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Navigating healthcare system gaps across the obstetric fistula continuum of care: a multi-province qualitative study in Zambia

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Abstract

Background

Obstetric fistula remains a severe maternal morbidity in low-resource settings, yet limited evidence describes how women navigate symptom recognition, care-seeking, treatment, and recovery across different healthcare contexts in Zambia. This study explored women's experiences across the obstetric fistula continuum of care.

Methods

We conducted a multi-site qualitative study with 21 women from the Eastern, Luapula, and Lusaka provinces of Zambia who had lived with obstetric fistula for at least 6 months. Semi-structured interviews were conducted between December 2024 and February 2025. Data were analyzed using reflexive thematic analysis within an interpretative phenomenological framework. Empowerment Theory informed the interpretation of individual, interpersonal, and structural influences on access to care and recovery.

Results

Four themes emerged: response and coping strategies, barriers to treatment access, psychosocial impact, and priorities for improving fistula care. Although most women sought medical care after recognizing symptoms, access to treatment was delayed by referral gaps, long travel distances, financial constraints, limited specialist services, and prolonged waiting times for visiting surgical teams. Participants also described substantial psychosocial and economic consequences, including social isolation, disrupted intimate relationships, and loss of livelihoods.

Conclusions

Women with obstetric fistula in Zambia actively seek care, but geographic, financial, and health-system barriers shape their treatment trajectories. Strengthening referral pathways, expanding specialist capacity closer to affected communities, and improving frontline provider preparedness, including among nurses and midwives, may reduce treatment delays and support recovery.

Background

Obstetric fistula is a severe but largely preventable childbirth injury characterized by an abnormal communication between the genital tract and the urinary or gastrointestinal tract, resulting in continuous urinary and/or fecal incontinence (1, 2). In low- and middle-income countries, obstetric fistulas predominantly arise from prolonged obstructed labor in the absence of timely, high-quality obstetric

care. However, the contribution of iatrogenic obstetric injury has increased in recent years (3, 4). Recent estimates suggest that approximately 386,000 women aged 15–49 years are living with obstetric fistula globally, with the burden disproportionately concentrated in sub-Saharan Africa, reflecting persistent inequities in access to skilled birth attendance and emergency obstetric care (3).

Although immediate catheterization may manage selected cases, surgical repair remains the principal treatment for established fistulas to restore continence, dignity, and social functioning (5, 6). However, timely access to fistula treatment is often constrained by health-system barriers, including shortages of specialized services and skilled providers, weak referral and information systems, and financial and geographic obstacles to healthcare access (7–9). Nurses and midwives are particularly relevant to these pathways because they provide much of the frontline maternal healthcare and may influence early recognition of fistula, the provision of information, referrals to specialist services, and continuity of care (10). Consequently, many women live with prolonged incontinence and its far-reaching consequences, including social isolation, marital disruption, reduced economic participation, and psychological distress (11–13). Although qualitative studies from several sub-Saharan African countries have documented the psychosocial burden of obstetric fistula and the coping strategies women adopt (6, 10, 14, 15), fewer studies have examined how women navigate the continuum of care, from symptom recognition and care-seeking to referral, treatment, and recovery, and how health-system factors shape these experiences across diverse settings.

In Zambia, existing evidence largely derives from facility-based studies that describe clinical characteristics, surgical outcomes, and barriers to care, offering only a partial understanding of how women navigate obstetric fistula across diverse geographic and healthcare contexts, including interactions with frontline healthcare providers and referral services (16–18). However, little is known about how social and health-system factors shape women's experiences along the pathways to diagnosis, treatment, and recovery. In this study, we examined how women in Zambia interpret and navigate life with obstetric fistula across the continuum of care, from symptom recognition and care-seeking to treatment and recovery, within social and structural constraints.

Methods

Study design

This qualitative study was informed by interpretative phenomenology and analyzed using reflexive thematic analysis to explore how women with obstetric fistula in Zambia understood and navigated pathways to diagnosis, treatment, and recovery (19, 20). Additionally, the Empowerment Theory informed the study's interpretive orientation and served as a sensitizing framework for understanding how agency was exercised and constrained across individual, interpersonal, and structural contexts (21).

