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CLINICAL ARTICLE

Healthcare providers' perspectives on the social reintegration of patients after surgical fistula repair in the eastern Democratic Republic of Congo☆

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ABSTRACT

Objective: To understand perspectives of local health providers on the social reintegration of patients who have undergone fistula repair in the eastern Democratic Republic of Congo. *Methods:* In a qualitative study, semi-structured individual interviews were conducted with patient-care professionals working with women with fistula at HEAL Africa Hospital (Goma) and Panzi Hospital (Bukavu) between June and August 2011. The interviews were transcribed and themes elicited through manual coding. *Results:* Overall, 41 interviews were conducted. Successful surgical repair was reported to be the most important factor contributing to patients' ability to lead a normal life by all providers. Family acceptance—especially from the husband—was deemed crucial for reintegration by 39 (95%) providers, and 29 (71%) believed this acceptance was more important than the ability to work. Forty (98%) providers felt that, on the basis of African values, future childbearing was key for family acceptance. Because of poor access and the high cost of cesarean deliveries, 28 (68%) providers were concerned about fistula recurrence. *Conclusion:* Providers view postsurgical childbearing as crucial for social reintegration after fistula repair. However, cesarean deliveries are costly and often inaccessible. More work is needed to improve reproductive health access for women after fistula repair.

1. Introduction

Genital fistula refers to an abnormal connection between the vaginal or uterine cavity and the urethra, bladder, ureters, colon, or rectum. This devastating condition affects approximately 2–3 million women worldwide, with an incidence of 50 000–100 000 new cases every year [1,2]. Not surprisingly, most of these cases are preventable and occur in areas with poor emergency obstetric care, where the incidence can reach 2–5 cases per 1000 deliveries [3].

Genital fistula is a life-altering condition. In up to 83% of women with an obstetric fistula, the child is stillborn or dies within the first few weeks of life [4]. In addition to experiencing urinary and/or fecal incontinence, women with fistula have frequent infections, pain, vaginal stenosis, and malnutrition [5]. Socially, these women experience social isolation, divorce, societal rejection, low self-esteem, and economic impoverishment from job loss [6,7]. Fortunately, studies have shown that the success rate of repair can be as high as 80–95% [8], which has inspired the creation of fistula repair programs.

These fistula repair programs have led to the recognition that undergoing medical treatment is not enough to address the acute and chronic social, psychological, and economic consequences that women face even after successful repair. The WHO guidelines [9] emphasize that patients with fistula differ in their need for social support, experience with stigmatization, socioeconomic background, and etiology of their injury. WHO recommends that social reintegration programs include a range of services to address the patients' varying needs, such as skills training for income generation, counseling, family reintegration, community education/advocacy, transportation grants, and research to better understand the determinants of fistula development and outcome [9]. Examples of fistula programs that include reintegration services can be found across Africa [10,11]. However, despite more emphasis on social reintegration, Velez et al. [12] found that some health workers in Malawi failed to refer patients after fistula repair to social services because they felt that these services were unnecessary once the patient had been treated. Therefore, for fistula repair programs to be successful, it is crucial to consider the perspectives of local health providers on the social reintegration process of women after fistula repair.

Unfortunately, there are few studies focused on analyzing the barriers and the social reintegration needs of women after fistula repair in the eastern Democratic Republic of Congo (DRC). Furthermore, no study

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has examined the perspectives of healthcare providers caring for women with fistula on the social reintegration challenges faced by these women. Since the mid-1990s, the eastern DRC has seen prolonged war, massive population displacement, and poverty. The number of conflict-related deaths has reached 5.4 million, and there is an epidemic of sexual violence, a high maternal mortality ratio (540 per 100 000 live births), and an increasing fistula burden that is exacerbated by a disrupted healthcare system [13,14]. Although the incidence of genital fistula is not available for the DRC, a previous study concluded that the prevalence is 1.57 per 1000 women in Sub-Saharan Africa [15].

HEAL Africa Hospital and Panzi Hospital are centers in the eastern DRC that have fistula programs. HEAL Africa Hospital is a tertiary-care hospital in Goma, North Kivu, which is run by a Congolese nongovernmental organization. A fistula care program was introduced in 2003 and an average of 100–150 fistula repairs are now performed per year. A fistula reintegration program provides training in the income-generating skills of bread-making, soap-making, and sewing. A community outreach team also conducts community educational sessions about the etiology and treatment of fistulas with the goal of decreasing fistula-associated stigma. Additionally, there is a full-time counselor who provides psychosocial care for all patients with fistula, along with educators who teach reading and writing. Panzi Hospital is a large regional referral hospital in Bukavu, South Kivu, with a fistula program that has served 400–500 patients per year since 2006. It has a similar reintegration program, with training in sewing, basket-weaving, literacy, and basic business skills.

