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Social Support among Women with Genital Fistula in Uganda

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Abstract

Resulting from prolonged obstructed labour, iatrogenic and traumatic aetiologies, female genital fistula in low-resource settings causes a significant physical and psychosocial burden. Social support is an important mechanism to build resilience to health challenges. This study aimed to understand the role of emotional, informational and tangible social support for Ugandan women affected by fistula. Thirty-three participants who had had fistula surgery 6-24 months prior to the study were recruited from Mulago Hospital in Kampala, Uganda. Data from in-depth interviews (n=16) and 4 focus group discussions were analysed thematically using a social support framework. Various individuals were key providers of social support across the different domains. They included family, friends, community organisations, and other women affected by fistula. Social support was critical in helping women cope with fistula, access fistula care, and post-repair recovery. Women relied heavily on tangible and emotional support to meet their physical and psychological needs. Support-enhancing interventions for women and their families, particularly those offering emotional and tangible support, may be a promising strategy for improving the experiences and quality of life of women affected by fistula.

Keywords

female genital fistula; social support; recovery; reintegration; Uganda

Introduction

In low-resource settings, female genital fistula is largely caused by prolonged obstructed labour in combination with decreased access to emergency obstetric care, and iatrogenic or

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traumatic aetiologies. It results in severe physical and psychosocial complications including urinary and/or faecal incontinence, neurological injury, infection, genital ulceration, stigmatisation, poor mental health and reduced economic opportunity (El Ayadi et al. 2020; Arrowsmith, Hamlin and Wall 1996; Waaldijk and Elkins 1994). The World Health Organization (WHO) reports female genital fistula affects up to two million women worldwide, with 50,000-100,000 annual incident cases. Sub-Saharan Africa is disproportionately affected with approximately 30,000 new cases yearly (de Bernis and Lewis 2006; Wall 2006).

The physical and psychological complications of fistula can inhibit a woman’s ability to lead her normal life, including social participation (El Ayadi et al. 2017; El Ayadi et al. 2019). Fistula-related stigma is significant and may persist following surgical repair, regardless of continence status, hindering psychosocial recovery (Human Rights Watch 2010). However, social support in the form of the psychological and material resources provided by an individual’s social network (Berkman and Glass 2000), may help women cope with the challenges of living with and recovering from fistula. Social support can influence health by increasing coping and resilience, alleviating emotional distress, improving mental health, and facilitating care access (Berkman and Glass 2000; Kong and Wertheimer 1994; Heaney and Israel 2008). For individuals with other chronic diseases, social support has been shown to buffer against pathological states (e.g., depression), enhance disease acceptance and decrease health-related stress (Pearlin et al. 2014; Andrews, Tennant, Hewson and Vaillant 1978; Strom and Egede 2008; Kong and Wertheimer 1994). Research among women with fistula has found that social support is associated with lower depression, higher self-esteem and can aid recovery by helping women emotionally heal and reintegrate into society (Dennis et al. 2016). However, the key social support mechanisms and pathways for women with fistula are not well elucidated, despite the importance of this for intervening to improve women’s experiences with fistula.

Increasing our understanding of sources of social support among women with fistula across four key social support domains (i.e. emotional, instrumental, appraisal and informational), and the impact of this support on women’s ability to meet their physical and psychosocial needs, could guide the development of social support programming to reduce barriers to care and improve women’s quality of life. To contribute to this evidence base, we sought to understand women’s experiences of social support before and after genital fistula surgery and their perspectives on the role of social support in recovery and reintegration using qualitative data from women in Uganda.

Methods

We analysed data from a qualitative study assessing post-repair recovery and family and community reintegration among women accessing female genital fistula repair surgery at Mulago National Teaching and Referral Hospital (Mulago Hospital) in Kampala, Uganda. Full details of the study are published elsewhere (El Ayadi et al. 2017; Byamugisha et al. 2015; El Ayadi et al. 2019). Briefly, participants received fistula surgery at Mulago Hospital six to 24 months prior to the study, gave a telephone contact at surgery, spoke Luganda or English, and lived within 100 km of Mulago Hospital. Women were screened for eligibility over the telephone; 33 eligible women participated in an in-depth interview (n=16) or focus group discussion (FGDs; four groups comprising 17 participants). The in-depth interviews used open-ended questions to understand women's lives prior to fistula, their experiences developing and living with fistula, treatment seeking, and their experiences reintegrating back into their communities. Each FGD explored mood; role and interactions with family; and role and interactions with community pre- and post-fistula repair to further understand how fistula affected reintegration back into their families and communities.

