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## Women's experiences of fistula-related stigma in Uganda: a conceptual framework to inform stigma-reduction interventions

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### Abstract

Fistula-related stigma is common. The absence of a unifying conceptual framework prevents a nuanced understanding of the nature of fistula-related stigma, comparison across contexts and the ability to contrast with other stigmas. It also hinders intervention development. We conducted in-depth interviews or focus groups with 60 women who had undergone fistula surgery 6–24 months prior at Mulago Hospital in Kampala, Uganda in 2014. Transcripts were analysed for experiences and consequences of enacted, anticipated and internalised stigma. Narratives revealed experiences with enacted stigma, including gossip, verbal abuse and social exclusion. Women also anticipated and feared stigma in the future. Internalised stigma reports revealed shame and low self-esteem: self-worth reduction, feeling disgraced and envisioning no future. Consequences included social isolation, changes to normal activities, non-disclosure and poor mental health. Refining stigma theory to specific conditions has resulted in a more nuanced understanding of stigma dimensions, manifestations, mechanisms and consequences, permitting comparison across contexts and populations and the development of stigma-reduction interventions. These lessons should be applied to fistula, acknowledging unique features: concealability, the potential for treatment, lack of community awareness and the social consequences of stillbirth. Reducing fistula-related stigma requires timely surgery and supportive care, stigma-reduction interventions and addressing the complex societal structures that perpetuate fistula.

### Keywords

Stigma; genital fistula; obstructed labour; maternal morbidity; Uganda

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Disclosure statement

All authors declare no conflict of interest.

## Introduction

Female genital fistula is a debilitating injury resulting in urinary and/or faecal incontinence. Most fistulae result from prolonged obstructed labour, with fewer resulting from iatrogenic or traumatic aetiologies. As many as 2 million women are living with fistula globally, most in sub-Saharan Africa and Asia (Adler et al. 2013; Wall 2006), with up to 100,000 annual incident cases (de Bernis 2007). Female genital fistula from obstetric causes results in severe physical, psychological and social sequelae (Ahmed and Holtz 2007; Roush 2009; Turan, Johnson and Polan 2007). Women commonly experience infections, vaginal and genital ulcerations, difficulty walking without assistance and secondary infertility. Neurological injury, gynaecological morbidity and orthopaedic trauma also occur.

Women affected by obstetric fistula experience devastating social and psychological consequences because of the stigma that surrounds their condition (Alio et al. 2011; Bangser 2006). Although stigma is a known significant challenge for women living with fistula, the incomplete elucidation of the nature, different dimensions and sources of stigma, the relationship between stigma and psychological and behavioural outcomes and the factors influencing all of these, within a conceptual framework, limits theory and the evidence-based optimisation of clinical and social services for stigma reduction, preventing women affected by fistula from achieving a higher quality of life. Relationship challenges are prevalent in women's narratives of fistula, with frequent citations of divorce, abandonment or relegation to secondary wife status where polygamy is common. Other reports discuss limitations on cooking or participating in social events or religious rituals (Bangser 2006). Verbal abuse is common (Bangser et al. 2011; Mwini-Nyaledzigbor, Agana and Pilkington 2013). The consequences of stigmatisation include depression, low self-esteem and social isolation (Alio et al. 2011; Donnelly et al. 2015).

The lack of application of a robust conceptual framework to women's experiences of fistula-related stigma limits our ability to develop a more nuanced understanding of these experiences, compare and contrast fistula-related stigma across geographic and cultural contexts, contrast with other health condition-specific forms of stigma and, most importantly, to inform interventions to mitigate and reduce stigma to improve quality of life. In contrast, significant scholarly work refining HIV-related stigma theory has occurred over the past decades, resulting in a nuanced understanding of HIV-related stigma dimensions, manifestations, mechanisms and consequences (Turan et al. 2017), permitting the development and evaluation of stigma-reduction interventions (Stangl et al. 2013). Similar interventions are needed to improve the lives of women with fistula, given the burden of stigma. Thus, we sought to understand and classify women's fistula-related stigma experiences, employing a fistula-related stigma conceptual framework adapted from the HIV literature, within a qualitative study among Ugandan women repaired for obstetric fistula.

