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ORIGINAL RESEARCH

Giving Voice to the Experiences of Rwandan Women With Urogenital Fistula

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Abstract

BACKGROUND Urogenital fistula is a debilitating condition that women can develop following obstructed labor. The primary objective of this study was to reveal illness narratives of Rwandan women with urogenital fistula to appreciate their unique experiences. The secondary aim was to identify common themes that emerged when women discussed their experiences living with fistula.

METHODS Women presenting for urogenital fistula repair at Kibagabaga Hospital were asked to participate in the study. Eleven participants were asked questions designed to elicit their understanding of their condition and the social and emotional consequences of their fistula. All interviews were anonymous. Transcribed interviews were examined for relative themes to categorize responses into larger domains.

FINDINGS Common themes were identified from the interviews on topics of what barriers existed to having a successful delivery, the socioeconomic and psychosocial consequences of developing a fistula, and each woman's understanding of her fistula. Excerpts from patients' illness narratives illustrated these themes.

CONCLUSIONS These narratives can be used to appreciate the variations in each woman's understanding of her medical condition and the changes that occurred in her life as a result of her fistula. Through patients' narratives, physicians can improve their appreciation of cultural differences to design targeted educational and preventive interventions.

KEY WORDS obstetric fistula, obstructed labor, Rwanda

INTRODUCTION

Urogenital fistula is a debilitating condition that women can develop after obstructed labor. An estimated 3.5 million women suffer from urogenital fistula; the majority of whom are found in Africa, Asia, and Oceania.[1,2] A woman who develops obstructed labor may labor for days, eventually delivering a stillbirth. Subsequently, ischemic trauma may result in a fistula between her vagina and bladder and/or rectum.[3]

A successful delivery may be limited by insufficient access to intrapartum care or inadequate transportation to a health care facility.[4] Women with fistula are typically made to divorce their spouse and banished from their communities, suffering these physical wounds alone.[1,5] However, factors limiting a woman's access to emergency health

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care and the consequences of the resulting fistula vary by woman, cultural beliefs, and the values of her community.[6] These factors should be illuminated and better understood to reveal each woman's unique story, as well as common experiences.

By eliciting patients' illness narratives, physicians may better appreciate the different views and experiences with which a patient approaches health care and how she contextualizes her medical condition.[7] The concept of cultural competency is too often equated with associating race and ethnicity with stereotypical practices.[7] Thus, it is important to encourage patients to share their unique perception of their condition, and to appreciate the existing variation within a patient population. Additionally, dissimilarities amongst patients' experiences, and shared ones, can be used to inform public health interventions for communities with different cultural practices.

Currently, urogenital fistula research largely focuses on demographic characteristics, outcomes, and medical needs of patients. Medical literature focuses on the tragedy of fistula through descriptive statistics, but does not typically reflect what patients think and feel.[8] The primary objective of this study was to begin to reveal illness narratives of Rwandan women with urogenital fistula in order to appreciate each woman's unique experience. The secondary objective was to identify common themes that emerged when women discussed their experiences living with fistula.

METHODS

This qualitative study explored the experiences of Rwandan women with urogenital fistula. Interviews occurred during a mission trip (February 1-13, 2014) of the International Organization for Women and Development (IOWD) at Kibagabaga Hospital in Kigali, Rwanda. Project approval was received from the Institutional Review Board of Women & Infants Hospital, Providence, Rhode Island, and the Rwandan Government's National Health Research Committee and National Rwandan Ethics Committee.

The IOWD is a nonprofit organization that pairs American and Rwandan health care personnel to provide surgical care to women with fistula. Preceding each mission, radio announcements inform women of the arrival of US physicians who provide care to women leaking urine and/or feces. Women who identify as needing these services then present for evaluation and possible treatment.

All women presenting to the IOWD team with a confirmed urogenital fistula were eligible for participation. Women without fistula and those <18 years of age were excluded. Once Rwandan government research approval was granted near the end of the mission trip, groups of patients were approached in the tents in which they slept and volunteers were asked to participate in the study. This was purposive sampling. Participating women verbally answered 10 questions, adapted from questions designed by Arthur Kleinman for eliciting patients' illness narratives. An interview guide explored each patient's understanding of her fistula and the psychosocial consequences of her condition (Table 1). Demographic information, including age, marital status, and obstetrical history, was also verbally collected from the women.

US and Rwandan medical students conducted interviews in a private setting in Kibagabaga Hospital. Patients provided informed consent for the study and for audio recording the interviews. Due to high rates of illiteracy among the study population, the Rwandan medical students verbally explained documents in Kinyarwanda. These same students then translated interview responses into English at the time of the interview. Interviews lasted 25 to 60 minutes. Recordings were

Table 1. Interview Guide

1. Tell me about your problem of leaking urine and/or feces
2. What do you call this illness/the problem?
3. Why do you think this happened to you?
4. Why do you think you developed this problem when you did?
5. How do you think the fistula works? What does the fistula do inside your body?
6. How do your family members or friends feel about this problem?
7. What could you do before this problem started that you can't do now?
8. Tell me how it feels to leak urine and/or feces everyday
9. What do you fear most about leaking urine and/or feces?
10. What results do you hope for?