In the current analysis, we examine women's lived experience of social support and the impact of social support on living with fistula including recovery and reintegration. We defined recovery as physical healing and reintegration as a process through which women psychosocially recover from fistula and re-engage within their communities to the extent that they desire (El Ayadi et al. 2017). We conducted thematic analysis of in-depth interview and focus group transcripts incorporating both deductive and inductive approaches (Clarke and Braun 2014). Deductive analysis adapted and applied the social support framework used to create the a priori codes which included emotional, tangible, informational, and appraisal domains (Figure 1) (Berkman and Glass 2000; House 1981).

Inductive analysis was used to identify themes that developed throughout the analysis. After the themes had been identified and data summarised, quotations representing participants' voices were selected. The research team for the parent study comprised Ugandan and US maternal health clinicians and researchers. In-depth interviews and focus groups were conducted by the same female Ugandan interviewer, with an additional moderator present for FGDs. Participants first completed a brief sociodemographic questionnaire. Qualitative data were then collected in Luganda, the local language, and data were transcribed and translated to English for analysis. Coding was undertaken jointly by a Ugandan interviewer (HN) and a US mixed-methods researcher (AE) using Atlas.ti software. The current analysis was conducted by a US postgraduate student (EH) supervised by the mixed-methods researcher (AE) with feedback provided by the larger Ugandan and US research team.

Social support conceptual framework

Our theoretical orientation for this analysis, adapted from Berkman, Heaney, House and Strom, (Strom and Egede 2008; Berkman and Glass 2000; House 1981; Heaney and Israel 2008) describes the hypothesised relationships between social support and health behaviours. The four broad social support domains are: emotional support, defined as love, sympathy, caring, and understanding; tangible support, referring to concrete help, often through financial assistance, gifts or services; informational support, advice or information meeting an individual's particular need; and appraisal support, or help in decision making (Berkman and Glass 2000). Appraisal support was included in the framework for comprehensiveness; however, this domain was not explicitly probed for within the interview and focus group guides and reference to it was not present within our data, thus it is not included within the analysis presented here.

The conceptual framework incorporates factors influencing social support, including sociodemographic/sociocultural characteristics, social network characteristics, perceptions of availability and need, and general health and stressors (Berkman and Glass 2000; Strom and Egede 2008; Heaney and Israel 2008). Bidirectional relationships are acknowledged between health behaviours and social support with general health and stressors, and between health behaviours and healthcare access. For women with fistula, social support influences post-repair recovery and reintegration, general health, health behaviours and healthcare access. It impacts health behaviours through influencing an individual's ability to seek care, cope with and become resilient to their condition.

Ethical considerations

The study protocol was approved by the Makerere University College of Health Sciences Research and Ethics Committee (Ref# 2014-052) and the University of California, San Francisco Human Research Protection Program, Committee on Human Research (IRB# 12-09573). All study participants provided informed consent and confidentiality was assured. Pseudonyms are used throughout this paper.

Results

Socio-demographic and reproductive characteristics of study participants

Participants' median age was 23 years (IQR 18-28) at fistula development and 30 years (IQR 24-37) at study participation (Table 1). Time with fistula varied: 42% reported living with fistula for more than five years while 12% had fistula for less than one year. Most women were married or living together with a partner (75%). Most women (63%) had not completed primary education. Just under half of participants (46%) had no living children.

Overview of women's experiences with social support

Participant narratives highlighted the importance of social support in managing and recovering from fistula. Greater emphasis was placed on the role of social support while women were managing fistula symptoms, and some participants described the importance of social support extended beyond recovery. Findings are organised along the major themes identified across three social support domains: sources of social support, types of social support received, and the impact of social support (Figure 2).

Sources of Social Support

Participant narratives revealed a variety of relationships were providers of social support, and these varied in their overlap across the different social support domains (Figure 3). Support overlapping across all three domains was provided by husbands, healthcare workers/hospital systems, and community members. Overlapping support between two domains, most frequently emotional and tangible support, was largely provided by female family members (i.e. mothers and sisters) and less frequently by other female family members (e.g. aunts, mothers-in-law and other relatives). Beyond immediate friends and family, common sources of tangible and emotional support included religious community members. Overlapping emotional and informational support was uniquely attributed to other women affected by fistula; such women shared similar experiences and a few women mentioned their important role in treatment seeking.

Individuals providing uniquely tangible support included extended family or employers. Many women identified the radio as an important non-interpersonal source of information about fistula repair.

As the most common source of all support types, husbands represented critical support sources for women. Many women shared how their husbands stood by them while they lived with fistula, despite commonly voiced fears of abandonment or replacement by a second wife.