## Materials and methods

This qualitative study was conducted within a larger study on family and community reintegration among women accessing fistula surgery at Mulago Hospital in Kampala, Uganda. Women were eligible for participation in the study's qualitative phase if they had

received fistula surgery within the prior 6–24 months, spoke Luganda or English, resided within 100 km of Mulago Hospital, provided a telephone number and were capable of providing informed consent. Of 45 eligible women, 33 participated; 1 was not interested, and 11 were not re-contacted for participation as the research team felt they had reached thematic saturation after the 33 participants (Saunders et al. 2017).

Ugandan research staff conducted written informed consent procedures with all participants in person. Study staff administered a short quantitative survey to capture age, ethnicity, religion, socio-economic status, marital status, educational attainment, pregnancy and obstetric history, general health and continence. Women subsequently participated in semi-structured in-depth interviews (n = 16) or focus group discussions (n = 17; four groups). In-depth interviews captured women's experiences living with fistula; in particular, women were asked how having fistula changed their role within their family, household and community; how it affected their relationships, including how people treated them; and how it impacted on their daily activities. Focus groups largely targeted women's post-surgical reintegration experiences (our primary study objective), yet women's comparisons between experiences living with fistula and following repair surgery provided rich data on stigmatisation and were included in this analysis.

We described the socio-demographic characteristics of participants using Stata v14 software (StataCorp, College Station, TX, USA). Transcripts from in-depth interviews and focus group discussions were coded using inductive and deductive codes within Atlas.ti software and analysed thematically for women's experiences of stigma across our conceptual framework. Thematic analysis occurred concurrent with data collection to assist in determining achievement of thematic sufficiency.

### Stigma conceptual framework

Figure 1 presents our conceptual framework for fistula-related stigma, adapted from Turan et al. 2017 and Turan and Nyblade 2013. In these frameworks, stigma is generally categorised into four distinct but interrelated dimensions: enacted, anticipated, internalised and perceived community. *Enacted stigma* refers to verbal or behavioural discrimination directly experienced by individuals, including such experiences as name-calling, refusing to touch a stigmatised individual or to use items that that individual has used, or any other behaviours signifying devaluation. *Anticipated stigma* refers to an individual's fears of enacted stigma that they may face during the course of their daily lives, generally or in specific contexts. *Internalised stigma* refers to the implications on an individual's sense of value or self-worth due to internalisation of societal attitudes about individuals with their particular condition, or experiences of enacted stigma. *Perceived community stigma* reflects perceptions of detrimental attitudes and practices towards individuals with the condition. Although perceived community stigma was not specifically assessed in the current study, we include it in our conceptual framework. Stigma occurs and is perpetuated by context-specific values of conditions, their causes and consequences and the overarching societal power structures (Link and Phelan 2001, 2006), represented by *social and contextual factors* and *structural stigma* within our framework. The framework also includes *intersectional stigma* to acknowledge that the stigma experience is influenced not only by condition-specific stigmas,

but also by prevalent stigmas of the other social identities that individuals concurrently hold, including but not limited to gender, socio-economic status, and race or ethnicity (Logie et al. 2011; Turan et al. 2017).

## Results

Socio-demographic characteristics of study participants are shown in Table 1. Median age at interview was 30, while median age at fistula development was 23. The majority of women had not completed primary education (63%). Time lived with fistula varied, with 12% affected for less than one year, but 42% for over five years. Most women reported living with their husband/partner (76%). Household ownership of assets varied by type, with most households having a radio (88%) or mobile phone (88%), and fewer possessing piped water (15%), a refrigerator (9%) or a flush/pour toilet (6%).

Stigma heavily featured in women's narratives of the impacts that fistula had on their daily activities and lives. Stigma experiences were classified using three stigma dimensions: enacted, anticipated and internalised. We present the consequences of fistula-related stigma within a separate section, highlighting the contributions of unique stigma dimensions as relevant.