Study setting and participants

The study was conducted in Eastern, Luapula, and Lusaka provinces of Zambia. Eastern and Luapula provinces were selected because previous research has documented a high burden of obstetric fistula and substantial geographic barriers to specialized surgical services in these predominantly rural settings (9, 16, 22). Lusaka, Zambia's capital and a major referral center, was included to capture experiences in an urban healthcare context and to triangulate the findings.

Twenty-one women were purposively recruited to ensure variation in age, geographic location, and treatment status. Women were eligible if they were aged 18 or older, had lived with obstetric fistula for at least six months, and were able to provide informed consent.

Data collection

Data were collected between December 2024 and February 2025 through semi-structured, in-depth interviews. Participants were identified with assistance from clinical staff at Mansa Central Hospital in Luapula Province, St Francis Mission Hospital in Eastern Province, and Chilenje Level 1 Hospital in Lusaka Province, all of which provide specialized fistula care.

An interview guide, informed by the study objectives and existing literature, was developed and piloted across all three provinces to ensure clarity, cultural relevance, and contextual appropriateness. The English version of the interview guide is provided as Additional file 1. The guide explored women's experiences across the continuum of care, including symptom recognition, care-seeking pathways, barriers to diagnosis and treatment, psychosocial consequences, coping strategies, social support, and recommendations to improve fistula services.

We conducted the interviews in participants' preferred language (Bemba, Nyanja, or Chewa) with trained female research assistants who were native to the respective study regions. Additionally, the interviews took place in private settings, either at participants' homes or at health facilities, according to participants' preferences, and lasted 30–60 minutes.

The lead researcher (SM), a male Zambian fluent in all three interview languages, supervised data collection, audio-recorded the interviews with participants' consent, and documented contextual observations in reflexive field notes. His role in the study was explained to participants before the interviews. Audio recordings were transcribed verbatim and translated into English in collaboration with professional translators and research assistants. The research team, comprising the research assistants and the local and international researchers, reviewed the transcripts against the original recordings to ensure linguistic accuracy and preserve contextual meaning.

Data analysis

SM and NVP analyzed the transcripts using reflexive thematic analysis, consistent with the study's interpretative phenomenological orientation. Analysis was conducted inductively using latent coding in NVivo 14 to examine the underlying meanings in participants' narratives. Following Braun and Clarke's

six-phase framework, the analysis involved familiarization with the data, generation of initial codes, development and refinement of themes, theme review, theme definition, and reporting (23, 24).

Coding and theme development were iterative and interpretive. Related codes were grouped into candidate themes that reflected shared experiential patterns while preserving individual meaning. Emerging themes were subsequently reviewed and refined by SM, NVP, BMC, DMM, VRL, NN and LWM, in consultation with the research assistants, to strengthen analytical depth, internal coherence and conceptual distinctiveness.

SM maintained an audit trail documenting coding decisions, thematic development and reflexive considerations throughout the analytical process (25). Reflexive field notes, peer debriefing and member checking with selected participants were used to enhance the trustworthiness of the findings (26–28). The Empowerment Theory informed the interpretive phase of the analysis by facilitating examination of how agency, interpersonal relationships, and structural conditions shaped women's navigation of fistula care and recovery.

Use of artificial intelligence-assisted tools

During manuscript preparation, Grammarly Pro was used to support language editing, clarity, and organization of selected text. This tool was not used for study design, data collection, coding, data analysis, or the generation of findings. All outputs were critically reviewed and verified by the authors. No identifiable participant data, interview transcripts, or other confidential research data were entered into these tools.

Results

Participant characteristics

Twenty-one women from Eastern, Luapula, and Lusaka provinces participated in the study, representing diverse geographic, social, and treatment contexts, including women awaiting surgical repair and those who had undergone repair, with or without persistent incontinence. Participant characteristics are presented in Table 1.

