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Sources of support for women experiencing obstetric fistula in northern Ghana: A focused ethnography

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ABSTRACT

Objective: we explored how women in northern Ghana who have or have had obstetric fistula and those close to them perceive support.
Design: focused ethnography, that includes in-depth interviews, participant observation, and scrutiny of relevant records.
Setting: a fistula treatment centre in a regional urban centre and three remote villages located in northern Ghana.
Participants: the sources of data included in-depth interview ($n=14$), non-participant observation and interaction, as well as scrutiny of relevant health records and documents. Participants for in-depth interviews and observation included women affected by obstetric fistula, their partners, parents, relatives, nurses and doctors.
Findings: presentation of obstetric fistula information, particularly by Non-Governmental Organisations was not in a format that was readily understandable for many women and their families. Food and other basic requirements for daily living were not necessarily available in the fistula treatment centre. Travelling for care was costly and frequently not easily accessed from their communities. Fistula repair surgery was available at unpredictable times and only for a few days every one to two months.
Conclusions: women perceived support from spouses/partner, family members, and other relatives but much of this is limited to tangible support. Perceptions of support were particularly focused on access to information and finances.
Implications for practice: the implementation of strategies to increase support for women living with obstetric fistula include improving access to fistula repair treatment, directing resources to create a dedicated specialist fistula centre located where most cases of OF occur and providing education to front-line workers. Strategies to prevent fistula as well as identify and support safe motherhood practices are needed for women affected by obstetric fistula.

Obstetric fistula (OF), an opening between the vagina and rectum and/or the vagina and bladder, is a severe complication of childbirth (Wall, 2012; World Health Organization, 2007). It occurs most commonly following prolonged, obstructed labour causing the foetal head to become lodged behind the pubic bone. The soft tissues between the mother's pelvis and the foetal head are compressed for an extended period, limiting circulation and weakening the pelvic wall. Prolonged compression causes delicate soft tissue to die, resulting in a fistula and, if left untreated, urinary and/or faecal incontinence (Muleta, et al., 2010). When labour is obstructed the baby frequently does not survive (Cowgill et al., 2015).

In higher resource countries, particularly those with universally funded health care and skilled birth attendants, the incidence of OF morbidity due to obstructed labour is rare and those who have fistula have access to prompt surgical repair. Women living in the most impoverished nations, where healthcare is limited or unavailable and the rates of infectious disease and malnutrition are pervasive, the risk of developing OF increases (Bangser et al., 2011; Pope et al., 2011).

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Implications of OF are multitudinous. For women living with an unrepaired fistula not only the women themselves, but their families, and communities can.

be profoundly affected (Bangser et al., 2011). Many of these women cannot work, particularly if they have to handle food. Many are abandoned by their partners because of uncontrollable urinary/faecal excretion. Without a partner to provide financial support, women often experience difficulties in securing even their basic needs. While most OF can be treated surgically, associated stigma may result in many women remaining invisible to the formal healthcare system (Engender Health, 2004; Mwini-Nyaledzigbor, et al., 2013; United Nations Population Fund, 2015a). Women are often unaware that treatment exists or that they can access that treatment.

An estimated 2,000,000 women are currently living with OF and 50,000 to 100,000 more develop the condition annually; the majority living in sub-Saharan Africa (United Nations Population Fund, 2015b). Women with OF can experience uncontrolled leakage of urine and faeces resulting in quickly becoming social outcasts who remain hidden from society's view (Bangser et al., 2011, Pope et al., 2010). Thus, it is likely that these numbers do not capture the full extent of the associated morbidity.

High maternal morbidity rates are recorded in Ghana, including OF in approximately 1.8 per 1000 births (United Nations Population Fund, 2015a). Despite many initiatives to reduce maternal morbidity, disparities continue to exist between high and low-resource countries (United Nations Department of Economic and Social Affairs, 2015). In 2004, the UNFPA partnered with a not-for-profit organization to conduct an OF needs assessment in nine African countries including Ghana (Engender Health, 2004; Futa 2008). For Ghana, the majority of cases were found in three northern remote regions (Engender Health, 2004; Futa, 2008; Mwini-Nyaledzigbor et al., 2013).

