

“I AM A SLAVE.” EXPERIENCES OF WOMEN LIVING WITH OBSTETRIC FISTULA IN MALAWI

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Presentation outline

- Background
- Objective
- Methods
- Findings
- Discussion
- Conclusion



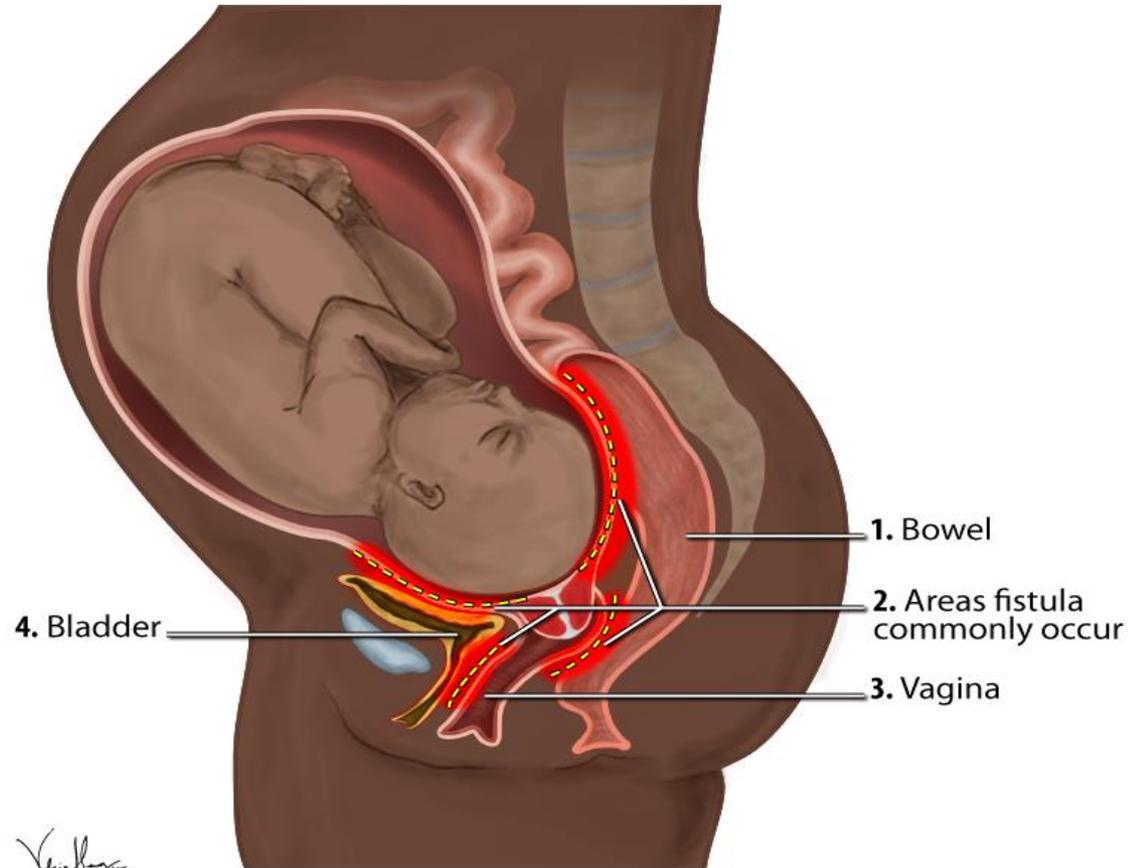
“I am more of a slave to this condition. Imagine, when I spend a night at a funeral, I stay awake the whole night, outside the house, while my friends are sleeping inside. ... I fear that my mat could get wet while I am a sleep, and people will laugh at me saying, “That woman urinated on her mat.” ...”

[Nabiyeni, 12 years living with fistula]

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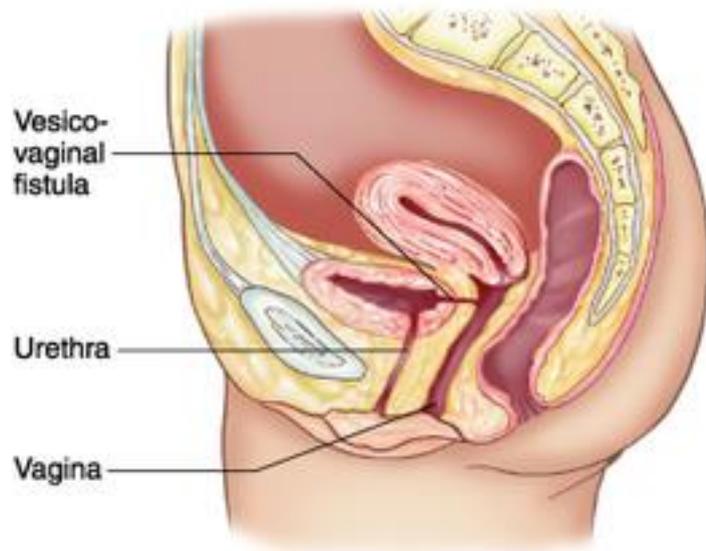


