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Original Research Article

Experiences of fistula survivors, a case study of Bungoma, Kilifi and Kiambu Counties, Kenya

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ABSTRACT

Background: Female genital fistula (FGF) continues being a leading cause of maternal morbidity, especially in developing countries. Mothers living in rural and marginalized areas are the most affected, worst scenario, most unaware of the condition. This study explored the living experiences of fistula survivors both pre and post-surgery, guided by the transaction model of stress and coping.
Methods: A cross-sectional study design adopted. Qualitative data collected, thirteen In-depth interviews and four Focused Group Discussions in three counties, Bungoma, Kilifi and Kiambu Counties, Kenya. These counties were purposively selected, being beneficiaries of a program aimed at ending fistula implemented by AMREF Kenya and Safaricom Foundation. All the study participants were program beneficiaries. Data was coded and thematically analysed using Nvivo.
Results: The study established that FGF survivors had a difficult lifestyle pre-treatment due to incontinence and blistering. Some thought of fistula as a usual occurrence after childbirth hence never sought any medical service. Most of the FGF had been caused by childbirth complications, most mothers reported self-isolating themselves and being stigmatized. Post-treatment, mothers reported positive support from family and community members in reintegration process and successful childbearing. Mothers reported that their dignity had been restored after surgery.
Conclusions: FGF causes mental health conditions among patients and survivors if society members neglect the reintegration process. Mothers still suffer in silence from fistula effects, need to support the treatment and reintegration processes through funding and policies that will enable create a world free of fistula, a leading cause of maternal morbidities.

Keywords: Female genital fistula (FGF), Incontinence, Childbirth, Self-isolation, Reintegration

INTRODUCTION

Female genital fistula (FGF) is a severe and debilitating medical condition characterized by an abnormal opening between the vaginal canal and either the urinary tract or rectum, leading to continuous, involuntary leakage of urine or faeces.[1] It is mostly caused by prolonged and obstructed labour without timely medical intervention, particularly in low-resource settings. Other causes include iatrogenic injuries during caesarean section, instrumental

deliveries and non-obstetric factors such as pelvic trauma, malignancy, radiation therapy, infections, and congenital anomalies.[2]

FGF disproportionately affects women in developing countries, where it remains a significant cause of maternal morbidity. In many rural communities, women are not only more susceptible to obstetric complications, due to poor access to skilled birth attendants and emergency obstetric care, but also frequently lack awareness that fistula is a treatable medical condition. In some cases, the condition is mistakenly perceived as a natural consequence of childbirth.[3-5]

The physical consequences of FGF which include chronic urinary or faecal incontinence, are compounded by psychological distress, marital disruption, economic vulnerability, and deep social stigmatization.[6,7] Survivors often face rejection from their families and communities, social isolation, loss of livelihood, and reduced participation in daily activities. These psychosocial effects can be as devastating as the physical symptoms, significantly impairing a woman's quality of life.[8,9]

Multiple factors contribute to the high burden of fistula in rural Kenya. Extrinsic factors include poor infrastructure, limited access to healthcare facilities, and inadequate capacity in existing health systems. Intrinsic socio-cultural determinants such as child marriage, female genital mutilation, gender inequality, and low educational and economic status of women also increase the risk of obstructed labour and fistula formation. Physiological vulnerabilities, including adolescent pregnancy, malnutrition, underdeveloped pelvises, and multiple or malpositioned births, further compound the problem.[10]

While the Kenyan government, alongside NGOs and international partners, has initiated efforts to provide free surgical repairs and awareness campaigns, many affected women remain untreated due to barriers such as limited awareness, geographical isolation, stigma, and lack of resources. As a result, many continue to suffer in silence.

Despite increasing attention to prevention and surgical repair, there is limited qualitative research capturing the lived experiences of women with fistula in Kenya. Understanding the social, emotional, and economic dimensions of their journeys is essential for developing comprehensive and culturally appropriate interventions. These must go beyond clinical treatment to include psychosocial support, community reintegration, and livelihood restoration.

This study addresses this critical gap by exploring the personal, social, and emotional experiences of fistula survivors in Bungoma, Kilifi, and Kiambu Counties. It aims to generate insights that can inform health policy, strengthen health systems, and support the design of holistic, survivor-centred programs that promote dignity, recovery, and resilience.