Table 1
Characteristics of participants according to their province of residence in Zambia

	Eastern	Luapula	Lusaka
	N = 5 (23.8%)	***N = 12 (57.1%)***	***N = 4 (19.0%)***
Women's age group			
< 20	2 (40.0%)	0 (0.0%)	0 (0.0%)
20–34	1 (20.0%)	8 (66.7%)	0 (0.0%)
≥ 35	2 (40.0%)	4 (33.3%)	4 (100.0%)
Marital status			
Divorced	0 (0.0%)	3 (25.0%)	1 (25.0%)
Married	4 (80.0%)	7 (58.3%)	2 (50.0%)
Never married	1 (20.0%)	1 (8.3%)	0 (0.0%)
Widowed	0 (0.0%)	1 (8.3%)	1 (25.0%)
Parity level			
0	1 (20.0%)	1 (8.3%)	1 (25.0%)
1–3	1 (20.0%)	10 (83.3%)	2 (50.0%)
≥ 3	3 (60.0%)	1 (8.3%)	1 (25.0%)
Education Level			
Primary	2 (40.0%)	5 (41.7%)	3 (75.0%)
Secondary	3 (60.0%)	4 (33.3%)	1 (25.0%)
Tertiary	0 (0.0%)	3 (25.0%)	0 (0.0%)
Occupation			
Formal work	1 (20.0%)	3 (25.0%)	0 (0.0%)
Informal work	4 (80.0%)	9 (75.0%)	4 (100.0%)
Place of delivery			
Health Facility	5 (100.0%)	12 (100.0%)	3 (75.0%)
Home	0 (0.0%)	0 (0.0%)	1 (25.0%)
Fistula status			
Not repaired	1 (20.0%)	3 (25.0%)	0 (0.0%)

	Eastern	Luapula	Lusaka
	N = 5 (23.8%)	***N = 12 (57.1%)***	***N = 4 (19.0%)***
Repaired and dry	4 (80.0%)	8 (66.7%)	2 (50.0%)
Repaired but leaking	0 (0.0%)	1 (8.3%)	2 (50.0%)

Four interrelated themes described participants' experiences of living with obstetric fistula and navigating the continuum of care: (1) response and coping strategies, (2) barriers to treatment access, (3) psychosocial impact, and (4) priorities for improving fistula care. The thematic structure is summarized in Table 2. Participant quotations are attributed using anonymized identifiers that indicate the province of residence (EA = Eastern Province, LP = Luapula Province, and LS = Lusaka Province) and the participant number.

Table 2
Thematic summary of obstetric fistula experiences with participant frequency, coding references, and illustrative codes.

Main theme	Sub-theme	Participants (n) [a]	Coding references [b]	Example codes
1. **Response and coping strategies**		19	34	Seeking care from the hospital
	i. *Initial response to fistula*	10	12	Relying on the healthcare provided for guidance
				Focusing on finding medical treatment
	ii. *Coping and self-care strategies*	16	22	Acceptance and determination to find treatment
				Regular cleaning to reduce the smell and interact with others
				Personal hygiene and self-isolation to avoid shame
2. **Barriers to treatment access**		20	43	Treatment centers far off
	i. *Distance barrier*	7	7	Long distance to the fistula treatment centers
				Limited information about fistula management
	ii. *Fistula management information*	8	9	Lack of knowledge about condition severity
				Lack of information about making appointments
				False information from friends about treatment
				Delayed care due to lack of transport money
	iii. *Financial barriers*	9	12	Sanitary towels are expensive and not available nearby
				Expensive personal hygiene products

[a] *Number of individual transcripts (participants) in which a specific theme or sub-theme was identified.*

[b] *Total number of times a particular theme or sub-theme was coded across all transcripts.*