BACKGROUND : HOW IT COMES ABOUT

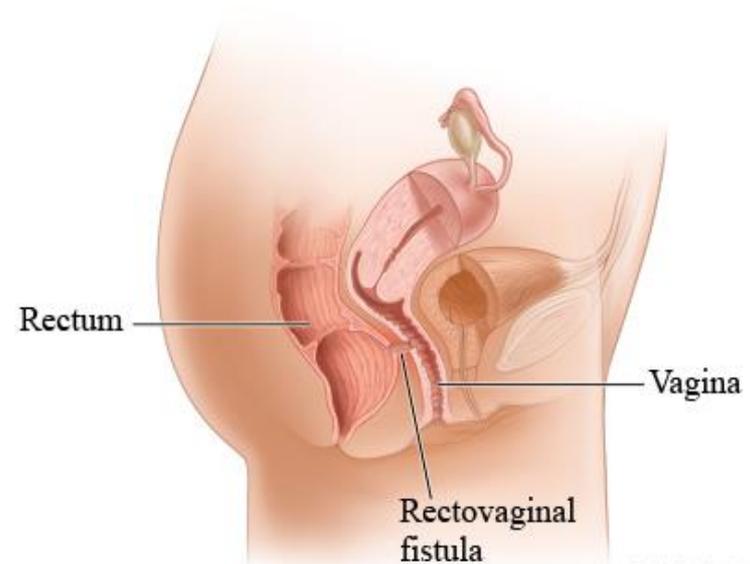


CLASSIFICATIONS OF OBSTETRIC FISTULA

Vesico-vaginal fistula



Recto-vaginal fistula



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BACKGROUND CONT'D

- Over 2 million currently suffering with the condition in SSA and South Asia [WHO 2018]
- Affects 50000 to 100000 women every year [WHO 2018]
- In Malawi approximately 20000 women affected
- Obstetric fistula is preventable through accessible emergency obstetric care, especially C/S [WHO 2018]



BACKGROUND CONT'D

- Unfortunately, in developing countries like Malawi such services are not readily available leading to prolonged obstructed labor and obstetric fistula
- Fistula has many consequences on the affected woman
- Physical: wetness, vulva sores and blisters, foot drop
- Psychosocial: social isolation, divorce, stigma



BACKGROUND CONT'D

- Lack of surgeons with technical skills to repair fistula lead to prolonged suffering with condition
- There are limited studies on experiences of women living with fistula in Malawi necessitating this study



OBJECTIVE

- To gain a deeper understanding of lived experiences of women with obstetric fistula in Malawi
- To help inform interventions that could help improve the quality of life for the affected women and prevent new fistulas



METHODS

Setting

Country : Malawi

Population: 17 Million

Bwaila Fistula Care

Centre, Lilongwe



METHODS CONT'D

- ❖ **Design:** Qualitative conducted between June 2015 and September 2016
- ❖ **Sampling:** Purposive and snow ball sampling
- ❖ **Participants:** women with fistula, family members, KI, community members
- ❖ **Data collection:** In-depth interviews and FGDs
- ❖ **Data analysis:** Thematic analysis



ETHICAL CONSIDERATION

- Approved by the College of Medicine Research Ethics Committee(COMREC) of the University of Malawi, and registered with the Norwegian Centre for Research Data .



THEORETICAL FRAMEWORKS

- The three delays (Thaddeus and Maine 1994)
- Stigmatization (Goffman 1963)



FINDINGS

- Findings in this presentation is a summary of three published papers:
- “I am a person but I am not a person”: experiences of women living with obstetric fistula in Malawi **published in BMC Journal Pregnancy and Childbirth**
- "Community perceptions of obstetric fistula in Malawi" **published in the Journal of Culture, Health ,and Sexuality**
- A road to obstetric fistula in malawi: capturing women's perspectives through a framework of three delays **published in the International Journal of Women's Health**



FINDINGS

- Characteristics of women with fistula who participated in the study



FINDINGS

Table 1 Characteristics of women with fistula (n=25)

Age range (years)	16-67 (mean=38)
Years with fistula (range)	3 months- 47 years
Single	2
Married	14
Divorced	5
Widowed	4
ANC	
Attended	21
None	4
First pregnancy	8
Subsequent pregnancy	17
Days in labor (range)	1-5
Hospital deliveries	19
Home deliveries	6
Labor outcome	
Live baby	2
Stillborn	23



