Development of an intervention to improve mental health for obstetric fistula patients in Tanzania

Melissa H. Watt a,*, Sarah M. Wilson a,b, Kathleen J. Sikkema a,b, Jennifer Velloza a, Mary V. Mosha c, Gileard G. Masenga c, Margaret Bangser d, Andrew Browning d,e, Pilli M. Nyindo c

a Duke Global Health Institute, Durham, NC, USA
b Department of Psychology and Neuroscience, Duke University, Durham, NC, USA
c Department of Obstetrics and Gynecology, Kilimanjaro Christian Medical Centre, Moshi, Tanzania
d Maternity Africa, Arusha, Tanzania
e Selian Lutheran Hospital, Arusha, Tanzania

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A B S T R A C T

Obstetric fistula is a debilitating childbirth injury that has been associated with high rates of psychological distress. Global efforts have helped to link women to surgical repair, but thus far no evidence-based interventions exist to address the psychological needs of these women during the hospital stay. In this paper, we describe the development of a psychological intervention for women in Tanzania who are receiving surgical care for an obstetric fistula. The intervention was developed based on theories of cognitive behavioral therapy and coping models. Content and delivery were informed by qualitative data collection with a range of stakeholders including women with fistula, and input from a study advisory board. The resulting intervention was six individual sessions, delivered by a trained community health nurse. The session topics were (1) recounting the fistula story; (2) creating a new story about the fistula; (3) loss, grief and shame; (4) specific strategies for coping; (5) social relationships; and (6) planning for the future. A trial run of the intervention revealed that the intervention could be delivered with fidelity and was acceptable to patients. A future randomized control trial will evaluate the efficacy of this intervention to address the mental health symptoms of this population.

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1. Introduction

A vaginal fistula is a hole between the vagina and either the bladder or rectum, which causes uncontrollable leaking of urine and/or feces and a persistent bad odor. The majority of women who develop a vaginal fistula do so after obstructed labor that is not relieved by a Cesarean section, but there is also growing concern that operative injuries from poorly performed Cesarean sections account for a growing proportion of fistulae (Onsrud, Sjoveian, & Mukwege, 2011; Raassen, Ngongo, & Mahendeka, 2014). A vaginal fistula is also possible from non-obstetric causes, including operative injuries during a hysterectomy or through an act of violent sexual trauma. It is estimated that approximately 2 million women worldwide are living with an obstetric fistula, with up to 100,000 new cases per year, primarily in very low resource and rural settings (Stanton, Holtz, & Ahmed, 2007). For these women, the impact on their lives can be devastating. Fortunately, surgical care is increasingly available for fistula repair. However, there is critical need to also address the psychological morbidity of this patient population. Studies have shown that women with obstetric fistula have high rates of depression (Balogun, 1994; Weston et al., 2011) and other mental health impairments (Browning, Fentahun, & Goh, 2007; Goh, Sloane, Krause, Browning, & Akhter, 2005), and low quality of life (Pope, Bangser, & Harris Requejo, 2011). Integrating mental health treatment with surgical repair could improve the overall well-being and functioning of these women, but no empirically tested mental health intervention exists for this patient population.

The psychological damage of an obstetric fistula may result from the traumatic childbirth and/or the resulting physical condition itself (Goh et al., 2005; Semere & Nour, 2008). Women
who develop fistulae due to obstructed labor typically experience several days of painful labor, usually ending in stillbirth, and sometimes accompanied by neurological damage and a cluster of other gynecological morbidities (Arrowsmith, Hamlin, & Wall, 1996). These traumas are compounded by the chronic and humiliating condition of leaking urine and/or feces. About two thirds of a Tanzanian sample of women with fistulae reported social isolation due to their leaking (Bangser et al., 2011), and studies in other settings observed fistula associated with divorce (Ahmed & Holtz, 2007), stigma (Yeakey, Chipeta, Taulo, & Tsui, 2009), depression (Balogun, 1994; Weston et al., 2011), and general mental health dysfunction (Browning et al., 2007; Goh et al., 2005). Our own research has identified rates of depression and post-traumatic stress disorder among fistula patients that are significantly higher than women recruited from other gynecological clinics (Wilson, Sikkema, Watt, & Masenga, 2015).