### Enacted stigma

Participant narratives revealed a variety of experiences with enacted stigma, ranging from gossip and verbal abuse, distancing and rejecting behaviours, to exclusion from family and community activities. Many women reported that fistula changed how people in their community treated them. Manifestations of enacted stigma originated from different individuals, including community members, co-workers, friends and extended and close family members.

**Gossip and verbal abuse**—Overwhelmingly, one major and consistent type of stigma reported was gossip, referred to locally as 'backbiting'. This often occurred indirectly, where respondents learned from others what was said about them: 'I always knew. In fact, some of them would come and tell me what they were talking about me in my absence' (28-year-old interviewee). Others experienced backbiting directly. Respondents shared how they were the target of verbal abuse by community members: 'Back in my village, they would even laugh and yell at me saying, "look at Mr X's wife, she is leaking!"' (28-year-old interviewee).

Participants reported this verbal abuse as being perpetrated even by family and friends:

[People, including my grandmother and even my siblings, would] come and abuse me. They had nicknamed me *lunyolo*, meaning someone who urinates. (19-year-old interviewee)

Your friend could come to your home and tell you how others had been talking about you ... saying that you leak, you smell offensively and they're wondering which kind of illness you're suffering from. Others could say you're rotting, because why would you be like that when you sit somewhere you leave the place wet. (37-year-old focus group participant)

At school, my fellow teachers call me ‘damaged’. (37-year-old interviewee)

**Distancing and rejecting behaviours**—In addition to direct and indirect verbal abuse, women with fistula were the targets of a variety of distancing and rejecting behaviours due to their condition. Various individuals were named as perpetrators, but primary within these narratives were male partners who ‘chased’ (i.e. forced them to leave their marital home) or abandoned women due to their fistula:

My husband chased me; his relatives told him, ‘chase that woman, she’s smelling, can she cook for us food and we eat it?’ I left that place [the house I built and gave birth from]; all this because of fistula. (50-year-old focus group participant)

Women who remained with their partners described the situation as tenuous, at risk of dissolution and fraught with interpersonal challenges. Threats of relationship dissolution were common, and sometimes contingent on the fistula healing.

For me things changed immediately, [my baby’s] dad wanted to get another wife there and then. I told him, if you found me [with fistula from the beginning], get another woman. I think he later on thought twice and ... he told me that let’s try to treat that illness, if it heals, we stay together, if it fails, you go back to your home .... (21-year-old focus group participant)

Partners were described as being impatient or frustrated with the situation, particularly where they were unwilling to have sex with their wives with fistula. One woman described the effect of fistula on her relationship in simple terms: ‘If you’re married, love seriously reduces’ (47-year-old focus group participant).

Where women also lived with co-wives, having fistula provided an additional point of contention and competition. One woman shared the following experience,

The biggest challenge I got [was] from my husband’s co-wives, they were always telling him that if they were him, they would have chased me already. The third wife to my husband would always use [the fistula] as a way of abusing me; when we would have an argument just like women do, she would remind me that I have fistula, just to abuse me. (43-year-old focus group participant)

Another woman described the challenge to living in a polygamous relationship:

My husband had other women so it was really hard for him to enter a smelling room yet there was another one which was well scented. (47-year-old focus group participant)

Stigmatising behaviours from other individuals largely occurred within the household, likely due to the significant self-isolation reported among our participants. Common manifestations of enacted stigma within the household included excluding women from common sleeping areas, asking them to eat alone, refusing to eat food they cooked and refusing to care for the woman:

[People at home were uncomfortable when I was cooking food. When] I would pass by someone, [I] would see this person's facial expression changing. (51-year-old interviewee)

We lived with [my sisters and] I had a feeling that even when I cooked for them, they wouldn't eat the food ....[Whenever I cooked], they would say, 'I will eat later at night!' and I would realise that no one has eaten. (22-year-old interviewee)

Two respondents received exceptionally poor treatment from their siblings:

[My siblings] didn't care much about me; they felt disgusted with me. At times they didn't want me to do anything ... they didn't want me to cook; they didn't want to eat the food I prepared. I would dine with them [only] when my mum was around. When my mum wasn't around, they would ... bring the food to my bedroom and say, 'never mind, just eat from here'. (28-year-old interviewee)

