

Reports

"...Our support is not enough": a qualitative analysis of recommendations from informal caregivers of women with female genital fistula in Uganda

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Informal caregivers remain critical across the care continuum for complex and stigmatized conditions including female genital fistula, particularly in lower-resource settings burdened by underfunded health systems and workforce shortages. These caregivers often provide significant nonmedical support in both community and facility settings, without pay. Despite their unique insight into the lived experiences of their patients, few studies center the perspectives of informal caregivers. We asked informal caregivers of women seeking surgical treatment of fistula in Kampala Uganda for their ideas about what would improve the recovery and reintegration experiences of their patients. Economic empowerment and community capacity building emerged as primary themes among their responses, and they perceived opportunities for clinical medicine and global health to strengthen strategies for fistula prevention through reintegration. Informal caregivers urged simultaneous investment in women's economic status and community capacity to build fistula-related awareness, knowledge, and skills to improve inclusion of both fistula patients and their informal caregivers.

Female genital fistula is the occurrence of an abnormal opening between the vagina and the bladder or rectum causing urinary and/or fecal incontinence. Global estimates suggest that more than half of a million people are living with this condition and that the burden is almost exclusively in sub-Saharan Africa and Southern Asia.¹ In Uganda, 0.5% to 4.3% of women have reported lifetime symptoms of female genital fistula.² Underfunded health systems and overburdened health workforces are among the intersecting reasons that informal caregivers such as family members or close friends are necessary to support fistula patients across the care continuum.³⁻⁵ Even though informal caregivers provide significant nonmedical support for their patient in both community and facility settings, literature summarizing their perceptions remains sparse.

The specific positionality of informal caregivers equips them with unique insight into the lived experiences of women with female genital fistula.⁶⁻⁸ A recent study in Guinea asked a myriad of fistula care stakeholders—including informal caregivers—for their perspectives on how to improve quality of life for women post-repair and reported a universal recommendation for multidisciplinary strategies involving social and economic support in addition to medical follow-up.⁹ These findings expand upon recommendations previously published from a patient perspec-

tive among women with fistula in Malawi which focused on social aspects of increased awareness and education toward reducing stigma to improve quality of life.¹⁰ Care recommendations have also been documented from clinical providers, though prioritize the implementation of approaches proven to be clinically effective such as bladder catheterization duration.¹¹ Community-based perspectives provide an important supplemental viewpoint about local priorities and needs. Additional investigation is needed to understand the nuanced needs across fistula-prevalent settings and to inform approaches that advance positive post-repair health outcomes and reintegration.

In a recent study exploring the experiences of informal caregivers of women with fistula, we thematically analyzed 43 participant responses from in-depth interviews (n=21) and five focus group discussions (n=22) of primary informal caregivers of women with female genital fistula seeking care at Mulago National Referral and Teaching Hospital in Kampala, Uganda in 2015.¹² We descriptively analyzed quantitative data from caregiver's sociodemographic and caregiving characteristics questionnaires (n=43). Using a convergent mixed-methods approach enabled investigation of the path to caregiving, the roles and responsibilities of caregivers, and the perspectives of caregivers on a variety of topics concerning the experiences of both caregivers and

Table 1. Informal caregiver quotes illustrating recommendation sub-themes related to economic empowerment for female genital fistula patients

Economic Empowerment Subtheme	Example Quote
Provision of money	<i>"The support she may need is money [...] to help her survive [...] like she was here while not working, she may get back home and need to buy everything and she may not even know where to begin from. [...] It may help her buy what she needs, I can't say that she needs this or that but she knows better what she needs. (Caregiving Neighbor, age 17, female)</i>
Provision of nutrition	<i>"And maybe if there is also money to buy food. Sometimes the patient may need a different dish yet the caretaker cannot buy it for her since s/he doesn't have that money. The patient may need chicken or liver but the caretaker may not be able to get it to his/her patient since s/he doesn't have that money." (Caregiving Husband, age 33, male)</i>
Provision of supplies	<i>"[Helping patients to endure fistula] requires that one always has materials such as cotton wool and to ensure that she never runs out of that wool. Well, there are certain patients that get diarrhea and need pads made for mature people. If she never runs out of the materials she uses, then she would not feel so worried; she would feel motivated, otherwise she would feel discouraged if she doesn't have those materials." (Caregiving Sister, age 25, female)</i>

their patients. While the previously described manuscript centered caregiving experiences and outcomes, “Support recommendations” from the caregivers regarding mechanisms and strategies to improve the fistula care landscape emerged as a unique and prominent code throughout qualitative data analysis is further investigated and summarized here.

