Secrecy inhibits support: A grounded theory of community perspectives of women suffering from obstetric fistula, in Kenya

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A B S T R A C T

Aim: this study aimed to gain understanding of the views of community members in relation to obstetric fistula. Design and method: a qualitative, grounded theory approach was adopted. Data were collected using in-depth interviews with 45 community members. The constant comparison method enabled generation of codes and subsequent conceptualisations, from the data. Setting: participants were from communities served by two hospitals in Kenya; Kisii and Kenyatta. Interviews took place either in the home, place of work, or hospital. Findings: the core category (central concept) is ‘secrecy hinders support’. This was supported by three themes: ‘keeping fistula hidden’, ‘treatment being a lottery’ and ‘multiple barriers to support.’ These themes represent the complexities around exposure of individual fistula sufferers and the impact that lack of information and women’s status can have on treatment. Keeping fistula secret reinforces uncertainties around fistula, which in itself fuels myths and ignorance regarding causes and treatments. Lack of openness, at an individual level, prevents support being sought or offered.
Conclusions: A multi-layered strategy is required to support women with fistula. At a societal level, the status of women in LMIC countries needs elevation to a level that provides equity in health services. At a national level, laws need to protect vulnerable women from mistreatment as a direct result of fistula. Furthermore, resources should be available to ensure provision of timely management, as part of routine services. At community level, awareness and education is required to actively engage members to support women locally. Peer support before and after fistula repair may be beneficial, but requires further research.

Background

An obstetric fistula is a devastating, and usually preventable, childbirth complication, whereby prolonged or obstructed labour results in damage to the vesico-vaginal/recto-vaginal septum. The hole that is formed in the septum leaves women incontinent of urine, faeces or both (World Health Organization, 2007). Despite being eradicated in high income countries, it continues to be a major problem in low income countries, and affects the poorest and most vulnerable women (Wall, 2006; Semere and Nour, 2008). It has been estimated that between 50,000 and 100,000 women are affected by obstetric fistula, annually (World Health Organization, 2014), and several million cases currently exist in sub-Saharan Africa and South Asia (UNFPA, 2013). A number of factors contribute to high rates of fistula, including inadequate health services, poor access to care, inequity, female genital mutilation, poverty and poor communication (UNFPA, 2013).

In addition to the physical pain (Muleta et al., 2008; Donnelly et al., 2015), caused by the continual leakage of urine, afflicted women suffer socially (Turan et al., 2007; Muleta et al., 2008; Donnelly et al., 2015); and emotionally (Khisa et al., 2011; Mselle et al., 2011; Khisa, 2016). These women are often abandoned by their husbands (Roush, 2009; Gebresilase, 2015; Khisa et al., 2016), have poor living standards (Gebresilase, 2015), have little means of employment (Arrowsmith et al., 1996), and are rejected by their local community (Khisa et al., 2016).
A recent systematic review of qualitative research (Lombard et al., 2016) recognised the difficulties faced by women post-fistula repair, finding that women were unable to forget their fistula experience, despite the passing of time. Lack of belonging and a learnt mistrust acts as a particular barrier to psychological recovery (Khisa et al., 2016).

A number of initiatives have taken place to support women with fistula, both before and after surgical repair (EngenderHealth, 2006, 2011; Diallo, 2009; Donnelly et al., 2015; Watt et al., 2015). However, despite such initiatives, many community members remain ignorant to the causes of fistula, proposing that it is the woman's own misdemeanour that has led to her disability (Omari et al., 2015). Gaining a deeper understanding of the reasons why community members fail to support women with fistula is pivotal to developing effective strategies. Yet, as identified in the systematic review by Lombard et al. (2015), there is currently a lack of good qualitative research on which to base such strategies. Thus, this research aims to explore the meaning attributed to women with fistula by exploring the perceptions of key stakeholders and members of the communities where these women reside.