Some of my brothers and sisters wouldn't drink tea from my house. It was like they thought that it was my urine that I would put in the kettle and prepare for them. (35-year-old interviewee)

**Exclusion from community social life**—Participants were excluded from events or activities due to their fistula. For example, several women reported not being invited to participate in community events such as weddings or other gatherings, whereas they were invited previously. Other women reported community members having a reduced interest in the roles they had previously provided, such as selling things in the market or other informal sector services. For example, one woman who had been a hairdresser reported that after the fistula, 'No, they no longer called me to style their hair' (22-year-old interviewee), also reducing her income. Finally, others reported losing the support of friends due to their condition:

No one had ever had such a condition before .... I remained [friends] with the person who knew the condition I was passing through, but the rest, no .... [My other friends did not come close] because [I was] full of urine. (47-year-old focus group participant)

I had no one who wanted to invite me for parties. No one could invite me basing on the way I was, unless if this person was so close to me. And this person would call me for burial, and I would put on like two *gomesies* (traditional dresses) and I couldn't sit when I reach there, I would stand so that this urine passes out freely because if I sat people would talk about me. I never went for any occasion. (30-year-old focus group participant)

### Anticipated stigma

Narratives of anticipated stigma largely reflected women's fears of enacted stigma including backbiting and other verbal abuse and discriminatory perceptions. The following quotations reveal something of the stigma anticipations that women held:

I wasn't going anywhere .... In the village, I wasn't moving around because as soon as you leave, this person would start talking about you. (50-year-old focus group participant)

I feared people imagining things about me, for instance, thinking that I was always soaked up even when I was standing up. You know someone who's always wet is a baby, and I didn't want to be thought of that way, I always wanted to keep my dignity. I never told them the truth I also don't know why. I saw the fistula issue to be very abnormal in that even when I recovered it is still shameful, so I always wanted to keep it a secret. (39-year-old interviewee)

### Internalised stigma

Narratives revealed pervasive shame and low self-esteem among study participants. Some women described a loss in their self-worth or self-importance, while others reported feeling disgraced, envisioning no future. Participants described themselves as 'bad' or 'outcasts'.

I felt worthless .... I felt ashamed in front of my kids and husband, even to a few friends that would come to visit me .... So, I felt fed up of life. (28-year-old interviewee)

It's a very serious problem, let me tell you, even your character changes .... You realise that you have no future no matter what, because however much you were a friend to someone, discrimination starts .... You yourself you see as not worthy, so all in all, you just see that life has come to a standstill, you see yourself as worthless. (34-year-old focus group participant)

Particularly poignant were discussions by respondents sharing the shame that they felt when their condition became evident to their young children and their feelings that stemmed from their children's innocent questions or reactions to seeing their mothers leaking urine.

[My] children started realising [that I was leaking urine], and saying whenever mum leaves a place, she leaves urine. They were whispering this until the 7-year-old child told me, 'Mum, you urinate on the bed, so I will sleep with you today since you urinate on the bed [like me]'. ... I felt bad and ashamed amidst my children. (37-year-old focus group participant)

If you have children at home and you get such a problem, you get ashamed in front of your children and if they're still young, they can even back-bite you asking themselves if even adults urinate on bed. For him, he can say it jokingly, but as an adult you feel hurt because there's no way you can advise this person that someone doesn't urinate where s/he is seated when you yourself are doing that same thing. (47-year-old focus group participant)

### Consequences of stigma

Many women described the significant consequences that stigma imposed on their daily lives. These largely fell within the themes of self-imposed social isolation, changes to normal household activities, non-disclosure of fistula and poor mental health.



**Self-imposed social isolation**—Women shared a preference for limiting their mobility, staying at home most or all of the time. This included avoiding social events such as weddings, religious services, family gatherings, funerals, etc., even when they were invited.