The aim of the present research was to understand the perspectives of local health providers on the social reintegration process of patients who have undergone fistula repair at these two referral hospitals. The hope was to learn about their perceptions of the social reintegration needs of their patients, their experiences with the existing programs, and what gaps remain in the current reintegration services, which would have implementation and policy implications for these fistula repair programs.

2. Materials and methods

For the present qualitative interview-based study, all patient-care professionals who work with women with fistula—i.e. physical therapists, nurses, social workers, general surgeons, obstetricians/gynecologists, generalist physicians, and counselors/psychologists—were eligible for participation. These providers were identified by the hospital administrations and approached by research staff for interview from June 30 to August 15, 2011. It was emphasized that participation was completely voluntary and all information obtained would remain anonymous and only be presented in aggregate. Verbal informed consent was obtained from eligible participants with participation in the interview as confirmation of consent. The research protocol was approved by the institutional review boards of the two hospitals and by the University of California, San Francisco, USA.

One interviewer (N.Y.) not affiliated with either hospital conducted individual interviews lasting 20–50 minutes in French. A semi-structured questionnaire (Supplementary Material S1) was used to understand the respondents' views of the following themes: what was provided in existing counseling after fistula repair, the most important factors for successful reintegration, and gaps in the existing fistula repair programs. All interviews were recorded, transcribed, and manually coded in French. The interview transcriptions were analyzed independently by two researchers bilingual in French and English (N.Y. and N.B.). Dominant themes were elicited from the interviews and translated into English.

3. Results

Forty-one interviews were conducted, 17 at HEAL Africa Hospital and 24 at Panzi Hospital. No providers declined to participate. Various types of healthcare providers were interviewed (Table 1). The average number of years worked with women with fistula was 4.63 years. The coded interviews did not demonstrate a notable difference in responses between the two sites or between the different types of healthcare provider.

Table 1
Characteristics of the providers interviewed.[a]

Characteristic	Total (n = 41)	HEAL Africa Hospital (n = 17)	Panzi Hospital (n = 24)
Duration of experience, y	4.6 (0.75–10)	3.6 (0.75–10)	5.3 (1–10)
Provider type			
Obstetrician/gynecologist	4 (10)	2 (12)	2 (8)
Physical therapist	6 (15)	3 (17)	3 (13)
Resident physician	2 (5)	2 (12)	0
General surgeon	2 (5)	2 (12)	0
General physician	7 (17)	2 (12)	4 (17)
Counselor/psychologist	4 (10)	4 (24)	0
Nurse	9 (22)	2 (12)	8 (33)
Social worker	7 (17)	0	7 (29)

[a] Values are given as mean (range) or number (percentage).

Every provider commented on the plight of women with fistula and nearly all providers mentioned that these women are discriminated against, abandoned, and rejected by their husbands, their community, and people generally. Several providers attributed the women's social isolation to the malodor caused by the woman's incontinence, which prevents close contact and marital intimacy.

When asked about what instructions they give women after fistula repair, all providers stated that they advised the women to avoid sexual relations for at least 3 months after surgery and that any subsequent deliveries needed to be at a hospital by cesarean, not at a health clinic. Most healthcare personnel also counseled the patient about family planning (36 [88%]), doing pelvic exercises (25 [61%]), and avoiding heavy lifting/work for 3 months (22 [54%]). Two (5%) individuals—both female nurses—also said that they counseled the patients to drink plenty of water to avoid forming renal stones; 1 (2%) nurse counseled patients to avoid infections by keeping their perineum clean.

Everyone interviewed was aware of the existence of social reintegration programs for their patients with fistula and could name several of the reintegration services that his/her healthcare institution offers. All providers believed that the social reintegration services at their institution are useful. Many providers at HEAL Africa Hospital (11 [65%]) expressed a hope that more consistent funding would be available for these programs. Similarly, many providers (7 [29%]) at Panzi Hospital felt that the social reintegration programs should be "reinforced" through more funding. More than half (21 [51%]) the providers mentioned that psychotherapy in addition to capacity building through vocational training is an invaluable service for their patients. Some providers noted that the community education about genital fistula has been helpful for the women's reintegration. Although both hospitals have community-based follow-up of patients, 17 (41%) providers noted that there needs be closer follow-up to understand a woman's physical as well as psychosocial conditions after she returns to her village.

Successful surgical repair was reported by all providers to be the most important factor contributing to patients' ability to lead a normal life. Family acceptance—especially from the husband—was deemed crucial for reintegration by 39 (95%) providers, and 29 (71%) considered this acceptance to be equally or more important than the ability to work and generate income. Many providers emphasized that it is the husband who needs to accept the woman and be counseled on her condition and the steps to full recovery after her surgery. A male physician at HEAL Africa Hospital emphasized that finding work was only secondary to gaining the husband's support.