Theoretical framework

The study was informed by the Transaction Model of Stress and Coping, which helped in understanding how fistula survivors cope with stressful events and eventually become channels of change in the society after recovery. It explains that when people are confronted with stress, they evaluate the significance of a stressor as stressful, positive, controllable, challenging, or irrelevant. This prompts efforts to cope with the stressor. They assess their perceived ability to change the situation and manage their emotional reaction to the threat. This will be mediated by actual coping strategies.[11] Fistula survivors face threats to their physical well-being due to incontinence and pain, emotional and social wellbeing due to the stigma and isolation by the community members.

This model conceptualizes coping efforts along two dimensions, that is, the problem focused and emotion focused coping strategies. Problem management strategies, which are more adaptive for stressors that are changeable, are directed at changing the stressful situation. In this context, use of napping to control incontinence, going for surgery, joining support groups among others. Emotion-focused coping efforts, which are more suitable when the stressor is unchangeable, are directed at changing the way one thinks or feels about a stressful situation. In this context, self-isolation, denial, and avoidance.[12]

METHODS

Study design

The study used a cross-sectional study design utilizing qualitative data in an exploratory descriptive approach to assess the life experiences of fistula survivors both pre-and-post surgery in Bungoma, Kilifi and Kiambu Counties of Kenya. The qualitative data collection methods used were Focused Group Discussions (FGDs) and In-depth Interviews (IDI). The discussions were held in an environment that was conducive and promoted free interactions so that the women would narrate their experiences freely considering this being a sensitive area.

Study setting

Data was collected in the month of February 2025 in Bungoma, Kilifi and Kiambu Counties. Interviews were conducted in the fistula centres within the Counties. The selection of counties was guided by the fact that the three counties were the implementation sites of integrated fistula programme. Fistula camps were carried out in the three counties and a total of 236 women benefited from fistula surgeries and Psychosocial supports. Additionally, fistula centers were established in each county for sustainability purposes. In Bungoma County the following hospitals were used: Mt. Elgon Sub County Hospital and Cheptais Sub County Hospital for FGDs,

Bumula Sub County Hospital, Webuye Sub County Hospital, Naitiri Sub County Hospital, Mahonge, Lugulu Mission Hospital and Kopsiro Model Health Centre for IDIs. In Kilifi County, the following facilities were used: Malindi Sub County Hospital for FGD, Kambi Ya Waya Dispensary, Gongoni Health Centre, Mjanaheri Dispensary, Bomani dispensary and Mkaomoto Dispensary for the IDIs.

In Kiambu County the following hospitals were used: Thika Level Five Hospital for FGD, Nyathuna Level Four Hospital, Ruiru Level Four Hospital and Githunguri Health Centre for IDIs. The facilities were purposively selected, being the referral centres for fistula patients from their catchment community areas.

Study population

The target population of the study were women of reproductive age who received obstetric fistula screening and treatment from Amref Health Africa and Flying Doctors Society of Africa (FDA) operated Camps within the previous three years in Bungoma, Kilifi and Kiambu Counties. The study utilized thirteen (13) In-depth Interviews (IDIs) and four (4) Focused Group Discussions (FGDs). The total sample size was 44 fistula survivors divided proportionately to the Fistula survivor reached out by the project in the three counties. A list of fistula patients was produced by the AMREF team and the study participants randomly selected within the catchment areas. All the respondents were women above 18 years of age.

Data collection and analysis

Focus Group Discussion (FGD) and In-Depth Interview (IDI) guides were used to guide the discussions. The discussions were conducted by well-trained female research assistants under the supervision of the evaluation team, who also served as the corresponding authors. Each FGD consisted of eight (8) fistula survivors seated in a semi-circle arrangement to foster open expression, in a private and quiet setting conducive to confidentiality. The IDIs were held in private rooms, involving only the fistula survivor and the research assistant to ensure privacy and comfort.

All interviews were conducted in Swahili to accommodate participants regardless of literacy levels. All respondents were comfortable with the language used. The interview guides explored key thematic areas including coping mechanisms before corrective surgery, the treatment journey, transition after surgery, reintegration experiences, sexual and reproductive health, and persistent incontinence.

Discussions were audio-recorded to ensure accurate translation and transcription. The collected data were transcribed and translated from Swahili into English. The evaluation team, together with the project team, reviewed the transcripts and identified five major themes, which were analyzed using NVivo software. The five themes included: (1) coping mechanisms, (2) self-isolation and rejection, (3) impaired marital status and sex life, (4) support for rehabilitation, and (5) social support during the reintegration process.