> It was my husband [who supported me] because in most cases, when the woman gets [a] problem [like fistula], she is normally taken to her [natal] home [for her family] to take care of her and then [the husband] returns to his home and has peace of mind. But my husband never left me here alone; he would come back, and we would sleep together…. Really, I thank my husband because he never left me on my own. (Evelyn, 37-year-old interviewee)

A few participants emphasised the ongoing importance of support from their husbands following fistula repair. As Patricia explained:

> My husband has helped me since I was ill. He was sending me money and providing what I needed and even now that I am healed, he helps me with the garden work, he hires people to help me in cultivating sweet potatoes. (Patricia, 33-year-old focus group participant)

Types of Social Support

Women's narratives described various emotional, tangible, and informational support offered by the sources identified above. Major types of emotional support included verbal encouragement and prayer. Major types of tangible support included financial, labour and goods assistance, while informational support was described as advice, largely concerning the availability of fistula care.

Emotional Support—Verbal encouragement and prayer were the main types of emotional support identified by study participants. Verbal encouragement reassured women that they were likely to heal from fistula and helped them to stay strong during their recovery. Women described how knowing that others were praying for them to heal helped them accept their condition and have hope that they would heal. The importance of verbal encouragement from family members was shared by multiple participants:

> My moods were really terrible. I never wanted to eat, and it was always my mother-in-law who was strengthening me, telling me to stay strong and that I will be fine. Even my husband was telling me that I will be fine and that in Mulago [Hospital] they could repair me and I [would be] fine. (Najat, 29-year-old focus group participant)

> [My relatives] tell me to be strong and that time will come when I will be fine…. I also feel good [when people tell me that] because instead of dying, these people are there comforting me. Even if you give someone nothing tangible, if you have given

> him/her encouragement, it will be relative to something. (Hanifah, 35-year-old interviewee)

Encouragement received at the repair facility from women who had previously had fistula was reported to be particularly important especially for participants who had not previously known anyone else with the condition. Hearing the experiences of other women, particularly successful repair stories, helped participants feel less alone and hopeful that they too would recover.

> When I left my home and came here to the hospital, I saw others in the same situation. From the ward, women would come with their babies to encourage us and tell us that they also [had been] leaking but had healed. (Mariam, 28-year-old interviewee)

> There was one thing that was so helpful to me; when I was at the ward, we would sit and talk with the [older] ladies and as I was telling them about my problems, one lady told [me], “Don’t worry, and be strong.” (Stella, 28)

Women described the important role of prayer as emotional support. A few women spoke about how their families, religious leaders and broader church communities would pray for their recovery. One 32-year-old interviewee, Sylvia, described her family’s support through prayer: ‘[my mother and sister] used to pray for me, they could also bring pastors to pray for me. They forged all ways to see that I don’t get worried’. Another woman shared that her church community prayed for her to accept her condition and heal from it, which made her feel stronger: “Pentecostal Christians would come here to pray for me, and the pastor would encourage me…I became strong and put the pain aside” (Afiya, 24-year-old focus group participant).

Tangible Support—In our participant sociodemographic survey, 63% of women reported being financially dependent on their husbands, and 3% financially dependent on others, which signals the level of need for tangible support among this population. Examples of tangible support reported in this study ranged from financial support to resource provision (e.g., food, clothes, or soap), and labour (e.g., help with household chores such as cooking, cleaning or fetching water).

Financial assistance—Many women were unable to work due to fistula, putting them at an economic disadvantage and causing dependence on others. Monetary support was used for various needs ranging from food, clothes and children’s school fees to supplies for fistula care such as diapers or cloths for incontinence management, and transport for fistula care:

> [All the family money was spent on me] because we went to many different hospitals and where we went first, they asked for money…It was 370,000 USh (US$100) and then I also spent 120,000 USh (US $30) to hire a special car from the village to bring me to the hospital…. My mother-in-law [was the one] who gave us that money. (Namazzi, 20-year-old interviewee)

Husbands also provided a range of financial support from assistance in accessing fistula care to paying for caregivers to assist their wives, to providing money for them to manage their condition. As Miremba explained,

> [My sister] asked me whether I was going [for fistula repair] and I didn't have money then, but my husband looked for the money. That time he was still at the co-wife's place, I had 20,000 USh (US $5) with me and I boarded off to Mulago but he later came and gave me 50,000 USh (US $14) and other essentials like a jerry can and basin because I had left home empty-handed…. [My husband] didn't come to visit me though he was sending me money. (Miremba, 21-year-old focus group participant)

Narratives concerning the importance of financial support from other family members included the following:

> I had hope because my family existed. They made me some investments and I started getting some money, so my normal life revived. Unless [women are working during the time they had fistula], her capital [will be] finished [by the time she has had surgery], then she could be worried how to start up again. I think that is a challenge. But personally, I never had any problem because my elder sister was there to help me. (Aidah, 22-year-old interviewee)

Assistance with resources—Resources such as food (i.e. bread, sugar, tea) and clothes were also critical needs due to women's inability to work and were often provided by family members, friends or community organisations. Hospitals and community organisations often provided short-term support after the operation, while family members and friends were a source of goods assistance both during fistula and while women were recovering following fistula repair.