When I acquired that illness, I spent three years without going to church. [I would only attend when the religious] services took place in different homesteads instead, but I would feel uncomfortable, [especially] when I had to get close to the Father .... I never wanted to be amidst people. Whenever they were about to read bible verses, I would excuse myself and go home because I was feeling so ashamed because how could the Father call me up and people see my clothes leaking. (24-year-old focus group participant)

It was me that became hard-hearted instead, because it was me that wouldn't go there to their places for reasons that they would discriminate me. I wouldn't go to their homes. The problem was actually with me and it was because of the sickness I was suffering from that caused me not to enjoy hanging out with them; I would prefer staying at my home. (35-year-old interviewee)

In addition to self-isolating from community members and avoiding community events, women also described how they did not want visitors to enter their homes, even those offering some assistance.

At home, everything changed because even if your friend still loved you, the moment you heard him/her knocking on the door, you would ask yourself, what has brought this person? I always wanted to keep in my room alone without anyone crossing my face, I separated from people, I wanted to be alone with my condition .... I wanted them to leave me alone because I had distanced myself from people and yet I had nothing else to do. Even if it was work you couldn't do it, even you yourself you wouldn't get the desire, even poverty became too much. You live in a very bad state, everything becomes disconnected, and you lose connection with people and stay alone in the world. (47-year-old focus group participant)

For me, the time reached when my home was always locked and when you would come, it would appear as if there's no one there, yet I have just locked myself inside there. (21-year-old focus group participant)

In relationships where women's partners accepted them despite their condition, internalised stigma exacted an impact. Several women felt that they should sleep alone despite living with their partners, an option which was accepted by some but not all. Other women personally made the decision to return to their parents' home instead of remaining with their husbands.

**Changes to normal household activities**—Several participants reported altering their household activities due to stigma anticipations. One woman shared that she had stopped cooking after developing fistula:

I had a feeling that maybe if I prepare meals, [my family] would somehow feel disgusted, [that they] would not eat it because they feel disgusted given my leaking condition. (22-year-old interviewee)

**Non-disclosure of fistula**—Disclosure of fistula was difficult for many women due to stigma anticipations. This led some women to keep their condition secret, even when this negatively impacted them or their relationships. Women feared that disclosure would spread through the community, resulting in gossip and verbal abuse.

I [only told the health worker and not any other person] because I never wanted to be backbitten by people in the village. I kept it to myself because I never wanted to be laughed at or a centre of attraction for the people. (30-year-old interviewee)

Several narratives revealed a particular fear that the community's lack of familiarity with fistula could result in its being attributed to HIV, which was more familiar. One participant shared her recommendation that fistula not be disclosed in order to avoid people spreading rumours:

People say a lot of things so it's better to keep quiet .... You can even be suffering from malaria and people will start saying that you have HIV so if you have the chance of not letting some people know, the better. (24-year-old interviewee)

Even for those who did not disclose their fistula to community members, changes in the women's regular behaviours were observed by others and attributed to other reasons. Some were felt to be antisocial. One woman noted that women in her community questioned why she travelled so frequently, not knowing that it was to the hospital: 'They conclude that maybe I have a lover in Kampala, because they are not aware of my situation'. (28-year-old interviewee)

While some women who did not disclose their fistula to important people in their lives did so after successful surgery, others discussed persistent stigma anticipations: 'I saw the fistula issue to be very abnormal; even when I recovered it is still shameful, so I always wanted to keep it a secret' (39-year-old interviewee).

Although non-disclosure was protective for several women, it had a lasting impact on community relationships for others. One woman described how her decision not to disclose currently affected her relationships: 'Up to now, some people do not trust us because we hid so much information from them' (37-year-old interviewee).