RESULTS

The results section has been organized into the five thematic areas identified during data analysis, namely coping mechanisms, self-isolation and rejection, impaired marital status and sex life, support for rehabilitation and social support during the reintegration process. The sociodemographic characteristics have also been highlighted in the first section.

Participants characteristics

The average age of the participants was 47 years with most of them having their first child between 15 to 19 years. Most of them were married having had multiple deliveries with an average of 3 births. Additionally, the highest level of education completed by most of the respondents was primary level.

Coping mechanisms

The most common symptom for FGF is incontinence which is characterized by involuntary passage of urine and feaces through the vagina. The thought of the waste passing is devastating to these women and those they live with. Therefore, most survivors gave us a recap of how life was so unbearable before treatment until they resorted to alternative risky methods of hiding the waste. Sometimes they get blistered and burnt by the urine especially when they napped for a longer time without changing or taking a shower. Here is what they had to say:

"I got fistula when I delivered my second baby, he was so big and I delivered at home with the help of a traditional birth attendant (TBAs). They would insert their hands inside my birth canal trying to forcefully bring the baby out. So immediately I started experiencing urine and feaces leakage. This was in the year 1986. I tried napping myself with blankets, but it did not work rather I got seriously blistered due to the incontinence." IDI 2.

"I tried to nap myself with blankets, but the malodour was so bad I had to avoid being in spaces where people were. I bought pads to a point I exhausted money and started using blankets which I could wash and re-use." FGD 1.

"During delivery, the baby was so big so as I pushed, he tore me up. I was advised to sit while tightly holding the legs together, but it did not work I had spoilt my private

part. Every time air would pass uncontrollably. The feaces would fall in the house without notice, it became unbearable to travel due to the use of napping." FGD 2.

The situation was dire such that some women sought traditional methods of healing because they felt the health facilities were not healing their conditions. Some of the women went to traditional healers as described below:

"At some point I decided to seek assistance from a mganga (traditional healer) thinking it was a curse, I even paid him Kshs. 10,000 but never got help/cured. IDI 6.

"I got fistula from my first child, when I reached home, I would release feaces after eating, urine would just pass by, I was told that I was cursed and I just ignored." FGD 1.

Self-isolation and rejection

FGF clearly lowered the self-esteem of these women, majorly because of the fetor that would accompany the leaking urine. Most of them isolated and stigmatized themselves before even the community and family members rejected them. They reported locking themselves up in their houses and avoided all social gatherings or anywhere they would meet with other community members. Here is what they reported:

"This condition made us lose friends, because whenever we would see women sitting together, we would fear joining them due to embarrassment and the bad smell of leaking urine." FGD 1.

"We used to hide ourselves and could not socialize with people fearing a leakage would occur." IDI 11.

"*This really made me worried, and I isolated myself for three months, during this time my husband and even my biological mother abandoned me*." FGD 3.

"When I visit some of my friend's house, I would just sit outside." FGD 2.

"I was afraid of walking, going to church and joining community meetings because urine and feaces were just passing even after putting blankets." IDI 1.

"Started a business but customers ran away because of the smell." FGD 4.

"After delivery, I started experiencing the release of urine uncontrollably with bad smell, I didn't know the cause, the baby was just fine but I had incontinence, I couldn't even walk, people abused me, family put me aside." FGD 3.

Impaired marital status and sex life

Most of the women reported that their marriage life was highly affected by FGF. Some said that their husbands abandoned them and married other wives while others were made to sleep on separate beds due to the malodour. Here are some of the excerpts:

"Experiencing fistula with urine coming with feaces, I knew I would heal, I thought it was a normal thing in women after birth and that did not raise any alarm in me until my husband sent me back to my maternal home." FGD 1.

"After delivery, I got home and started having involuntary passage of urine and feaces, I went back and enquired from the doctor about the signs but the he did not know about the fistula. I had no peace in my marriage for one year." FGD 2.

"…My husband then got married to a second wife since I couldn't do anything in the house. This never affected me since what made me worried was my health and most people told me that I could not undergo operation." FGD 4.

However, despite some mothers being abandoned by their husbands they still went ahead and had more babies with them despite their conditions as narrated below:

"My husband rejected me and at some point my sexual life was affected. Sometimes he would disappear for an year. I also gave birth at home and had 6 babies at home with that condition." FGD 5.