Main theme	Sub-theme	Participants (n) [a]	Coding references [b]	Example codes
	iv. *Healthcare workers' competence*	10	15	No specialist surgeon nearby
				Faced bad staff attitude
				Medical team negligence
3. **Psychosocial impact**		20	81	Stopped work due to psychological affliction
	i. *Work and livelihood*	9	9	Stopped heavy work
				Job loss due to travel for treatment far off
				Stopped business
	ii. *Mental health effects*	10	19	Worried about people's perceptions
				Sleep deprivation to control bladder
				Feeling out of control
				Lost hope due to repair failure
				Humiliated by family and friends
				Distressed due to the fistula injury and fecal leakage
				Worries about husband's desertion
	iii. *Intimacy and sexual activity*	13	15	Intimacy not a priority
				Painful and disgusting sexual intercourse
				Diminished sex drive
				Uncomfortable having sex
	iv. *Social life and interactions*	14	18	Ashamed to meet with people

[a] *Number of individual transcripts (participants) in which a specific theme or sub-theme was identified.*

[b] *Total number of times a particular theme or sub-theme was coded across all transcripts.*

Main theme	Sub-theme	Participants (n) [a]	Coding references [b]	Example codes
				Self-seclusion for fear of stigma
				Discreet to avoid ridicule
				Self-isolation to avoid public ridicule
	v. *Family and friends support*	14	20	Ridiculed and not helped
				Received transport money contributions
				No family support
				Encouraged by churchmates
				Endured derogatory comments
4. **Priorities for improving fistula care**		11	14	Increase the number of fistula repair specialist surgeons
	i. *Recommendations for improved fistula treatment*	11	14	Improved staff attitude
				Improved information and communication
				Improve and scale up healthcare infrastructure.

[a] *Number of individual transcripts (participants) in which a specific theme or sub-theme was identified.*

[b] *Total number of times a particular theme or sub-theme was coded across all transcripts.*

Response and coping strategies

Most participants described recognizing urinary or fecal leakage as a serious health problem and seeking medical attention soon after symptom onset. Women recounted attending health facilities, following referral instructions, and traveling to specialized treatment centers.

"I immediately rushed to the clinic, where they advised me to go back after two days. I went back there after two days had passed. The nurses advised me to go to Chilenje Hospital in Lusaka, where a specialized doctor could assist me." (EA_04)

In addition to seeking medical care, participants described several strategies for managing incontinence in their daily lives, including maintaining personal hygiene, using sanitary products, and modifying their social interactions.

"I used to wear clean pads to avoid the urine smell, including when friends and relatives visited me. I also did this to make sure that my husband was not bothered." (EA_04)

Participants also described adjusting their routines and relying on personal resilience while waiting for treatment.

Barriers to treatment access

Participants reported several challenges in accessing treatment, including inadequate referral information, limited availability of specialized services, and variable interactions with frontline healthcare providers.

"The nurse I met at the health facility rudely turned me away without examining me or providing me with helpful information about where I should go to seek help." (LP_03)

Furthermore, participants from the Eastern and Luapula provinces frequently described traveling long distances to access specialized surgical services and facing financial constraints due to transport costs as major barriers they experienced.

"The challenge was that I had to travel a long distance to seek medical treatment." (LP_01)

In contrast, some participants from Lusaka described shorter travel distances and easier access to referral facilities.

"Here in Lusaka, I was able to reach the hospital without much difficulty. I just went there when I was referred." (LS_04)

In addition to transport-related challenges, participants from Eastern and Luapula provinces described prolonged waiting periods at provincial referral hospitals for specialist surgical teams visiting from Lusaka. Women recounted traveling from their villages to treatment centers, only to remain on waiting lists until the next repair camp was organized.

"When I arrived at the hospital, they told me that the doctors who perform the operation had not yet come from Lusaka, so I had to wait for the next camp." (LP_12)

"I traveled from my village to St. Francis Hospital, but I was informed that I would have to wait because the specialist team only comes during certain periods." (EA_09)

Some participants described the financial and social challenges associated with repeated travel between their homes and referral hospitals while awaiting surgery.

Additionally, some participants described the costs of managing symptoms while awaiting treatment, including expenses for soap and sanitary products.