Methods

Study design

Symbolic Interactionism (Blumer, 1969) informed the grounded theory methodology adopted. A key element was gaining understanding of the impact of social interactions with fistula sufferers (and other community members) on participants’ views and experiences. Grounded theory enables one to gain a deeper understanding of the topic of interest, moving beyond simple descriptive accounts to the development of theory (Rees, 2011). Grounded theory is an approach with the ability to respect the views of participants, allowing the theory to emerge directly from the data (Glaser, 1992). The Straussian approach was used in this study (Strauss and Corbin, 1998), chosen primarily because it adopts an iterative and inductive process. The inclusion of literature, field notes, memos and data, adds strength to the approach through the process of constant comparison, enabling understandings to be contextually grounded.

Theoretical sensitivity was maintained, as, although the authors are health professionals and familiar with the topic of obstetric fistula, they had no understanding of what may emerge from the data as community views have seldom been sought in this topic. The team had no predetermined expectations and an open stance was maintained.

Setting

The study was conducted in two communities in Kenya, where fistula is prevalent. In East Africa, 5400 new vesicovaginal fistulas are estimated to occur yearly; Kenya accounts for 1500 of these, with 90% being obstetric in origin (Kenya National Bureau of Statistics and ICF Macro, 2010). Here, about 46% of births occur at home (Kenya National Bureau of Statistics and ICF Macro, 2010); delayed decision-making at the household and facility level, contribute to fistula prevalence, thus affecting the most vulnerable women. Participants were accessed from two urban settings, Kisii and Nairobi; hospitals within these settings have at least 5 new fistula patients weekly. These settings were chosen as gatekeeper support was available and they were areas in which midwives had been trained in conducting high quality research.

Ethical considerations

Ethical approval was gained from the Universities of Nairobi and Manchester. All volunteers were provided with written and verbal information, in local language, and written consent obtained. Confidentiality was assured, and the use of pseudonyms ensured anonymity. Given the sensitivity of the topic, a distress policy was in place, although this was not required. The distress policy was a written document, tailored to the study topic, which contained referral pathways and action points, which could be triggered by the verbal and non-verbal responses of participants. Contact details of appropriate health professionals and counsellors, however, were made available. Participants were informed that they could refuse to answer any questions and could stop the interview at any time. Hard data were stored in locked cupboards, accessible only to the research team. Electronic data were stored in password protected, encrypted files.

Participants

We had already explored women's experience of living with an obstetric fistula, in a previous study (Khisa et al., 2016). Khisa’s study, demonstrated the impact of community support (or lack of support) on individual women’s experiences. We wished to explore this further, in this current study. In keeping with Grounded theory (Strauss and Corbin, 1998), a purposive theoretical sampling strategy was adopted. The initial purposive sample was drawn from three groups of participants: (1) male partners of women who had suffered with fistula, but now were repaired; (2) male members of the local community; and (3) female members of the local community. Key stakeholders, which included health professionals, policy makers and other influential persons, were added, as directed by the initial data analysis. The sample size was determined by data saturation, which was reached.

Recruitment

Recruitment took place over a three month period, from June 2015 to August 2015. Two trained research midwives (JO, MM) from the Lugina Africa Midwives Research Network (2016) carried out the recruitment. Male partners were approached in the post-operative clinic, 2 weeks following his wife's fistula repair. Initial contact was made by a clinician, who notified the research midwife only if permission to consider the study had been granted. Written and verbal information were supplied to the partner, who was given time (up to 4 weeks) to consider participation. Written consent was obtained for those who agreed to participate. Male and female community members were recruited through snowball sampling. The initial cohort was approached through known contacts, who then suggested others, whose perspectives were believed to add to the understanding of the phenomenon. This respondent-led sampling optimised the chances of obtaining a maximum variation sample. Stakeholders were recruited from two hospitals, the ministry of health, private organisations and non-governmental organizations. In all cases informed consent was gained and contact details of the research team were supplied.

Data collection

Data were collected between June and September 2015 using individual face to face interviews. Interviews were carried out by two trained local LAMRN midwives (LAMRN, 2016). Demographic details were collected at the beginning of the interview, using a researcher-administered questionnaire. Additionally, the interviewers kept field notes to capture any nuances within the interview process and to document non-verbal communications, such as body movements and facial expressions.

In-depth interviews were chosen to increase the authenticity of the data (Silverman, 2016), as participants were encouraged to provide...