Nearly all the informal caregivers of patients with female genital fistula interviewed (95%) for the study described above were the woman’s family members which suggests that they may have intimate knowledge and an important perspective about the impact that fistula has had on their relative’s life.¹² Most informal caregivers also described living and/or staying in the same household as their patient. Broadly, informal caregivers experienced a similar socio-economic context, educational attainment, and other shared demographic characteristics including the reality that most (84%) were female. Furthermore, most informal caregivers in our study reported providing care for an average of 22.5 hours a day and described a variety of caregiving tasks across community and hospital settings. The near continuous presence with their patient and the provision of personal caretaking tasks provides a unique appraisal of persistent gaps in care across the fistula continuum and strengthens their ability to discern potentially effective strategies to support fistula patients more comprehensively.

RECOMMENDATIONS FROM CAREGIVERS

Informal caregivers were asked for their ideas about what would improve the recovery and reintegration experiences of women with female genital fistula. *Note that in this study, we have purposefully maintained informal caregiver’s use of the word “patient” to describe their care recipients.* We categorized caregiver recommendations into two primary themes according to repeated patterns that emerged across responses: 1) economic empowerment, and 2) community capacity building. Most caregivers discussed topics within both themes at different points of their narratives; quotes demonstrating various aspects of each theme appear

throughout Tables 1 and 2. Several key subthemes emerged for each primary theme. Reoccurring recommendations within economic empowerment included the provision of money, food, and drink to meet nutritional needs, and supplies such as pads or soap (Table 1). Subthemes of community capacity building included community education about fistula, increased engagement of males, improved belonging among fistula patients, and building support for holistic reintegration post-repair (Table 2). Recommendations throughout these themes were shared at a similar frequency by both female and male informal caregivers and by individuals providing care for various amounts of time.

ECONOMIC EMPOWERMENT

Recommendations for economic empowerment were primarily aimed at improving the patient’s status during and after their hospital stay. Clear subthemes emerged centering the need for provision of money, nutrition, and supplies (Table 1). Informal caregivers justified the provision of money by explaining the diversity of needs from patient to patient and by suggesting that unrestricted funds would empower her to get what she truly needs. They also specified food and beverages as well as supplies such as pads, soap, and medication to manage and mitigate the symptoms of fistula and surgical repair as more universally shared needs. For the latter two subthemes, some informal caregivers recommended the provision of cash to fistula patients while others suggested the direct provision of the resources to assist with the management of fistula symptoms. Additionally, many informal caregivers made recommendations across several of these topics.

One informal caregiver also pointed out that the fistula patient may have been the primary income-earner in the home, responsible for school fees, household rent, or medical expenses, among other costs. This informal caregiver explained that the provision of supplies including pads, food, clothing, and medication within the hospital setting benefits both the patient and her family who may otherwise experience a “standstill” as resources are diverted to cover treatment-related costs. Caregivers further hypothesized that the provision of additional resources and support

Table 2. Informal caregiver quotes illustrating recommendation sub-themes related to community capacity building to support female genital fistula patients