"Even for sanitary towels and soap for bathing and laundry, I had to ask others to help because I could not work for money in that condition." (EA_03)

Psychosocial impact

Participants described psychological distress, changes in social relationships, and disruptions to their livelihoods following the onset of obstetric fistula. Several women reported leaving employment or reducing their participation in economic activities.

"I lost my job because of absenteeism for fear of smelling urine at work. I was mentally devastated." (LP_11)

Women also recounted experiences of social rejection, feelings of sadness, and changes in how they perceived themselves.

"I felt like a shadow of the woman I once was. I had the urine odor everywhere I went, and my relatives turned away from me as if I were cursed." (EA_01)

Many participants also described avoiding social gatherings and limiting interactions with others due to concerns about urinary odor and public embarrassment.

"I do not socialize because of fear of being humiliated due to the urine odor, so I stay home." (LP_10)

Participants further reported changes in intimate relationships, including separation, divorce, and reduced sexual activity.

"My husband divorced me and moved in with another woman because he could not cope with the urine odor caused by my fistula condition." (LS_01)

Priorities for improving fistula care

Participants identified several areas for improving fistula care, including increasing the availability of specialized services, reducing travel distances, and strengthening referral systems.

"I would appeal to the government to construct more hospitals in far-flung places so that people do not have to travel long distances for delivery or to undergo surgery when they have fistulas." (LP_08)

Participants also emphasized the need for frontline healthcare providers, particularly nurses, to have basic knowledge of fistula and available referral and treatment services.

"I would ask that all the nurses and other clinical healthcare providers should have basic information about fistula, such as where to get help." (LP_11)

The recommendations focused on the availability of specialized services, healthcare provider capacity, and access to information.

Discussion

This study examined how women living with obstetric fistula in Zambia navigated healthcare gaps across the continuum of care, from symptom recognition to treatment and recovery. Women reported seeking medical attention soon after recognizing urinary or fecal leakage and using various strategies to manage the physical and social consequences of incontinence while awaiting treatment. Despite these efforts, participants faced multiple barriers to accessing specialized care, including inadequate referral guidance, dismissive interactions with healthcare providers, long travel distances, financial constraints, and prolonged waiting times for specialist surgical teams. Women also described substantial psychosocial and economic consequences, including social isolation, disrupted intimate relationships, loss of livelihood, and emotional distress. Finally, participants identified decentralized services, improved referral pathways, and better-trained healthcare providers as priorities for improving fistula care.

Our findings suggest that delays in fistula treatment cannot be explained solely by delayed care-seeking by affected women (7, 29, 30). Most participants in our study reported seeking healthcare soon after recognizing symptoms and adhering to referral recommendations, even when this required repeated travel and substantial financial sacrifice. Women also described adopting self-directed strategies, including intensive hygiene practices and selective social withdrawal, to preserve dignity and social participation while living with the condition. These findings extend previous research documenting the social consequences of obstetric fistula in sub-Saharan Africa by showing how women actively navigate treatment pathways within constrained healthcare systems (6, 14, 15).

Participants' narratives highlighted multiple barriers across the continuum of care. In addition to geographic distance and transport costs, women described inadequate referral guidance, negative encounters with healthcare providers, and prolonged waiting periods to see specialist surgical teams. While similar barriers have been reported in other low-resource settings (7, 30, 31), our findings provide further insight into how gaps in provider communication, referral coordination, and service distribution shape treatment trajectories even after women engage with the healthcare system. The comparatively easier access reported by participants in Lusaka further illustrates the influence of geographic proximity to specialized services.

Nurses and midwives may be particularly important in addressing these gaps because they provide frontline maternal healthcare and contribute to fistula recognition, referral, treatment support, and continuity of care (32–34). In our study, participants described contrasting experiences: some received appropriate referral advice from nurses, whereas others reported being turned away without adequate assessment or information. Participants themselves identified basic knowledge of fistula among nurses and other frontline providers as a priority for improving care. Evidence from other sub-Saharan African settings similarly identifies provider knowledge, training, and health-system capacity as important

components of fistula prevention and care (32–34). Strengthening competencies in fistula recognition, respectful communication, initial counseling, and referral may therefore reduce missed opportunities for timely specialist assessment, particularly where fistula surgery remains concentrated at referral facilities.

