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The role of counseling for obstetric fistula patients: Lessons learned from Eritrea

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Abstract

Objective—The goal of this study was to evaluate the first formal counseling program for obstetric fistula patients in Eritrea.

Methods—To evaluate the impact of the counseling program, clients were interviewed both before pre-operative counseling and again after post-operative counseling. A questionnaire was used in the interviews to assess women's knowledge about fistula, self-esteem, and their behavioral intentions for health maintenance and social reintegration following surgical repair. In addition, two focus groups were conducted with a total of 19 clients assessing their experiences with the surgical care and counseling.

Results—Data from the questionnaires revealed significant improvements in women's knowledge about fistula, self-esteem, and behavioral intentions following counseling. Focus group data also supported increased knowledge and self-esteem.

Conclusion—Evaluation of the short-term impact of an initial formal counseling program for fistula patients in sub-Saharan Africa affirmed the positive effects that such a program has for fistula patients, with increased knowledge about the causes of fistula, fistula prevention and enhanced self-esteem.

Practical implications—Culturally appropriate counseling can be incorporated into services for surgical repair of obstetric fistula in low-resource settings and has the potential to improve the physical and mental well-being of women undergoing fistula repair.

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Background

Obstetric fistula is a complication resulting from childbirth that affects the lives of millions of women and girls throughout the developing world. Approximately two million women are living with obstetric fistula today, mainly in Sub-Saharan Africa, the Middle East and southern Asia; approximately 50,000 to 100,000 new cases occur each year, mainly in women between the ages of 14 and 19 [1]. These non-anatomical holes between the urinary tract or rectum and the vagina can result in numerous physical consequences, including urinary incontinence, fecal incontinence, renal failure, secondary infertility, and neurologic damage [2]. Fistula generally develops in cases of obstructed labor with failure of a delivery to progress [3]. The devastating physical consequences have profound social implications; affected women are often victims of isolation, stigma, poverty, abuse, and abandonment [4, 5].

Eritrea is located in the “fistula belt” in north sub-Saharan Africa where early marriage and pregnancy are coupled with poor access to obstetric care and high maternal mortality ratio (630 per 100 000 live births) [6]. The Eritrean Ministry of Health (MOH) and The United Nations Population Fund (UNFPA) are working to address the problem of obstetric fistula. In 2003, a fistula needs assessment was conducted in Eritrea, revealing the health and social consequences of this complication [7]. The incidence of fistula is projected to be 1 to 3 per 1000 deliveries in areas without access to emergency obstetrical services, yielding an estimated 93-277 new cases a year in Eritrea with a backlog of 930 to 2770 cases [8]. Since 2002, the Ministry and UNFPA have coordinated the annual visits of a team of U.S. obstetrician/gynecologists. During these trips, the visiting surgeons have performed a number of complex fistula repairs on women seeking treatment, and have trained Eritrean physicians in surgical management. To date, nearly 400 repairs have been performed as result of these efforts.

During a surgical trip held in November 2004, in-depth interviews were conducted with Eritrean fistula repair clients and family members [8]. These interviews revealed a lack of information provided to fistula patients before and after surgical repair. Patients received little or no information regarding the causes of fistula. In addition, there were discrepancies in information provided about surgical repair, the recovery period, and the period following discharge from the hospital. Based on these findings, the team decided to initiate a counseling program for fistula patients to increase women's awareness about their own bodies, prevent complications following surgery, and contribute to the prevention of future fistulas. While the primary goal of the fistula program was to educate clients about fistula and its prevention, secondary goals were to build women's self-esteem and help prepare them for social re-integration [9].

Methods

The counseling program was designed and implemented between April 2005 and March 2006. The program's development was guided by a draft curriculum from EngenderHealth for teaching essential counseling skills to health professionals who interact with fistula clients [10]. Prior to its use in Eritrea, this curriculum had not been piloted in other countries. The MOH selected a group of nurses and public health workers to serve as counselors. Over the course of three days, these six individuals were trained in the pre- and post-operative counseling of obstetric fistula patients. Though the training was facilitated by one of the field researchers, all participants took an active role in teaching one another. Specific segments of the training were lead by the trainees themselves (i.e., those trainees who had experience working with fistula patients were able to lead discussions about

medical management). Table 1 shows a list of skills attained from counseling training, as well as the information covered in pre-operative and post-operative counseling sessions.

During February and March 2006 the six trained counselors provided counseling to a total of 47 fistula clients in Dekemhare, Eritrea, a small town located 40 kilometers southwest of the capital city, Asmara. One-on-one pre-operative counseling was provided to each client the day prior to surgery. This counseling was tailored to meet the needs of each woman in respect to her specific type of fistula, her symptoms, and the type of surgical management she was likely to require. One-on-one post-operative counseling was provided to each client between post-operative day one and three. Prior to discharge, each patient received discharge instructions verbally, which included information about self-care and the importance of follow-up medical care. In addition, each patient was given a written copy of the instructions to take home.