Assistance with household responsibilities—Participant narratives of support with household responsibilities highlighted changes in women's role within the household due to fistula. Urinary and/or faecal incontinence created discomfort and pain, making it difficult for women to undertake household duties/tasks. In addition, women also had to refrain from strenuous activity for a few months after surgery to prevent fistula repair breakdown. Because women were less able to keep up with household chores, they needed help from others. This help was provided by husbands, other family members (including children) and friends.

Women whose husbands remained by their side described how their husbands took on roles previously held by women within the household such as preparing food and cleaning clothes:

> I would sometimes not cook for [my husband because I was in pain], but the neighbours would help me out. [My husband] sometimes decided to wash for himself like on Saturdays and he would wash all the clothes. I would be available but couldn't wash because there was a time when the wounds would be so painful especially if I walked so much that day. (Afiya, 24-year-old focus group participant)

> I had left all the family responsibilities to my husband…. He had no problem because even the children I had were a bit mature so they could do some of the

> things…. He could help me with the clothes, for example, so the children could cook food. (Patricia, 33-year-old focus group participant)

Children and friends also provided tangible assistance by taking on tasks the women were unable to do themselves due to their physical limitations:

> My young child could help bring for me things which I couldn't lift. Also, my friend's wife could cook for me and sometimes help me bring for me things which I couldn't lift. They continued encouraging me and bringing me back to the normal life. (Angella, 33-year-old focus group participant)

> Even my eldest son had stopped me from farming, but because I am a grown up, I have to do something so I would go and dig a bit, but when it comes to fetching water, I have a tap at home and these heavy tasks, my children assist me. (Najat, 29-year-old focus group participant)

One woman disclosed how cultural norms influenced who could provide her with certain types of assistance:

> I made my maid such a close friend in that she started reaching places she even never initially went to like my bedroom because my mum couldn't go there [this is a taboo culturally]. The maid became a close friend so that she could assist me [with bathing] until my husband could come back. (Susan, 39-year-old interviewee)

Informational Support—Informational support needs largely centred on seeking care for fistula repair. Specifically, husbands, health workers and other women affected by fistula advised participants where to seek repair:

> [My husband] immediately went out to different people to find a solution to my problem…. He made several calls to different people, [and] spoke to someone on the phone who told him that she had heard over the radio that there would be an operation for women suffering from fistula…. Another person told us that there was a camp for such people in Mulago Hospital. (Evelyn, 37-year-old interviewee)

> After two months I remembered that among my friends I have a health worker. I took long before telling her, but I think if I had done this earlier, I would have got treatment earlier. So, when I talked to her, she informed me that Mulago offers that treatment. This is where she works. (Susan, 39-year-old interviewee)

Impact of Social Support

Women's narratives revealed how social support impacted their ability to access care, to cope with and accept their condition and helped them reintegrate back into their families and communities.

Access to care—Participants' narratives described how tangible and informational support helped women access care, particularly by paying transport expenses to and from a known health facility. Women also revealed how emotional support helped facilitate their access to care.

> For me it's my children [who support me]. I hadn't heard the announcement but my children in Mubende heard it and called me to inform me that they were going to repair patients with fistula. They encouraged me to come…. They wished me well and sold off the food and firewood they had come with so that I could get money to support me at the hospital…. I really felt good however much I was ill, I felt strong and encouraged. (Birabwa, 50-year-old focus group participant)

Coping with fistula—Women described how financial assistance and verbal encouragement, made them feel happy, confident and less alone which helped them cope with their condition. Coping included managing or concealing their incontinence with the use of disposable diapers or cloths provided by individuals who supported them. One woman mentioned how her daughter helped her afford diapers to manager her fistula:

> My first born would [send me money] because she had started working by [the time I developed fistula] and she would send me 10,000 USh (US$ 3) every other week. So, I would save [the money] and buy diapers without [telling] my husband. She would actually tell me not to show her father the money she would give me [and] it eased life for me. (Joyce, 35-year-old interviewee)

Participants also described how their ability to cope with the stress of fistula-related stigma was helped by emotional support, which made them feel accepted, understood and cared for.