Findings from an exploratory study conducted in the Upper East Region of Ghana highlighted the significant losses that women living with OF face including loss of newborns, family relationships, and livelihoods (Mwini-Nyaledzigbor et al., 2013). They worried about their odour and the difficulty experienced in using scarce resources to purchase soap to reduce that odour. The women also described loss, explaining that spouses and family members told them to 'stay away' (p. 451), sometimes permanently. All participants experienced challenges accessing OF treatment. Several did not know that treatment existed and others did not have the resources or knowledge to access it (Mwini-Nyaledzigbor et al., 2013; United Nations Population Fund, 2015a).

Despite a continuing commitment to improve maternal health, the 'Campaign to End Obstetric Fistula' has made little progress in preventing and treating OF and improving the lives of affected Ghanaian women (Futa, 2008). Many OF campaigns failed to include men and family members as key partners, subsequently limiting the success of maternal health OF prevention and treatment campaigns. This is a missed opportunity to gain a greater understanding of the availability and type of support women experience when making decisions regarding their reproductive health. Research where family members' perceptions of their role to support women in the prevention and management of OF was not found.

Our purpose was to gain insight into support available for women with OF by answering the question, 'How do spouses/partners, family members, close friends, relatives, and the women themselves perceive support provided to women affected by OF?'.

Methodology

A focused ethnographic approach is appropriate to investigate how those close to women (partners/spouses, mothers, close friends, siblings and children) as well as the women themselves in northern Ghana describe support that is provided to women with OF. This methodology is useful to gain a better understanding of experience that includes aspects of culture and way of life (Cruz and Higginbottom, 2013). Questions requiring focused ethnographic methods are those exploring a specific phenomenon such as the sub-culture of OF (Roper and Shapira, 2000). Data collection included participant and non-participant observation, in-depth interviews and informal conversations, examination of available documents to gain an emic perspective of a particular culture, and daily journaling of interactions and observations.

Setting

The study setting is in northern Ghana where a diverse multilingual population with distinct ethnic backgrounds resides (Government of Ghana, 2013). Northern Ghana has much less development and infrastructure than the coastal South and subsequently the healthcare system mirrors this difference. Access to healthcare is limited as most health facilities are located far away from rural villages or community settlements (Danso et al., 2007; Mwini-Nyaledzigbor et al., 2013). The shortage of skilled birth attendants and lack of proximity to facilities has limited access to healthcare in general but especially for pregnant women. Most Ghanaian women who have OF (70%) live in the three northern regions of Ghana. There is one teaching hospital and two government hospitals in the largest urban centre. An 11-bed fistula treatment centre, the primary site for this research, is a separate entity located on the grounds of a government hospital. At specific but often unpredictable times, treatment for OF is provided. Women attend this clinic from a large geographic region including neighbouring countries.

The fistula treatment centre was developed in 2009 in partnership with the UNFPA and is staffed by an obstetrician/gynaecologist director and approximately 10–15 nurses. Many permanent nurses who are employed by the government hospital do not have formal training in caring for women with OF. When not functioning as an OF repair centre, the facility operated in a way similar to that of obstetrics/gynaecology clinic. Approximately 350 OF repair surgeries were performed at the fistula treatment centre since the centre's inception and this number is currently less because of lack of funding and qualified staff (Physician, 2013).

Sampling and recruitment

Women who previously had an OF and who were either admitted to the fistula treatment centre or were living in one of three nearby villages as well as those close to these women (spouses, partners, friends, mothers, mothers-in-law, healthcare providers) were eligible for inclusion. With guidance of an experienced Ghanaian nurse-midwife Ghanaian, rapport was established with community gatekeepers. Initially, the first author began as a non-participant observer. During this period, she observed the interactions, activities and rituals of those associated with the fistula treatment centre.

Participants believed to be knowledgeable about the cultural group and able to provide key insights into OF were recruited (Roper and Shapira, 2000). The first point of contact for participants was through a key informant/translator who explained study details and presented the information letter in the local language. A small honorarium of soap and disinfectant was provided to those who formally enroled in the study. A water basin was donated to the fistula treatment centre as a general honorarium to all of those who participated in the study. These decisions were based on previous Ghanaian research, and suggested by the local ethics committee.