"My husband got tired of me and got married again, I isolated myself as community members thought I would infect them. My husband still came at night because during the day people would question him why he slept with a smelling woman and so we had another baby together." IDI 12.

"My husband never understood the situation and decided to leave me and married another person which was so difficult for me ." FGD 7.

"My children, family, community discriminated against me, my husband used alternative beds even though he never divorced me." FGD 2.

Nonetheless, in a few instances, the mothers responded that their husbands did not abandon them after they got fistula. Rather they helped them walk the recovery journey and this really helped them deal with the psychological stress the condition had subjected them. This is what they said:

"The situation never affected the relationship with my husband. My husband took good care of me, and he really

understood me since this happened in our first pregnancy." IDI 9.

"The person who received the text message about the treatment camp was my husband, and he called informed me about the camp in Webuye Hospital. When I was discharged, my husband took good care of me though I would pity him for doing the house chores. After 2 months, my husband called the hospital to enquire about having sexual intercourse, but he was advised to wait for the months that had been given, and he complied. He never discriminated against me throughout the fistula journey to the extent that we have always shared our bed." FGD 1.

"My husband kept supporting me on the situation, and was really understanding me, despite him going to work he would even help me out with some work in the house." IDI 4.

Key to note, most of the women reported that having fistula did not deter them from continuing with their sexual life. Some got pregnant again and delivered pre and post surgery, though had a little fear the condition would recur especially for those who delivered after the corrective surgery.

"I added some children after my husband came back, I got twins and the situation became worse. However, after treatment I never got any other baby." IDI 5.

"I observed the 6months period before getting intimate with my husband and life continued normally until now we are okay and happy." IDI 10.

"After the six months period I was scared of being intimate with my husband and upto now we have not had sex because of the fear of developing fistula again." FGD 2.

"We still experience fear through imagining that I can give birth and the tear comes back. However, we were assured that we can comfortably give birth after two years. This treatment has helped us, we are no longer embarrassed like before." FGD 3.

Support for rehabilitation and the transition

It was quite evident from the discussions, that women in these far-to-reach rural areas had no idea that they were living with fistula. They had come to terms with the incontinence and lived a day at a time. However, they looked forward to the support given by the various partners to undergo the corrective surgery and the transition back to their families and community were smooth. Here are some of the experiences:

"I sought treatment, but nothing was done since I had no money for operation and other health services. Then I was told to leave my contacts to be linked with an organization that treated fistula for free." FGD 4.

"When I was discharged, I found my husband waiting for me at the gate and warmly welcomed me. I explained to him the post-surgery care measures like washing the wound with warm salty water which he was happy to assist in preparing the water. Whenever my urine bag got filled at night, he always helped empty it. So, I can say I had a warm welcome and they even slaughtered a chicken to welcome me." FGD 1.

"It was announced through the church that there were medical camps that were giving treatment for free. My husband was hesitant about it, he would say that I would die in the hospital. However, I went for the treatment regardless of his hesitancy together with other family members." IDI 3.

Social support during the reintegration process

Once the fistula survivors have been treated through the corrective surgery, the next crucial part is reintegrating them back to the society that had isolated and rejected them. This process is paramount for the total healing of the fistula survivors and full resumption to their day-to-day work. The study aimed at understanding how the process of being accepted back to the community and family as a healed fistula survivor was. These women had varied experiences from full embracement to a few challenges along the process. However, key to note, is that with the community being enlightened about fistula and the treatment process, most of these survivors had reintegrated well into their societies. Here are some of the reintegration experiences as narrated by the FGF survivors:

"My reintegration has been good, and I became a fistula champion to help other women in similar conditions. Most believed it had no cure but now they have changed their mindset. I can now wear bright coloured clothes unlike before when I would only wear dull clothes." FGD 2.

"Before I had no peace at home but now am good, now am a pastor preaching the word of God because this programme helped me and God saw it through as I preach the message of fistula treatment." FGD 1.

"Despite all we faced while living with fistula, I can attest after the treatment I am okay, and I am a women's leader in this region as well as a Fistula Champion." FGD 8.

DISCUSSION

This study explored the lived experiences of women with female genital fistula (FGF) across five thematic areas, shedding light on the profound psychosocial, relational, and functional disruptions caused by the condition, as

well as the transformative role of surgical repair and community reintegration support.