Nearly all providers (40 [98%]) stated that future childbearing was crucial for family acceptance, especially from the husband. This was independent of the providers' professional level, gender, or personal sociocultural beliefs. According to the providers, patients with fistula adhere to the prevalent societal belief in Africa that a woman's worth

is based on her childbearing capacity. A female nurse at Panzi Hospital explained that by becoming pregnant, the woman would be considered fertile and "useful" again by African standards. A physical therapist at HEAL Africa Hospital elaborated that, in Africa, children are a sign of wealth, help the family by working, and signify a woman's status in the community. Although fertility is considered crucial to patients' reintegration into society, infertility was viewed as an obstacle to social reintegration because being childless is considered "taboo."

Nearly all providers (40 [98%]) believed that their patients of reproductive age want children after surgery, particularly if they developed a fistula in their first delivery and/or are childless. A few providers (4 [10%]) noted that less educated women seem to place more importance on conceiving after surgery than do more educated women. However, other providers (2 [5%]) commented that some patients are traumatized to the point of never wanting to be pregnant again or are content with their existing children.

Because many women live far from a hospital that provides cesarean deliveries and these deliveries are often cost-prohibitive, most providers (28 [68%]) were concerned that the fistula will recur during the next pregnancy. To reintegrate into society and please their husbands, the women would willingly be pregnant again even knowing that they would not be able to receive proper medical care during childbirth. According to a male obstetrician/gynecologist at HEAL Africa Hospital, access to hospitals is hindered by transportation costs, the lack of security (e.g. military road blocks) in the country, and the scarcity of well trained doctors in more remote hospitals. To address the cost of cesarean deliveries, many providers (28 [68%]) felt that cesarean deliveries—including transportation to these services—should be free or subsidized for women who have undergone fistula repair.

Some providers specified that the need for cesarean deliveries means that these women can only have 2–4 children. These providers were also concerned that the patients' spouses, families, and families-in-law could use this restriction and their higher cost of care as a reason to discriminate against them. One female counselor at HEAL Africa Hospital was concerned that the woman's in-laws could force her out of the family because of the potential additional health costs she would incur or that families would forbid their men to court these women despite successful surgical repair. To address these concerns, the providers advocated more community education and family reconciliation efforts.

4. Discussion

All healthcare providers at HEAL Africa and Panzi Hospital commented on the psychosocial as well as the physical consequences of genital fistula. Their description of the incontinence, discrimination, psychological trauma, and social isolation is consistent with studies that have analyzed the experiences of women with fistula [2,16–18].

The healthcare providers' counseling of these patients after fistula repair is also in line with the standard of care. There is some evidence that cesarean delivery decreases the risk of fistula recurrence [19,20]. Therefore, recommending cesarean deliveries for pregnancies after fistula repair is aligned with current best practices. In its guiding principles for obstetric fistula [9], WHO also advocates pelvic exercise, wound care, and other postoperative counseling.

At both hospitals, the providers were in agreement on the fact that economic, psychosocial, and educational projects are important for social reintegration and that the existing programs should be reinforced through consistent funding. Many Congolese providers specifically highlighted the utility of psychosocial services in the reintegration process.

The present research showed that most healthcare providers deemed family acceptance as the most critical element in the social reintegration of patients after fistula repair. A major theme was that childbirth is an important way to gain family and thus achieve reintegration into society. In a country where the fertility rate is estimated at 6.04 children per woman [14], it is not surprising that most healthcare providers believe that most women of reproductive age would like to have children even after the repair of their fistula. This finding is consistent with a previous study at HEAL Africa Hospital [21], in which 75% of women after fistula repair responded that they planned to have children in the future; 65% of these women wished to wait at least 1 year before conceiving.

Many providers were concerned that the patients lack access to cesarean deliveries and therefore are at risk for fistula recurrence. Owing to the conflict and extreme poverty, access to healthcare resources is very limited. In this region, the average cesarean delivery costs between US$40 and $150 [22], which is cost-prohibitive for many patients. This issue is compounded by the dangers of living in a conflict area with a healthcare personnel and resource shortage. In the DRC, there is one physician for every 10 000 people [23].

The small sample size and the geographic restriction to the eastern DRC limit the generalizability of the present findings. There was also the potential for response bias because providers were asked to comment on the existing fistula programs at their place of work. Attempts were made to minimize this bias by having an outside researcher perform the interviews and ensuring anonymity.

Understanding the providers' perspective and influence on social reintegration counseling and program development could improve the quality of these services. The present study reinforced the idea that childbearing after fistula repair is a reality that these women face. However, current international guidelines do not yet encourage fistula programs to include free obstetric care for women who have undergone fistula repair and are at high risk of fistula recurrence. Using the information from the present study, it is hoped that family planning and safe delivery after fistula repair will become a focus of the social reintegration programs via education for the participants as well as funds to support contraceptive use and cesarean deliveries for future pregnancies. More research is also needed to improve the awareness of, and access to, reproductive health among women after fistula repair and their families.

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Conflict of interest

The authors have no conflicts of interest.

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