**Mental health effects**—Fistula-related stigma resulted in severe mental health concerns, including depression. Two women shared having contemplated suicide, one stating, 'All in all I felt a lot of pain and I even prayed to God to take my life!' (28-year-old-interviewee). One woman described a failed suicide attempt:

I never thought I could heal, what remained of me was to eat my food and sleep; what else could I do? There was a time when I felt like should I get a knife. Actually, my husband is the one who found me. If he hadn't come, I was going to commit suicide .... He came from behind, my hand was up here, and he held it, then he asked me what I wanted to do. Then I told him you know what, I think my life has ended here. I don't have any future with this illness. (21-year-old focus group participant)

## Discussion

Across the dimensions of enacted, anticipated and internalised stigma, this study details significant and pervasive effects of fistula-related stigmatisation experienced by Ugandan women. Enacted stigma manifestations largely featured gossip and verbal abuse, interpersonal behaviours such as distancing, exclusion, relationship dissolution and marginalisation from community life. Women's stigma anticipations reflected their fears of the behaviours and experiences described under enacted stigma. Manifestations of internalised stigma included low perceptions of self-worth and shame. Stigma manifestations across these three dimensions were linked with important behavioural consequences, including social isolation from community, friends and partners; altering normal household roles; and hiding the fact that they had fistula. These in turn appeared to often lead to poor mental health. Although these findings are consistent with those documented in the previous literature, our study is the first to apply a robust conceptual framework to these experiences. This first step will strengthen the evidence base characterising the nature and nuances of fistula-related stigma and can guide intervention targets to mitigate stigma and improve health and quality of life among women affected by fistula.

Subsequent to Goffman's definition of stigma as a dynamic process of devaluation that 'significantly discredits' an individual in the eyes of others (Goffman 1963), a plethora of work refining stigma theory has occurred, largely in relation to HIV and physical or mental disabilities (Bos et al. 2013; Campbell et al. 2007; Deacon et al. 2005; Link and Phelan 2001; Parker and Aggleton 2003; Quinn and Earnshaw 2013). The refinement of stigma theory in HIV has resulted in a more nuanced understanding of HIV-related stigma dimensions, manifestations, mechanisms and consequences (Turan et al. 2017), permitting comparison across cultural contexts and population sub-groups and the development and evaluation of stigma-reduction interventions (Stangl et al. 2013). In their 2013 review of HIV-related stigma interventions, Stangl et al. report considerable progress over the prior decade with the vast majority of intervention studies reporting significant decreases in stigma (Stangl et al. 2013). While continued efforts are necessary to optimise HIV-related stigma interventions development, delivery and measurement, the application and refinement of stigma frameworks to this area has encouraged unification of language and concepts (Earnshaw et al. 2013; Turan et al. 2017); resulted in the development and validation of instruments to measure these concepts (Earnshaw and Chaudoir 2009); and allowed for comparison across populations, intervention approaches, targets and contexts (Genberg et al. 2009; Treves-Kagan et al. 2017).

Some lessons from stigma theory development in HIV and disability research can be applied to fistula-related stigma due to similarities in manifestations. Our study found that fistula-related stigma from the perspective of affected women fits well into the primary dimensions of *enacted*, *anticipated* and *internalised* used to frame other condition-related forms of stigma (Earnshaw et al. 2013; Holzemer et al. 2007). Indeed, during analysis, we found no need to introduce additional dimensions to frame the stigma experienced by our study participants. Similarly, the general categories of manifestations and consequences of fistula-

related stigma identified in this study (social isolation, lack of disclosure, etc.) were not unique to fistula (Deacon et al. 2005).

However, differences in the presentation of fistula versus other stigmatised conditions likely contribute to disparate stigma experiences. First, the primary presenting symptoms of genital fistula in the form of uncontrollable incontinence of urine or faeces are difficult to conceal and unpleasant to the woman and others around her. Moreover, in settings where fistula is prevalent, women typically have poor access to materials to manage incontinence in a way that could mask their condition, commonly padding themselves with cloth to absorb the urine, inevitably resulting in an unpleasant odour (Barageine et al. 2015; Mwini-Nyaledzigbor, Agana and Pilkington 2013; Roush 2009). In contrast, the identification of individuals with other stigmatised conditions may be less likely due to concealability; for example, the concealment of HIV-positive status is possible in the current era of widespread antiretroviral therapy access, as most individuals on treatment have no visible symptoms (Brener et al. 2013; Holmes et al. 2017).