The coping strategies employed by women living with fistula underscore the immense physical and emotional burden of incontinence. In the absence of appropriate medical care and information, many women resorted to makeshift solutions such as using blankets and reusable materials to manage the leakage. These efforts not only failed to contain the problem but also exposed them to secondary health risks, including skin blistering and infections. Similar findings have been reported in other studies, where women living with obstetric fistula adopted desperate and often harmful methods to conceal the odour and leakage, driven by shame and a desire to maintain dignity.[13,14] Similar to previous studies in African countries, the belief that fistula was because of spiritual or cultural curses led some women to seek help from traditional healers, indicating a gap in community-level awareness about the medical causes and treatment options.[3,14,15] Other studies in low-resource settings reported that cultural interpretations and limited health literacy contribute to delays in seeking biomedical care.[16]

Social withdrawal and isolation were common among participants, often driven by the embarrassment associated with the odour of leaking urine and feces. Many women reported self-stigmatization even before experiencing overt rejection from others, suggesting internalized shame as a powerful determinant of behavior. These results mirror previous research highlighting the deep psychosocial trauma associated with fistula, where affected women feel devalued and disconnected from social life.[17] The stigma extended to family relationships, with some women experiencing neglect or abandonment by close relatives, including their own husbands and mothers. In Malawi and Sierra Leonne, some women reported that they were abandoned by their spouses when it was discovered that fistula was becoming chronic and was disrupting their sexual relationships.[18] This reflects the deeply entrenched stigma associated with conditions perceived as unclean or shameful and reinforces the importance of community-level education and support interventions to foster empathy and inclusion.

FGF had a significant impact on marital stability and sexual relationships. Most women experienced abandonment or emotional distancing from their partners, with some forced into separate sleeping arrangements or deserted altogether. Marital breakdowns have been widely reported in fistula literature, often due to the physical implications of the condition and the associated stigma.[19]

However, it is noteworthy that a minority of participants described supportive spouses who actively participated in their care and rehabilitation. In Uganda, social assistance was crucial in helping women to deal with fistula, to access fistula care and to recover from fistula.[20] These narratives provide valuable insights into the potential for family-centered support models in managing post-repair reintegration. Interestingly, many women continued to bear children while living with the condition, indicating a complex dynamic where sexual relationships persisted despite social and emotional strain. Post-repair, concerns about fistula recurrence affected resumption of sexual activity, suggesting a need for more comprehensive sexual health counseling in follow-up care.

The transition from illness to recovery was facilitated by access to corrective surgery, often through community-based campaigns or referrals from health facilities. Previous research in Uganda and Bangladesh reported that women often received information about treatment through community-based campaigns including media channels and workshops.[21,22] Women expressed gratitude for the life-changing nature of the intervention, describing it as a return to normalcy. These positive experiences highlight the critical role of surgical outreach programs in bridging the access gap in remote areas. They also underscore the importance of timely identification, referral, and subsidized care in promoting recovery. The study also reveals the emotional and practical support provided by some spouses and family members during rehabilitation, which significantly eased the transition process. However, access to information about fistula treatment was often incidental, indicating a need for more systematic awareness campaigns.

Successful reintegration post-surgery was a pivotal theme in the recovery journey. Most women reported being embraced back into their communities, often assuming leadership or advocacy roles such as fistula champions or women's group leaders. This transformation from isolation to empowerment underscores the value of community sensitization efforts accompanying treatment interventions. Previous studies have shown that social reintegration is vital not just for physical recovery, but for restoring self-worth and social identity.[23,24] However, some women still encountered misinformation and stigma, with communities speculating about the cause of their absence or associating it with unrelated conditions like HIV. These challenges highlight persistent gaps in public understanding and the need for ongoing education to complement medical treatment.

CONCLUSION

The findings from this study illustrate the multifaceted impact of FGF on women's lives, from physical suffering and emotional distress to disrupted relationships and social exclusion. Yet, the recovery journey also revealed resilience, hope, and transformation, especially when women received surgical care and community support. Comprehensive fistula programs should not only focus on medical repair but also integrate psychosocial support, family counseling, sexual health education, and community reintegration initiatives to ensure holistic healing and empowerment of affected women. These findings call for continued investment in fistula

prevention, treatment, and post-repair programs to end the suffering of women living with this preventable condition. The experiences of the women in this study are relevant to other settings with similar socioeconomic contexts, especially in low-income countries.

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