To evaluate the impact of the counseling program, clients were interviewed once before pre-operative counseling and again after post-operative counseling. An interviewer-administered-questionnaire was used to assess women's knowledge about fistula, self-esteem, and behavioral intentions for health maintenance and social reintegration following surgical repair. Items to assess participant self-esteem were taken from the Rosenberg Self-Esteem Scale [11]. Small modifications were made to this scale by simplifying the questions to facilitate translation from English. The question, *"All in all, I am inclined to feel like a failure"* was replaced with *"I believe that I am not worthy of being around others because I have fistula,"* to make the scale more applicable to the experiences of fistula patients. Participants' responses were hand-recorded by the researchers conducting the interviews. All interviews were conducted in the participants' primary language. Informed consent was obtained from each client in their primary language prior to participation in the interviews.

In addition to the questionnaires, two focus groups were conducted with a total of 19 clients in order to further explore patient experiences with surgical care and counseling. All clients were consented for focus group participation at the time informed consent was obtained for pre-/post-counseling interviews.

Data from the questionnaires were analyzed using SPSS 12.0 Windows, Version 12. McNemar's Test was used to compare before and after responses for paired observations [12]. Focus group data were analyzed through review of the written transcripts for key concepts and domains.

Findings

Data from the questionnaires revealed significant improvements in women's knowledge about fistula, their self-esteem, and their behavioral intentions following counseling (See Table 2). After counseling women were significantly more likely to correctly identify fistula as a condition in which urine or feces leak from the vagina. The percentage of women who strongly agreed that fistula is preventable also increased significantly, as well as the proportion of women who could correctly identify specific ways to prevent obstetric fistula. Women also gained knowledge about the risks associated with surgery.

There was a statistically significant increase in women's self-esteem scores, from an average score of 13.6 out of 30 before pre-operative counseling to 27.9 after post-operative counseling. Initially, 71.4% of women strongly believed that they were not worthy of being around others because of their fistulas; this number decreased to 28.3% following counseling. Only 15.2% of women strongly agreed that they were a person of worth before receiving counseling. After counseling, this percentage increased to 71.4%.

Post-counseling responses to questions regarding behavioral intentions after surgical repair revealed that women were significantly more likely to state intentions to practice positive health behaviors. In particular, there were large increases in the percentage of women who intended to use family planning and improve their nutritional intake after the surgery. Following counseling, the majority of women expressed intentions to talk with family members (91%) and other community members (77%) about fistula and fistula prevention, compared to 26% and 34% respectively of women prior to counseling.

Focus group discussions revealed that clients benefited from the information they received in pre-operative counseling, which they felt prepared them for what to expect in the intra-operative and post-operative periods. One participant noted that the information she received pre-operatively helped her to make the decision to actually go through with the surgical repair. She stated,

“We were given all the information [about anesthesia and the operation] before the surgery. We were also given advice. We were told that we were going to be given pills, surgery gown and anesthetic. We are very thankful for that.”

A number of focus group participants said they felt better about themselves and their futures following treatment and counseling. As stated by one participant,

“I used to hate myself. But now, what I would like to do is to get well, take care of myself and my family.”

When clients were asked ways in which they felt the counseling program could be improved, a number of women stated that they wished their family members could also be counseled on fistula and fistula prevention. One client noted:

“ [Our husbands need to be hearing this information too. Because if I go home and tell him the nurses and doctors are telling me not to have intercourse for 3 months or more, he may not believe me.]”

Discussion and conclusion

Discussion

Evaluation of a formal counseling program for fistula patients in Eritrea has affirmed that such a program can have a significant short-term impact on fistula patients. The increase in women's knowledge about fistula and fistula prevention speaks to the benefit of having one-on-one counseling with a trained individual during which perceptions and misconceptions can be addressed. In addition, the program appears to have made a difference in women's self-esteem, as evidenced by both qualitative and quantitative data. Clients also clearly developed goals for health preservation and dissemination of information about fistula within their communities that they did not have prior to counseling.

There are a few limitations inherent in the design of this study. For one, the sample size was small, which often did not give sufficient statistical power to detect significant differences between pre-operative and post-operative responses. In addition, one could not completely control for the difference in counselors' styles. In order to minimize this difference in the future, the amount of time spent on each counseling session could be standardized. Finally, it was challenging to elicit feedback from focus group participants, which may have affected the quality of responses provided. This is likely related to the fact that it is unusual to ask for feedback on a service provided in Eritrean culture.

Ultimately, it will be necessary to develop a component of the program that also provides counseling to patients' family members. Clients expressed concern that they would be returning to their home areas with new information about their conditions that their family

members were not exposed to. Additionally, it is very clear from the initiation of this counseling program that many clients were open to the idea of family planning and eager to practice it. In the future, it would be of merit to design a follow-up evaluation, to determine the long-term impact that surgical repair and counseling can have on the empowerment of fistula patients.

Conclusion

This evaluation of the short-term impact of one of the first formal counseling programs for fistula patients in Sub-Saharan Africa indicates that such a program can have positive effects on fistula patients by increasing knowledge about fistula and improving self-esteem. To increase the benefits, counseling programs for fistula patients should involve family members and provide information on and access to methods of family planning.