Second, despite higher prevalence in particular geographies, female genital fistula remains relatively rare, thus community awareness and knowledge of fistula is typically low (Kasamba, Kaye and Mbalinda 2013; Omari et al. 2015). Indeed, many study participants reported no familiarity with the condition prior to developing it, and not knowing anyone else with the condition until they met other affected women at the hospital. Similarly, the lack of perceptions of stigma in the community may stem from the relative rarity of the condition. Thus, individuals and communities who are ill-informed on the causes and curability of fistula may rely on other health-related beliefs to understand the condition, as is noted elsewhere (Changole et al. 2018; Kasamba, Kaye and Mbalinda 2013). Indeed, our findings suggested some difficulty in community differentiation between HIV and other conditions. Furthermore, consistent with other stigma literature, cultural beliefs around illness as punishment for certain immoral behaviours have been identified as relevant for fistula, with studies reporting perceptions that fistula may occur due to promiscuous or other immoral behaviour, or witchcraft (Deacon 2006; Nalubwama et al., forthcoming), putting the blame for fistula on the woman (Turan and Nyblade 2013).

Third, the majority of women who develop fistula from obstructed labour experience stillbirth (Ahmed, Anastasi and Laski 2016), which may also be stigmatised. While we did not capture data describing stigma resulting from infant loss, we did not explicitly probe for this information, and it is possible that fistula-related stigma intersects with components of infertility-related stigma present in cultural contexts where fistula is prevalent (van Balen and Bos 2009). Finally, an individual's experience of a condition-related stigma will vary considerably by the presence and manifestation of structural and intersectional stigmas and the available coping strategies (Deacon 2006; Logie et al. 2011).

Intervention types and targets differ depending on the dimensions of stigma that are the most salient, as well as the identified mechanisms (Earnshaw et al. 2013). For example, coping resources and resilience, and treating health problems are strategies for addressing internalised stigma, whereas interventions targeting enacted stigma would focus more on changing the attitudes and actions of other community members. Some combination of

strategies is likely necessary; however, assessment across stigma domains can inform optimal resource use. Successful stigma-reducing interventions in the HIV literature have included strategies focused on reducing stigma through community or targeted education, skills-building, empathy development activities, counselling and support, biomedical intervention and policy change (Mak et al. 2017; Ma, Chan and Loke 2019; Stangl et al. 2013). Similar strategies may be effective for reducing fistula-related stigma with a focus on appropriate drivers, facilitators and levels. Further development of the evidence base can reveal how improvements to women's experiences with fistula are achievable through stigma-reduction interventions, and the specific mechanisms to use to secure such improvements. Likely gains include improved mental health, reduced treatment delays and reduced economic impact.

Self-imposed social isolation and non-disclosure were two important behavioural consequences of fistula-related stigma among women in this study that can be viewed as coping mechanisms for stigma management. While we did not explore the relationship between self-imposed social isolation or non-disclosure and treatment-seeking or access, it is plausible that women's efforts to conceal their condition delayed treatment receipt. Indeed, Baker et al. report social factors such as stigma and embarrassment as frequently reported barriers to obstetric fistula treatment (Baker et al. 2017).

### Limitations

The current study has several limitations. Results reveal a broad variety of fistula-related stigma manifestations across three dimensions. However, the study design limits our ability to identify the relative importance of each stigma dimension with respect to women's health and quality of life outcomes. We were also unable to identify the coping mechanisms and resiliencies that enable some women to succeed when challenged by fistula. Further research on such mechanisms is needed to inform future programming. Furthermore, our study was based at one specialised hospital in Uganda. Further research is also needed to apply this conceptual framework to the experiences of women with fistula in the different cultural contexts where the condition occurs and to incorporate the experiences of women who are unable to access treatment. Finally, our study population did not allow us to explore the dimension of perceived community stigma but represented more general beliefs about the characteristics or people with this particular stigma as measured at community-level, or stigma by association, e.g. stigma experiences due to being a family member or caregiver of an individual with a stigmatising characteristic. Subsequent research engaging with these issues will be important in order to develop a more complete understanding of fistula-related stigma.