> Two months [after developing fistula] my husband told me that [once I] accept that this has happened we [will] start to seek care…. For me I never believed that I had fistula I just saw it as impossible. I couldn't accept the condition and I never wanted people to know [about my fistula] because I was feeling ashamed. After two months when my husband and friends had talked to me together with health workers, [the] health workers really helped me a lot [and I was able to] settle, start eating, [and] loving my baby until I got treatment. (Susan, 39-year-old interviewee)

> It made me feel good [when they told me to stay strong and hopeful] because if people are encouraging you, then why should you de-motivate yourself. People who never knew me used to encourage me so I started getting self-confidence and I was like let me try to have that belief [that I will recover and] maybe I will be fine. (Kijai, 19-year-old interviewee)

Resilience—Women were particularly impacted upon by the influence of other women affected by fistula, whose stories and examples made them feel hopeful and encouraged them to stay strong during their recovery.

> I was encouraged because I knew there were other [women with fistula] like me…I was strong in the heart because I knew we were many, so it was my prayer that we would get healed…. When I saw them I knew I wasn't badly off, I knew there were others in a worse condition than [me]. (Sylvia, 32-year-old interviewee)

> There was one thing that was so helpful to me; when I was at the ward, we would sit and talk with the ladies and [hearing their stories helped me to believe] that I should keep strong and stay hopeful that maybe I would heal and bear kids again. (Stella, 28-year-old interviewee)

One woman who had lived with fistula for many years shared her experience of hopelessness to recover until she heard about another woman affected by fistula who had been cured, which helped her remain optimistic:

> A female health worker called me and she told me that, “they have told me you’re so bitter but please try to calm down because what we’re going to do is we are going to help you”, so she told me to have some faith that I will be fine and I told her that I will never be fine because I had spent a lot of time with the illness. She asked me how long have you spent with the illness? I told her fourteen years and she told me that I will be fine because there’s one person they had repaired, she was sixty years but she’s now fine and though she never conceived again but she’s doing her work very well. So, I was encouraged and because I had also seen the other woman who were healed, and she even conceived two children [and] my heart was strengthened. (Achen, 38-year-old focus group participant)

Reintegration—Women’s narratives revealed how those who had social support found it easier to reintegrate back into family life and resume their prior familial and social roles. Reintegration was easier when they had support systems that were accepting and supportive of their condition, provided financial assistance and helped with household chores.

> Things [that have helped me reintegrate] include having a good relationship with people. I have kept myself in good relationship with my friends, and they have greatly helped me in times of fistula illness. Even now that I have recovered, I still keep my friends… [and] my husband because he has supported me all the way. (Susan, 39-year-old participant).

Discussion

This study highlights the important role of social support in helping Ugandan women navigate the challenges of living with, and recovering from, genital fistula. Across different social support domains, this study found that women affected by fistula relied most heavily on tangible and emotional for improvements in health and well-being. Our findings delineate key sources and types of social support received and valued by women, which may inform the selection of potential intervention targets likely to improve resilience and quality of life among members of this population.

Women with fistula relied on multiple sources of social support ranging from close family members (e.g. husbands, mothers, sisters, etc.) to more distal individuals and organisations. The importance of a broad support system including multiple individuals for meeting the varied needs of women with fistula is consistent with findings from other research conducted in Ghana, Ethiopia and Tanzania (Dennis et al. 2016; Sullivan, O’Brien and Mwini-Nyaledzigbor 2016; Muleta et al. 2008; Ryan 2019). Support across multiple domains showed the versatility of an individual family member’s role in providing women with access to multiple types of support and resources. In contrast to Dennis et al. (2016) who report husbands as primary caregivers, our research described husbands as the primary financial supporters but female family members as the most important providers of other forms of tangible social support, highlighting important gender role distinctions. Interestingly, participants identified radio announcements as an important source of information regarding fistula care availability , which suggests that this and other methods to improve community awareness of fistula care are important in linking women to care (Tripathi, Arnoff and Sripad 2019; Marcus 2019).

Our findings are consistent with literature reporting financial dependence on family after fistula development due to treatment-related costs and difficulty working (Pope, Bangser and Requejo 2011; Jarvis, Richter and Vallianatos 2017). Financial assistance helped women overcome lost income from limited economic participation due to physical health challenges and stigma, met needs for products or materials to help women manage their condition, and facilitated women's treatment access (Baker et al. 2017). Tangible assistance with household chores was seen as critical post repair, a finding also present in studies from Tanzania (Pope, Bangser and Requejo 2011; Dennis et al. 2016). For some participants, community organisations played a key role in tangible and emotional support, as was also seen in Tanzania (Watt et al. 2014).