Consistent with previous studies from sub-Saharan Africa, women described profound psychosocial and economic consequences, including social isolation, stigma, marital disruption, and loss of livelihoods (5, 10, 14, 15). Many participants linked these experiences to prolonged, untreated incontinence, during which they were unable to maintain employment, participate in community life, or sustain intimate relationships. These findings reinforce the need to integrate psychosocial support and social reintegration interventions into fistula care alongside surgical treatment to address the condition's broader social and economic consequences (35–37). Within multidisciplinary fistula services, nurses and midwives may also contribute to continuity of supportive care by identifying psychosocial concerns, providing appropriate information and facilitating referral for additional support where required.

Participants' recommendations focused on expanding access to specialized services, strengthening referral pathways, and improving healthcare providers' preparedness. These priorities have direct implications for nursing and midwifery practice at the primary and secondary levels, particularly in symptom recognition, accurate referral information, respectful communication, and continuity of care. However, improving frontline provider capacity should complement, not replace, investment in specialist surgical services, functioning referral systems, and decentralized fistula care. Together, these measures may reduce barriers to timely treatment in Zambia and similar settings.

Strengths and limitations

This study provides in-depth insights into women's experiences of obstetric fistula across multiple geographic and healthcare contexts in Zambia. By including participants from both rural and urban provinces and capturing experiences at different stages of treatment, the study offers a nuanced understanding of how women navigate care pathways within structurally constrained healthcare systems. Furthermore, the use of interpretative phenomenology, reflexive thematic analysis, and an empowerment lens facilitated an examination of both individual experiences and the broader structural conditions that influence access to care.

Several limitations should be considered. First, the study did not include the perspectives of healthcare providers, including nurses and midwives, or those of spouses and relatives; these perspectives could have provided additional insight into referral processes, provider preparedness, and opportunities for improving fistula care. Accordingly, the nursing and midwifery implications identified here reflect women's experiences of care and should be complemented by research directly examining frontline providers' perspectives and practices. Second, women from other provinces and those living with fistula outside formal healthcare systems were not represented, and their experiences may differ. Future

research that incorporates multiple stakeholder perspectives and broader geographic representation could deepen understanding of fistula care pathways in Zambia.

Conclusion

Women with obstetric fistula in Zambia actively sought care, but geographic, financial, and health-system barriers delayed access to specialist treatment and hindered recovery. Strengthening referral pathways, expanding specialist fistula capacity closer to affected communities, and improving the preparedness of nurses, midwives, and other frontline healthcare providers in fistula recognition, referral, and respectful care may improve timely access to treatment. These measures should be accompanied by psychosocial support throughout treatment and recovery. Future research should examine approaches to decentralizing fistula services and strengthening continuity of care in Zambia and comparable settings.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the ERES Converge Institutional Review Board, Zambia (Ref. No. 2024-Jul-011), and the Ethics Committee of the Medical Faculty of Heidelberg University, Germany (Ref. No. S-683/2024). All participants provided written informed consent before participation, including consent for audio recording. The study was conducted in accordance with the Declaration of Helsinki.

Consent for publication

The manuscript includes anonymized participant quotations and contains no identifiable personal information. Participants provided informed consent for the use of anonymized data and quotations in research publications.

Competing interests

The authors declare that they have no competing interests.

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Author Contribution

SM conceptualized the study, led data collection and formal analysis, and prepared the original manuscript draft. BMC, NVP, NN, DMM, VRL, and LWM contributed to the study methodology and critically reviewed and edited the data-collection tools and the manuscript. All authors contributed to the interpretation of the findings, provided substantial intellectual input, and read and approved the final manuscript.

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Data Availability

The qualitative data generated and analyzed in the current study are not publicly available because they contain sensitive information, and sharing them publicly could compromise participant confidentiality. Data may be available from the corresponding author upon reasonable request, subject to applicable ethical and data-protection requirements.

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