### Conclusion

Findings from this study of the experiences of Ugandan women affected by genital fistula contribute to an increasing literature demonstrating the significant effects that fistula-related stigma has on women's health and quality of life. Beyond increasing efforts to prevent the occurrence of fistula, which is paramount, moving the field forward to reduce fistula-related stigma and its consequences requires a focus on improving women's timely access to fistula

surgery and supportive care, developing and evaluating evidence and theory-based programmes and interventions targeting stigma reduction, and addressing the complex societal structures perpetuating this condition and its consequences.

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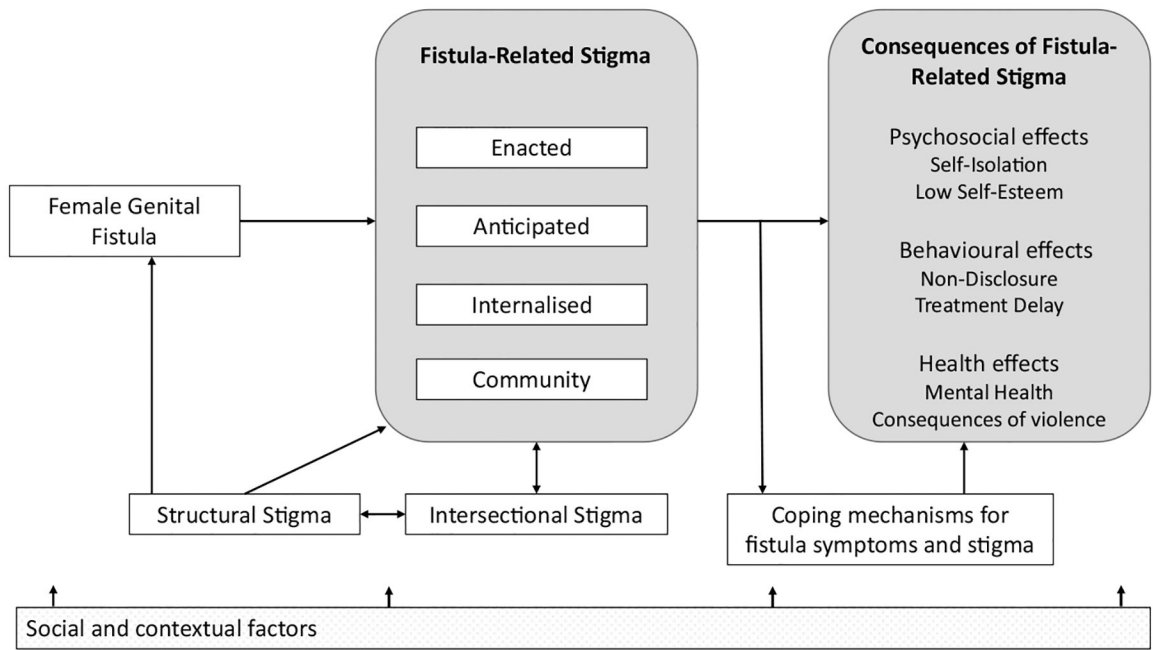
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**Figure 1.**  
Conceptual framework for fistula-related stigma.

**Table 1.**

Sociodemographic characteristics of study participants.

	Study Participants	
	n = 33	
	n	%
Age (median, IQR)	30 (24–37)	
Age at Fistula (median, IQR)	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
More than 5 years	14	42.4
Living Situation		
Alone	2	6.1
Husband <sup>a</sup>	25	75.8
Young children only	1	3.0
Adult children <sup>a</sup>	1	3.0
Other <sup>a</sup>	4	13.2
Educational Attainment		
None	2	6.1
Some primary education	19	57.6
Completed primary education	12	36.3
Occupation		
None	11	33.3
Vendor/shopkeeper	4	12.1
Farmer	11	33.3
Other	7	21.3
Primary Source Financial Support		
Self	11	33.3
Husband	21	63.6
Other	1	3.0
Household Assets		
Piped water	5	15.2
Flush/pour flush toilet	2	6.1
Electricity	10	30.3
Radio	29	87.9
Television	13	39.4
Mobile phone	29	87.9
Refrigerator	3	9.1
Living Children (median, IQR)	2 (1 –3)	

Notes.

<sup>a</sup>with or without young children.

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