Community Capacity Building Subtheme	Example Quote
Fistula Education	<p><i>“The people that are aware that that illness can be cured for instance us. You may advise and tell [a patient] that there is a department in [the hospital] that deals with fistula and that it can be cured. Now, like you people working in organizations, you should go to TV stations and radios. There are some that don’t have TVs but instead have small radios while some use radios installed on their mobile phones. And to schools too because personally, I first read about Fistula in “Straight Talk” magazine and there was a picture of a girl who gave birth while under age and she acquired that illness. So school children should be sensitized that if you give birth at the wrong time, fistula is possible and besides, that is how I too got to know about it. Well though I didn’t know much about it other than just the word itself, I have now seen it with my own eyes.”</i> (Caregiving Daughter, age 22, female)</p>
Male Engagement	<p><i>“How we can support them is that when we go back home, we do not force them into sexual activities or showing her a bad attitude when she asks for something [...] It requires that, if possible, you get a day and come to educate us on how we can handle our wives.”</i> (Caregiving Husband, age 23, male)</p>
Fostering a sense of belonging	<p><i>“The other thing that can help them is encouraging them because when they come here, they realize that they are not alone in that condition. Now imagine if you came to the ward and realized that you are alone with such problem, then that causes you depression. However, if you realize that you are not alone in that condition, where one may tell you, ‘I have come here three times’ and the other tells you, ‘I have been here four times’, and you realize that it is only the first time for you, that encourages you and ponder to yourself, ‘I thought I was alone!’ In that case even the sorrow you came with vanishes.”</i> (Caregiving Sister-in-law, age 38, female)</p>
Ensuring reintegration	<p><i>“What I want to happen when my mum goes back are the people in our community that didn’t believe that she would ever heal to feel ashamed. I want them to get loss of words. I want them to see her happy and no longer regretful like she used to previously.”</i> (Caregiving Daughter, age 22, female)</p>

within the hospital setting may contribute to reduced recovery time and an earlier return to income generation. For example, the provision of accurately dosed medication prior to discharge would make repeated trips to a pharmacy unnecessary, saving both time and money.

Informal caregivers were quick to specify that typical income-generating activities involving intense manual labor would no longer be feasible for their patient. In cases where a patient would be advised not to return to her pre-fistula work upon reintegration, she may require extended provision of money, nutrition, and supplies in addition to job-training support toward new income-generating activities. One informal caregiver specifically suggested sewing lessons while another proposed entrepreneurship training toward running a vegetable stand. Several mentioned that the temporary provision of economic empowerment alongside job training for long-term support would also address the fact that many patients feel ashamed to ask for help even though they would suffer without it.

COMMUNITY CAPACITY BUILDING

Recommendations for fistula-related education included ideas aimed at prevention, stigma reduction, and reintegration (Table 2). Informal caregivers were keenly aware of building community capacity to support women before, during, and after experiencing female genital fistula. Despite having heard of fistula, caregivers described not understanding how it could be prevented until after accompanying their patient in their experience. One caregiver shared that witnessing her sister-in-law’s experience encouraged her to not begin childbearing “too early” and to seek support when she does. Informal caregivers suggested widespread educational efforts engaging television

stations, radios, and newspapers, as well as schools, to ensure community members understood common contributors to fistula including early childbearing, lack of emergency obstetric care, and sexual assault. It was further recommended that campaigns promoting the provision of surgical repair be continued to ensure all women that experience fistula know that it is treatable, and very often curable. Caregivers also went on to suggest that education campaigns be expanded to include education about reproductive health more broadly. It is possible that widespread community education about fistula causes, management, and repair would also reduce social stigma surrounding the condition.

Several informal caregivers described the need for specifically engaging their patient’s spouse and other males in the community. In these instances, their comments were aimed toward addressing harmful social stigmas that further isolate women with female genital fistula and increase risks of infidelity and/or divorce. When asked about their patient’s experiences with reintegration following repair, informal caregivers suggested that many women avoid their spouse even during recovery following a successful surgical repair for fear of being perceived as ‘damaged’ or of being rejected. On the other hand, some described an increased risk of forced sex from intimate partners, which can add risk of repair breakdown. One female informal caregiver advised her patient to spend time healing at the patient’s parents’ home as the husband “might not control himself”. A male, husband, informal caregiver recommended education “on how we can handle our wives” and suggested that many fistula patients could be helped if “we do not force them into sexual activities”. Informal caregivers admitted that targeting spouses, specifically, could be a challenge as they may

not be likely to attend treatment with the patient and instead suggested broad dissemination of education.