In Tanzania, it is estimated that approximately 46,000 women are living with obstetric fistula (National Bureau of Statistics of Tanzania & ICF Macro, 2011). Fortunately, for many years, Tanzania has undertaken efforts to identify women living with fistulae and immediately refer them to free surgical repair (Fiander & Vanneste, 2012). The non-governmental organization Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) is conducting a nation-wide effort to identify and refer patients using community ambassadors and mobile phone technology to transfer fistula patients to medical facilities for ambaassador incentives and patient transportation (Fiander & Vanneste, 2012). Other hospitals providing fistula repairs in Tanzania are using similar strategies, as well as radio advertisements and community outreach trips to identify and refer women for repair. In 2011, close to 1000 obstetric fistula repair surgeries were conducted nationally (Ndahani, 2012). While surgery can address the physical symptoms of a fistula (Nielsen et al., 2009), surgery alone may not end the challenges that women with fistulae face. Although one study demonstrated reductions in depression immediately post-operation (Browning et al., 2007), other studies have pointed to continued fistula-related stressors and persistent depression after surgical repair, particularly among women who continue to have symptoms or pain related to their condition, and women who had lived with their fistula for a longer time (Elkins, 1994; Muleta, Hamlin, Fantahun, Kennedy, & Tafesse, 2008; Pope et al., 2011).

Holistic care for obstetric fistula patients should include mental health treatment as a complement to surgery, so that women receive comprehensive treatment and support for their condition. However, thus far, no evidence-based mental health intervention exists for this population. Women who are admitted for repair generally spend several weeks in the hospital, providing a window of opportunity to address the psychological symptoms accumulated from living with this socially marginalizing condition, and to develop coping skills to facilitate reintegration after repair. Although the need to address mental health issues in this population has been recognized (Muleta, 2006; Muleta et al., 2008; Pope et al., 2011) and is part of the WHO’s guiding principles of fistula management (World Health Organization, 2006a), to date no intervention studies have evaluated empirically-supported therapies to assist in psychological healing among fistula patients.

Evidence-based psychological treatment, based on cognitive behavioral therapy (CBT) (Beck, 2011) and the theory of stress and coping (Lazarus & Folkman, 1984) has the potential to improve the coping behavior and mental health symptoms of this patient population, and in turn to improve social well-being and functioning to promote successful reintegration to the community post-surgery (Fig. 1). In rigorous trials, CBT demonstrates impacts on mental health, quality of life, and shame, in both Western and non-Western contexts (Butler, Chapman, Forman, & Beck, 2006; DeRubeis & Crits-Christoph, 1998; Neuner et al., 2008; Neuner, Schauer, Klaschik, Karunakara, & Elbert, 2004; Swan, Watson, & Nathan, 2009; Tshabalala & Visser, 2011; Van't Hof, Cuijpers, Waheed, & Stein, 2011). The theory of stress and coping suggests that improvement in coping skills leads to an increase in positive emotionality, reductions in mental health dysfunction, and improvements in self-care (Folkman & Lazarus, 1988; Lazarus & Folkman, 1984; Penley, Tomaka, & Wiebe, 2002). While mental health treatments have been developed for physical disabilities in the United States (Dorstyn, Mathias, & Denson, 2011; Mehta et al., 2011; Thomas, Thomas, Hillier, Galvin, & Baker, 2006) and in low-resource countries (Daniel & Manigandan, 2005; Lundgren, Dahl, Melin, & Kies, 2006), an intervention for obstetric fistula patients must be tailored specifically to address physical health concerns, trauma history, stigma, and internalized shame. These dimensions of an intervention must, in turn, reflect the context of gender inequalities in which women develop and live with a fistula.

This study aimed to develop a mental health intervention for obstetric fistula patients that can be delivered concurrently with surgical treatment, thereby adding value to clinical services and taking advantage of the “window of opportunity” when patients are in the hospital. The purpose of this paper is to describe the intervention framework and the process of intervention development for the Tanzanian context, and to present results from a small trial run to examine the feasibility and acceptability of this clinic-based intervention for obstetric fistula patients.

2. Methods

2.1. Study site

All study procedures took place at the Kilimanjaro Christian Medical Centre (KCMC) in Moshi, Tanzania. The Department of Obstetrics and Gynecology (OG) at KCMC provides surgical repair of obstetric fistula free of charge and has a dedicated fistula ward. Once admitted to the fistula ward, patients typically undergo reparative surgery within one week and remain on the ward for two to four weeks after the surgery. Approximately 60 patients receive surgical repair for an obstetric fistula at KCMC each year.

2.2. Study overview

The development and feasibility testing of this intervention proceeded in three phases: (1) preliminary intervention development based on psychological theory and empirical research, (2) qualitative data collection to enhance and adapt the intervention curriculum, and (3) a small trial run of the intervention with 6 patients from the KCMC fistula ward. A study advisory board was convened early in the intervention development process, with representatives from fistula care providers, advocacy groups, community health workers, and representatives from the municipal Department of Health. All study procedures were approved by institutional review boards at Duke University, KCMC, and the Tanzanian National Institute for Medical Research.
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