Practice Implications

To our knowledge, this represents the first formal implementation and evaluation of a counseling program for fistula patients in Sub-Saharan Africa. This program, based on the counseling curriculum developed by EngenderHealth, can serve as a model for development of similar programs for fistula clients and their families in other countries. Finally, efforts to empower fistula clients and their family members will be in vain without interventions at the community level that emphasize the health and well-being of mothers [13, 14]. We have collaborated with the Eritrean MOH and UNFPA to pilot a community-based intervention for the promotion of safe motherhood and obstetric fistula prevention. Programs in other countries, including Ethiopia, have linked fistula repair to overall strategies for promoting safe motherhood [15]. We look forward to the day in which the occurrence of fistula in Eritrea and the rest of the developing world is a rare one, and when fistula clients are seen as strong agents for the promotion of safe motherhood.

“I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.”

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Summary of lessons learned

Structured counseling for obstetric fistula clients' can: increase clients' knowledge about what fistula is and what causes it, motivate clients' to take an active role in improving their own health, and build clients' self-esteem.

Education about obstetric fistula, its prevention, and its treatment must not be limited to fistula clients alone, but must be expanded to clients' family and community members.

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Table 1

Overview of skills attained from counseling training and topics covered in peri-operative counseling sessions.

Skills attained from counseling training	Topics covered in pre-operative counseling	Topics covered in post-operative counseling
<ul style="list-style-type: none"> Assess and acknowledge the clients' needs Listen to clients' concerns and answer their questions Provide clients with information about clinical care of obstetric fistula Provide clients with accurate information on fistula and fistula prevention, self-care, and length and outcome of treatment Explain conditions that are treatable and those that are not Help clients to plan for their lives after treatment Assist clients in making decisions about family planning and other reproductive health services 	<ul style="list-style-type: none"> Information on what causes fistula (dispelling myths about its causes) Case studies or stories of other women with obstetric fistula who have received repairs Information on how fistula can be prevented Information on the client's specific type of fistula and the operation that she will receive The scope of treatment and hopes for the future Possibilities for outcomes following treatment What to expect during the postoperative recovery period Information on operative and postoperative complications Encouragement to think about one's goals for life and health after surgical repair 	<ul style="list-style-type: none"> Information about patient's role in managing her condition postoperatively Information on options for clients with unsuccessful outcomes General information about reproductive health and rights as it pertains to fistula (i.e., information about family planning options that exist in Eritrea) Information about the importance of personal hygiene, good nutrition, and visits to the health center following discharge home Information on ways to work toward community and familial re-integration Reinforcement of information about fistula prevention Encouragement to share information with other women in the community about fistula and safe motherhood Ideas about how to share information with others about fistula and fistula prevention

Table 2
Summary of findings from evaluation of counseling program

Indicators of Knowledge about Fistula			
Variable	Pre-Counseling (n=46)	Post-Counseling (n=43)	Statistical Test* (n=43)
What is fistula?			
% with correct understanding of what fistula is [†]	45.7	79.1	P= .000 [‡]
What causes fistula?			
% indicating correct causes of fistula [§]	89.1	97.7	NS
% saying fistula caused by lack of skilled birth attendance	34.8	88.4	p= .000 [§]
Is fistula preventable?			
% who strongly agreed fistula is preventable	37.0	90.7	p= .000 [§]
% who agreed with four or more correct ways to prevent fistula ^{**}	52.2	90.7	p= .000 [§]
Indicators of knowledge about surgery			
% with strong understanding that risks are associated with surgery	19.6	51.2	p= .011 [§]
Indicators of self-esteem^{††}			
Mean self-esteem score	13.6	27.9	t= -4.252 p= .000 [§]
Minimum self-esteem score	5.0	3.0	----
Maximum self-esteem score	26.0	28.0	----
Indicators of behavioral intentions following surgery			
% who intend to use family planning	0.0	33.3	p= .000 [§]
% who intend to improve hygiene following surgery	13.0	44.2	p= .000 [§]
% who intend to improve nutrition following surgery	17.4	58.1	p= .000 [§]
% who will talk to family members about fistula	26.1	90.7	$\chi^2= 21.81$ p= .000 [§]
% who will talk to community members about fistula	34.8	76.7	p= .000 [§]

* McNemar's test for nominal variables, Binomial test for nominal variables with small numbers of cases in cells, and paired t-test for continuous variables.

[†],"Correct understanding" defined as description of fistula as leakage or urine or feces from the vagina.

[‡]Binomial distribution used.

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[§]“Correct” responses included: cephalopelvic disproportion, delay in going to health facility during labor, neglect of midwives or healthcare workers during labor, surgical errors, “difficult labor”, rape or sexual abuse, female genital mutilation, mal-positioning of fetus during delivery, delivering at home without the assistance of a skilled attendant, and early marriage and pregnancy.

^{**}“Correct” responses included: avoiding early pregnancy, receiving prenatal care throughout pregnancy, delivering in a health facility, using family planning to space pregnancies, and educate others about fistula.

^{††}Self-esteem score based on Rosenberg's self-esteem scale, with addition of “don't know” category, coded as 1.5. Maximum score possible is 30.