FINDINGS OF THEMATIC ANALYSIS

Three main themes

- Awareness, knowledge and perceptions about fistula
- Experiences of labour and delivery leading to fistula
- Physical, social, and psychological consequences of fistula



FINDINGS CONT'D

Awareness, knowledge and perceptions about fistula

- Participants, family, and community members were generally aware of women with a condition of leaking urine and or feces, but had limited understanding of how the condition comes about.
- ✓ Misconceptions about cause of fistula
- ✓ Caesarean section, witchcraft
- ✓ Sexually transmitted diseases
- ✓ Laziness to push baby out



FINDINGS CONT'D

Experiences of labour and delivery leading to fistula

- All participants encountered barriers in accessing emergency obstetric care, in a form of delays.
- Most participants (16) experienced two delays
- None of the participants experienced all three delays
- Mothers in-law made most of the decisions about place of delivery, mostly chose TBAs.



CONSEQUENCES OF OBSTETRIC FISTULA

Disrupted life styles

- Participants expressed living lives which were physically, socially, psychologically, and economically disrupted by the continuous leakage of urine and or feces, and the odor

- **Physical consequences**

Participants mentioned of changing their daily routines to accomodate the disruptions from their condition. Their daily lives were marked by washing, bathing, and changing



PHYSICAL CONSEQUENCES OF FISTULA

CONT'D

- Painful blisters and sores on genitalia and inner thighs, causing difficulties in movement
- Nadzimbiri, 21 years with fistula, explained: *“I feel itchy a lot, and painful sores develop down here (private parts). I pour water on them to reduce pain. But when there is no water, I just scratch and scratch until blood comes out, and that means more fire of sores. Iii ! hm, my friend, it is very pathetic”*



FINDINGS CONT'D

Psychosocial consequences of fistula

- Participants reported different experiences of stigma
 - ✓ Anticipated stigma
 - ✓ Internalized stigma
 - ✓ Enacted stigma



FINDINGS CONT'D

Experience of anticipated stigma

- Participants expressed **fear of involuntary** disclosure of their condition, and **disapproval, humiliation,** and **embarrassment,** so they resorted to keeping it secret
- So they isolated themselves and avoided social and religious gatherings, and other public places



FINDINGS CONT'D

- *“I ask myself, “if I go to the wedding and my clothes become wet with urine, are they not going to laugh at me?” So I just stay home.”*

[Naphiri, 12 years living with fistula]

- *“I feel embarrassed, ... “What if I go to church and I get wet there, what stories will I leave behind? Will I not be exposing myself?” So, I just stay home.”*

[Nashawa, 36 years living with fistula]



FINDINGS CONT'D

Experience of internalized stigma

- Some participants internalized the negative attitudes from others and developed negative perceptions about themselves, leading to **loss of self-identity/ feelings of worthlessness/loss of confidence**



FINDINGS CONT'D

“I was a person before[fistula], but now, even children spit when they see me. It is so, worrisome.”

[Nabanda, 4 years living with fistula]

“When my husband deserted me and married another woman, I never wanted to get married again, because I knew that, ‘I am a damaged person’.”

[Nambewe, 41 years with fistula]



FINDINGS CONT'D

Grief and anger

- Women expressed grief over the loss of control over their bodily functions and the loss of their babies
- *“Why does it have to be me? What is it with me? Are labour pains not the same? Girls younger than me, have given birth to three or four children, without any problem, but no, not me. Does God favour others with different kinds of labour pains?” It pains me a lot.”*
- [Naphiri, 27 years living with fistula]



FINDINGS CONT'D

Worry and sadness

- Most women felt sad and worried about their condition

“ I worry all the time and I cry. I am not at peace at all. In this world, people are living well, but not me.”

[Nabengo, 19 years living with fistula]



FINDINGS CONT'D

Suicidal thoughts

Two participants once thought of ending their lives due to their condition

- *“I thought, “I must just die, how can I be staying with urine all the time, how will I be living?” that is what came into my mind.”*

[Nasiketi, 4 months living with fistula]



FINDINGS CONT'D

Experiences of enacted stigma.

- Abandonment by spouse
- Five women were abandoned by their husbands due to fistula
- Two participants experienced verbal insults

Nankhoma 15 years with fistula reported being told,

- *“Go away from there, **water pool**”.*



DISCUSSION AND CONCLUSION

- Delays contributed a great deal to fistula formation among our study participant
- Waiting homes, improved referral systems, and increased accessibility to facilities may help reduce delays
- Prompt treatment of women with fistula may reduce suffering and minimize stigma
- Findings of this study add to existing knowledge.
- Transferable to settings similar to our study setting



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Thank you!