Consistent with prior research, having family or community member acceptance and emotional support improved women's experiences living with fistula (Bomboka, N-Mboowa and Nakilembe 2019). However, consistency of emotional support is varied across studies; our study participants reported receiving emotional support throughout their time living with and recovering from fistula whereas Dennis et al. described emotional support as limited to post repair (Dennis et al. 2016). Currently, literature identifying the importance of emotional support is limited and future research could usefully explore the role of emotional support among different populations affected by fistula.

Participants felt a renewed "sense of hope or courage" to focus on their healing after meeting other women with fistula. The important role of individuals with shared experiences has been described elsewhere in the fistula literature, (Sullivan, O'Brien and Mwini-Nyaledzigbor 2016; Pollaczek, Tavrow and Mohamed 2017) and strategies for capitalising on this important relationship appear within peer counselling and support programming developed for the management of other conditions (Prang, Newnam and Berecki-Gisolf 2018; Strom and Egede 2008). Where peer support programming has been integrated in fistula reintegration programmes, it contributes to improvements in emotional well-being (El Ayadi et al. 2020).

Overall, our analysis suggests that social support interventions may be an important way to improve the quality of life of women with fistula. Formal social support interventions which have sought to assist women with fistula have included a variety of intervention strategies ranging from purely counselling programming to peer support combined with economic investment, and counselling. Interventions trialled in Kenya and Eritrea suggest that pre and post-repair counselling may be effective in increasing emotional support (Bomboka, N-Mboowa and Nakilembe 2019; Pollaczek, Tavrow and Mohamed 2017). A Western Kenyan intervention has highlighted the positive effects of linking fistula survivors together through peer support groups facilitating psychosocial and economic empowerment activities (Pollaczek, Tavrow and Mohamed, 2017). Peer support group engagement enhanced women's social empowerment, emotional well-being, and community engagement. The intervention also sought to increase financial/economic independence through the peer support groups by incorporating business skills training and providing loans to the women. Peer support interventions for adherence to HIV antiretroviral therapy among women in sub-Saharan Africa have been shown to improve health behaviours/outcomes, social empowerment, destigmatisation and psychosocial well-being. Continued efforts are necessary to expand the application of this approach to women affected by fistula.

Strengths and Limitations

The use of an established theoretical framework framing that has been utilised in other studies assessing social support and health contributed to the validity of our study. Using women's narratives allowed us to incorporate women's voices and individual perspectives, providing nuanced detail into the complex nature of social support. However, the findings from the current study should be interpreted with limitations in mind, largely related to the secondary nature of our analysis, including the limited geographic region and hospital in Uganda. This limited our ability to further explore sociocultural practices and the impact these had on the support provided and precludes generalisation to a broader context. Finally, comprehensive assessment of social support should include attention to the appraisal domain, which we were unable to explore within this study.

Future research

Further research to understand options for applying these findings within an intervention framework optimising feasibility and acceptability would be impactful, including building on the experiences and lessons learned from existing fistula programming and from programmes using similar approaches for other conditions. Possible intervention targets include increasing emotional and financial support by creating support groups among individuals affected by the same condition, while also including other key stakeholders such as family members and husbands as well as financial support to increase independence and allow women to meet their daily needs.

Future research should be done within a variety of cultural settings to explore further how cultural practices influence social support and to understand the features of social support by various network actors across the fistula care continuum.

Conclusion

Findings from this study highlight the role of social support for women affected by fistula for coping with their condition, accessing fistula care and for improving post-repair recovery. Improving women's timely access to high quality obstetric care is of importance in reducing the prevalence of, and recovery from, this condition. At the same time, enhancing social support through targeted programming and support from family, community members, and social services could be a promising strategy for improving the experiences and quality of life of women affected by fistula.