There was also recognition for the need to increase their patient’s sense and experience of belonging both during fistula and during reintegration, following repair. Several informal caregivers specifically described the need to help their patient understand and believe that they were “not alone”. Some specifically recommended women’s groups or community recognition of informal caregivers to ensure allyship and advocacy for patients throughout the intense experience of fistula and surgery. Several informal caregivers perceived that increased community education may positively influence belonging and reintegration following fistula by equipping family and friends with knowledge about how to provide tangible, emotional, and psychological support along with informed encouragement about the likelihood of healing. Many perceived that their patient’s experience was improved simply by knowing they were “loved”. Still one informal caregiver explained that “...our support is not enough”, underscoring the need for broader systemic and community capacity building, beyond informal caregivers, to foster a sense of belonging for women with fistula as well as for ensuring holistic treatment and reintegration.

OTHER RECOMMENDATIONS AND INSPIRATION

Less frequently, informal caregivers described the need for and perceived benefits of increased access to health care as well as community health education and services; spiritual support including prayer and engagement with elders or religious leaders; and support for informal caregivers. Of these less common recommendations, individuals that had been caregiving for a year or more exclusively highlighted the need for improved mental health care for fistula patients. Furthermore, while both male and female caregivers recommended increased access to mental health support and improved accessibility to medicines, other topics emerged within more gendered patterns. Males more frequently described the need for increased hygiene and sanitation, particularly in hospital settings, and were more likely to recommend providing education, support, and care to informal caregivers to better support their patient. Females, on the other hand, were the only informal caregivers to recommend increased spiritual support. Several female caregivers suggested that recognition and acceptance that “God is the one who heals” enabled their patient to cope and persist.

Informal caregiver recommendations were motivated by a deep desire for their patient to fully heal and return to the life they lived before experiencing fistula. One informal caregiver shared “*What I want for my sister when she heals is to continue with her education.*” Another informal caregiver echoed this hope and dreamt that community members would “get [a] loss of words” when they witnessed her patient’s full healing (Table 2). Participants recognized their caregiving role as critical to sustaining their patient through the fistula experience while casting a vision for broader social and support shifts to ensure they could fully heal and thrive.

CONCLUSIONS

The perspectives of the informal caregivers in this study align with prior acknowledgement of the need for a resourceful and sensitive response to fistula from both clinical medicine and global public health, not unlike HIV/AIDS and tuberculosis strategies.⁵ Alongside continued investigation of successful support of patients with stigmatizing physical health conditions in similar settings, our findings lead us to believe that several concurrent investments to both fistula patients and their communities would improve the experiences of women with fistula. Recommendations from informal caregivers primarily suggested community- and societal-level changes to reduce experiences of impoverishment and marginalization that are exacerbated by fistula, aligning with prior recommendations for a holistic approach across the care continuum.¹³⁻¹⁵ These findings suggest that simultaneously strengthening women’s economic status and building her community’s capacity by broadly building fistula-related awareness, knowledge, and skills, is likely to improve the livelihoods and wellbeing of both fistula patients and their informal caregivers by mitigating financial burdens and lessening isolation. While economic empowerment will require action by the Ministry of Health or other high-level actors, community capacity building is possible with initiation by key community leaders and stakeholders as well as increased involvement of male partners beginning with fistula prevention and continuing through reintegration. These findings underscore the need for multidimensional strategies that mitigate post-repair vulnerabilities while promoting human flourishing.⁹ These recommendations add to the growing evidence that a variety of sectors must collaboratively invest in fistula reintegration to meet the unique needs of women that have experienced fistula and to ensure opportunities for health and dignity.

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Ashley Mitchell: conceptualization, analysis, writing; **Hadija Nalubwama:** investigation, data curation, review & editing; **Justus K. Barageine:** investigation, supervision, project administration; **Suellen Miller:** review & editing, funding acquisition; **Abner P. Korn:** review & editing; **Josphat Byamugisha:** review & editing; **Susan Obore:** review & editing; **Alison M. El Ayadi:** conceptualization; review & editing; supervision; project administration; funding acquisition.

COMPETING INTERESTS

The authors completed the Unified Competing Interest form at <http://www.icmje.org/disclosure-of-interest/>

(available upon request from the corresponding author) and declare no conflicts of interest.

