further, derailing the process of informed consent and leading to unrealistic expectations or complete misunderstandings.

5.4. Medical vulnerability

Medical vulnerability exists when patients have been selected for treatment partly because they have a condition which is interesting to others [17]. Obstetric fistulas are exotic pathologies to individuals from high-income countries, and so affected women can be regarded as “trophies” to be captured by visiting surgical teams. In some African countries where surgeons are paid on a case-by-case basis to perform fistula repairs, a woman with a fistula can become a prize through which the surgeon benefits by operating, irrespective of his skills. The best interests of the vulnerable patient might not always come first in these circumstances.

5.5. Allocational vulnerability

Patients seriously lacking in important social goods that will be provided as a consequence of participation or treatment are affected by allocational vulnerability [17]. Women with fistula have little income and often are from deprived rural areas. Frequently, they do not receive support from their husbands and families. A sense of community usually forms among patients while they are awaiting treatment and these communities are often accorded special treatment by well-meaning visitors who provide clothing, food, gifts, or presents. It is not wrong to provide such things to patients, but doing so raises the possibility that these incentives could, in some circumstances, be disproportionately influential to destitute women who could be uncertain as to whether or not to accept the treatment offered to them. Nevertheless, if adequate food, clothing, and shelter are not provided to vulnerable patients, they could be exploited or abused by others, such as by being forced to provide sexual favors in return for basic life necessities.

5.6. Social vulnerability

Patients who belong to a socially undervalued group are affected by social vulnerability [17]. Women with obstetric fistula are undervalued and are often stigmatized. Their unpleasant affliction can cause the local community to shun them. Even when their condition is not immediately obvious, they are ashamed, embarrassed, or even fearful, and they all have been psychologically injured. They are therefore vulnerable to exploitation by individuals who offer to help, because they might have nowhere else to turn.

5.7. Infrastructural vulnerability

The integrity and resources needed to manage care might not be present in the political, organizational, economic, and social context of the clinical settings [17]. The occurrence of obstetric fistulas in a community is itself evidence of inadequate local infrastructure. Fistulas are a dramatic expression of “structural violence” [19], which was defined by psychiatrist James Gilligan as “the increased rates of death and disability suffered by those who occupy the bottom rungs of society, as contrasted with the relatively lower death rates experienced by those who are above them. Those excess deaths (or at least a demonstrably large proportion of them) are a function of class structure; and that structure itself is a product of society's collective human choices, concerning how to distribute the collective wealth of society” [20].

Obstetric fistulas exist because the healthcare system is inadequate to meet the needs of pregnant women, especially those at the bottom of the socioeconomic pyramid.

6. Four principles of medical ethics

Since the middle of the 20th century, medical ethicists have emphasized the primary importance of four major principles governing care and clinical research activities. First, patients should be respected as people, worthy in their own right, who are ends in themselves rather than means to another end (respect for individuals). Second, physicians are obliged to do good and to put the best interests of their patients ahead of all other considerations (beneficence). Third, physicians have the obligation to avoid harming patients, particularly those who are most vulnerable (non-maleficence). Finally, patients with similar problems should be treated in a similar fashion (fairness). These principles originated in the Nazi war crimes trials at the end of World War 2 as the Nuremberg Code [21], were emphasized in the Belmont Report [22], and have since been incorporated into documents such as The Declaration of Helsinki [23] and the Charter on Medical Professionalism [24], which have been endorsed by multiple medical associations and specialist societies worldwide. These principles are now part of an “overlapping consensus” [25] regarding proper treatment of patients around the world.

7. A bill of rights for patients with obstetric fistula

Against the background of patient vulnerability and with these fundamental principles of medical ethics in mind, a bill of rights for patients with obstetric fistula is proposed (Box 1). The purpose of this bill of

Box 1

A bill of rights for patients with obstetric fistula.

- Every woman with an obstetric fistula has the right to be treated with compassion, dignity, and respect, irrespective of her socioeconomic status.
- Every woman with an obstetric fistula has a right to privacy. She has the right to refuse to be interviewed, photographed, or displayed in any fashion without her express consent. Receiving care at any institution where patients with fistula are treated should not be contingent on interviews, photographs, or displays that are not relevant to a woman’s immediate clinical care.
- Every woman with an obstetric fistula has the right to have the nature of her condition—its causes, prognosis, and possible treatments—explained to her fully and completely in a language she can understand. She has the right to ask questions about these subjects and to participate actively in deliberations about her care.
- Every woman with an obstetric fistula has the right to food, clothing, and shelter sufficient to sustain her basic needs while receiving care for her condition.
- Every woman with an obstetric fistula has the right to self-determination. She has the right to be free from coercion, proselytizing, or exposure to any form of undue influence when making decisions about how, when, where, or if she is to undergo treatment.
- Every woman with an obstetric fistula has the right to refuse treatment, to refuse to participate in research studies, and to leave obstetric fistula treatment centers whenever she chooses to do so, without penalty or retribution.
- Every woman with an obstetric fistula has the right to receive competent care from qualified doctors, nurses, social workers, and therapists during the course of her treatment.

rights is to help to ensure that women with obstetric fistulas are treated fairly. A forthright declaration that patients have these rights is important in view of their multiple vulnerabilities.

The obligations of surgeons and other caregivers during treatment of patients with fistula are well known and have been previously described [26]. There is a particular obligation to ensure that the care provided to women with obstetric fistulas is competent when such care is sponsored by international charities, relief organizations, and governmental foreign aid programs, all of which have their own fiduciary responsibilities to make sure that their programs operate at the highest ethical level. Third-party sponsors of fistula care activities should carry out regular, formal ethical audits of their programs to ensure that the rights of patients are honored and respected. Sponsoring organizations should make a fistula ombudsman available at all fistula care facilities to ensure that the rights of patients are respected and to provide recourse when they are not.

8. Conclusion

The adoption of a formal bill of rights for patients with fistula similar to the one proposed in the present report should be encouraged at all facilities where these women are treated. Formal acknowledgment of their rights would go a long way toward improving their care and ending the abuses that sometimes occur when vulnerable women find themselves in institutional settings. The international community of obstetricians and gynecologists should promote initiatives of this kind in the furtherance of gender equity, the protection of vulnerable populations, and the protection of women’s reproductive rights.

Conflict of interest

The author is the founder of, and a consultant to, The Worldwide Fistula Fund, a not-for-profit public charity supporting fistula care and related research. He also serves as President of Hamlin Fistula USA, a not-for-profit public charity supporting the work of Hamlin Fistula Ethiopia.

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