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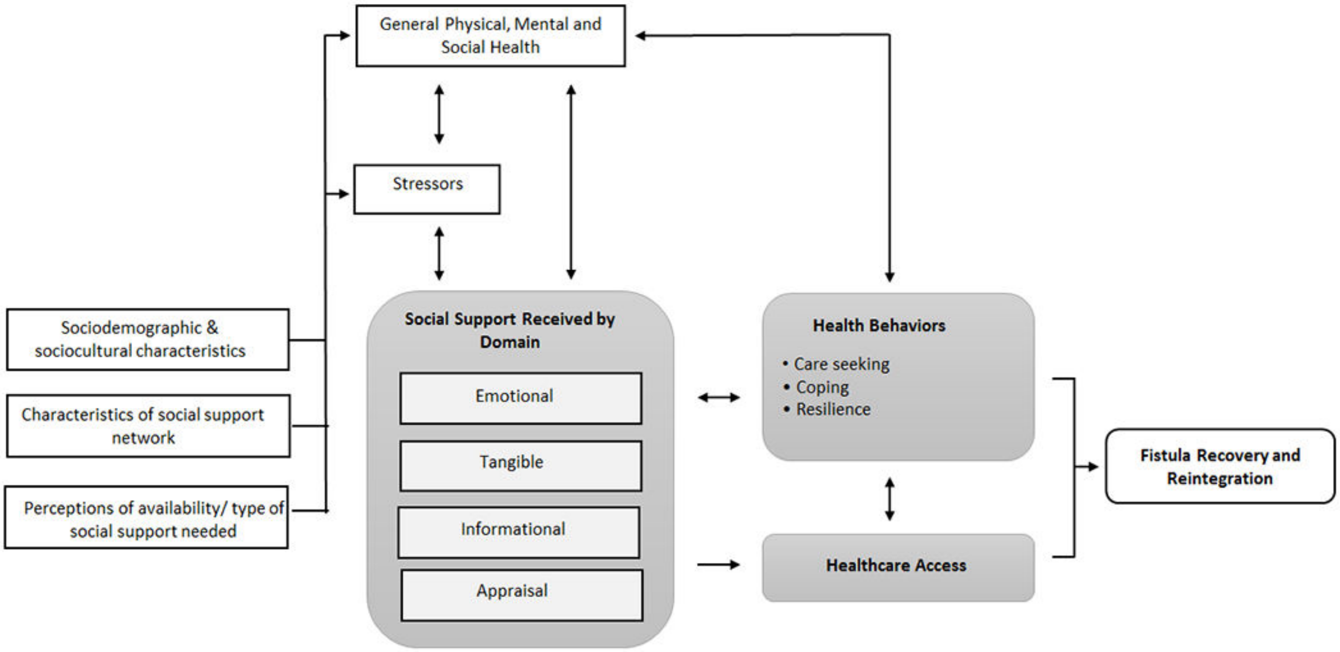

Figure 1.

Conceptual framework of the role of social support for female genital fistula adapted from multiple sources - Strom (2008), Berkman (2000), House (1981) and Heaney (2002)