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REFERENCES

1. Adler AJ, Ronsmans C, Calvert C, Filippi V. Estimating the prevalence of obstetric fistula: a systematic review and meta-analysis. *BMC Pregnancy Childbirth*. 2013;13(1):246. doi:10.1186/1471-2393-13-246
2. Uganda Bureau of Statistics Kampala, Uganda and The DHS Program ICF. Uganda Demographic and Health Survey 2016. Published online January 2018.
3. Hotchkiss E, Nalubwama H, Miller S, et al. Social support among women with genital fistula in Uganda. *Cult Health Sex*. 2022;0(0):1-16. doi:10.1080/13691058.2022.2041098
4. Sadigh M, Nawagi F, Sadigh M. The Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda. *Ann Glob Health*. 2016;82(5):866-874. doi:10.1016/j.aogh.2016.06.005
5. UNFPA. *Obstetric Fistula & Other Forms Of Female Genital Fistula: Guiding Principles for Clinical Management and Programme Development*. UNFPA; 2021. <https://www.unfpa.org/publications/obstetric-fistula-other-forms-female-genital-fistula>
6. Donnelly K, Oliveras E, Tilahun Y, Belachew M, Asnake M. Quality of life of Ethiopian women after fistula repair: implications on rehabilitation and social reintegration policy and programming. *Cult Health Sex*. 2015;17(2):150-164. doi:10.1080/13691058.2014.964320
7. Jarvis K, Richter S, Vallianatos H, Thornton L. Reintegration of Women Post Obstetric Fistula Repair: Experience of Family Caregivers. *Glob Qual Nurs Res*. 2017;4:2333393617714927. doi:10.1177/233393617714927
8. Pope R, Bangser M, Requejo JH. Restoring dignity: social reintegration after obstetric fistula repair in Ukerewe, Tanzania. *Glob Public Health*. 2011;6(8):859-873. doi:10.1080/17441692.2010.551519
9. Delamou A, Douno M, El Ayadi AM, Diallo A, Delvaux T, de Brouwere VD. Stakeholders' perceptions on improving women's health after obstetric fistula repair: results from a qualitative study in Guinea. *Afr J Reprod Health*. 2022;26(8). Accessed November 9, 2022. <https://www.ajrh.info/index.php/ajrh/article/view/3450>
10. Changole J, Thorsen VC, Kafulafula U. “I am a person but I am not a person”: experiences of women living with obstetric fistula in the central region of Malawi. *BMC Pregnancy Childbirth*. 2017;17(1):1-13. doi:10.1186/s12884-017-1604-1
11. Widmer M, Tunçalp Ö, Torloni M, Oladapo O, Bucagu M, Gülmezoglu A. Improving care for women with obstetric fistula: new WHO recommendation on duration of bladder catheterisation after the surgical repair of a simple obstetric urinary fistula. *BJOG*. 2018;125(12):1502-1503. doi:10.1111/1471-0528.15276
12. El Ayadi AM, Mitchell A, Nalubwama H, et al. The social, economic, emotional, and physical experiences of caregivers for women with female genital fistula in Uganda: A qualitative study.
13. Delamou A. Social and Reproductive Health of Women After Obstetric Fistula Repair: Insights from Guinea. In: Drew LB, Ruder B, Schwartz DA, eds. *A Multidisciplinary Approach to Obstetric Fistula in Africa: Public Health, Anthropological, and Medical Perspectives*. Global Maternal and Child Health. Springer International Publishing; 2022:377-392. doi:10.1007/978-3-031-06314-5_27
14. El Ayadi AM, Painter CE, Delamou A, et al. Rehabilitation and reintegration programming adjunct to female genital fistula surgery: A systematic scoping review. *Int J Gynecol Obstet*. 2020;148(S1):42-58. doi:10.1002/ijgo.13039
15. Khisa AM, Nyamongo IK, Omoni GM, Spitzer RF. A grounded theory of regaining normalcy and reintegration of women with obstetric fistula in Kenya. *Reprod Health*. 2019;16(1):29. doi:10.1186/s12978-019-0692-y