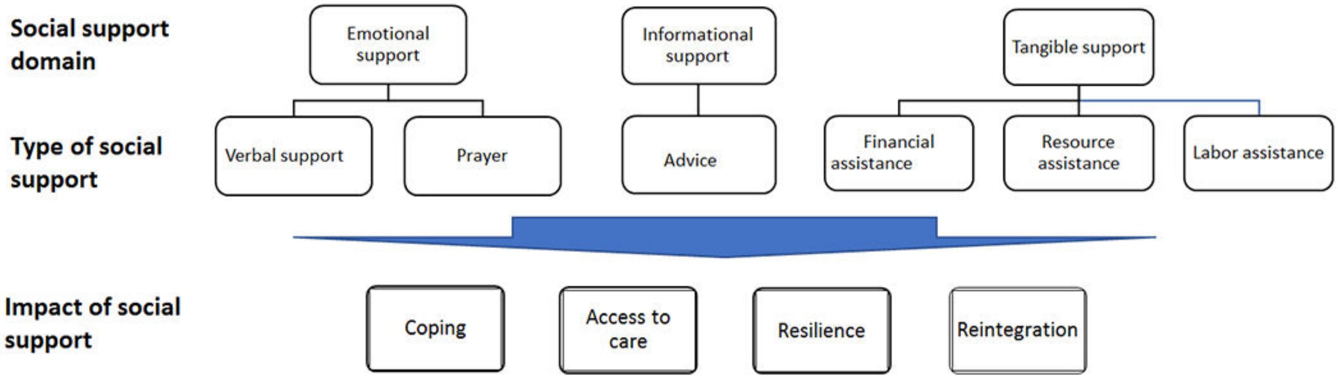

Figure 2.
Major themes identified across all three social support domains

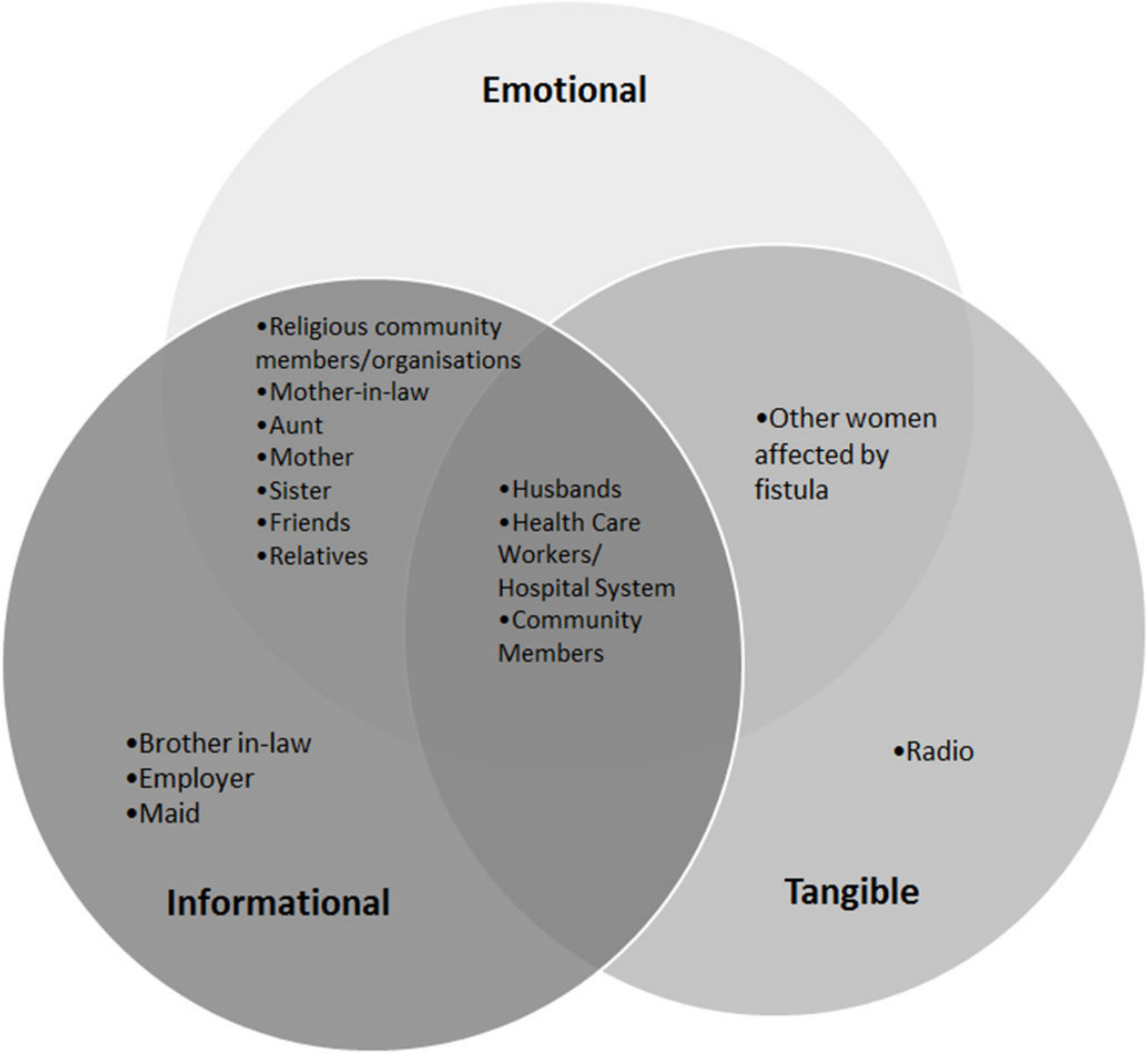

Figure 3.

Sources of social support by domain

Table 1.

Sociodemographic characteristics and reproductive history of study participants

	N=33	Percentage (%)
Age[a]	30 (24-37)	
Age at Fistula[a]	22.5 (18-28)	
Time Lived with Fistula		
<12 Months	4	12.1
1-2 Years	13	39.4
3-5 Years	2	6.1
>5 Years	12	42.4
Infant Survival, Fistula-Related Delivery	10	30.3
Living Children[a]	2 (1-3)	
Living Situation[b]		
Alone	3	9.1
Husband	25	75.8
Adult Children	1	3
Others	4	13.2
Educational Attainment		
None	2	6.1
Some Primary	19	57.6
Completed Primary	4	12.1
Any Secondary	8	24.2
Occupation		
None	11	33.3
Vendor/Shopkeeper	4	12.1
Farmer	11	33.3
Other	7	21.3
Primary Source of financial support		
Self	11	33.3
Partner	21	63.6
Other	1	3.0
Marital Status at time of interview		
Married or living together	25	75.7
Divorced/separated	8	24.2
Urinary incontinence status		
Continent	29	87.9
Incontinent[c]	4	12.1

Notes:

[a] median (interquartile range);

[b] with or without young children;

[c] about once a day (n=1), several times a day (n=1), all the time (n=2).