SILENT SUFFERING: CHALLENGES SURROUNDING FISTULA EXPERIENCE AND CARE

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4th March 2016
What is obstetric fistula?

• Maternal morbidity most often caused by obstructed labor that results in a hole between the vagina and bladder and/or rectum through which urine and/or feces leak.

• Women who suffer from fistula, usually lose their baby due to the prolonged obstructed labor; this is considered to be a double burden of obstetric fistula and stillbirth.

• Unrepaired fistula leads to a life of ostracism, stigma, and shame.

• Estimated 2 to 3.5 million women currently live with unrepaired fistula.
Global Fistula Map

This map displays 2013 data submitted by health facilities that provide obstetric fistula repair. Learn more about the Global Fistula Map Survey.

- Total Fistula Surgeries (2013)
  - 156 facilities reporting
  - 15,175 fistula surgeries
  - 42 countries

- Breakdown of fistula surgeries:
  - Up to 25: 26%
  - 26 - 50: 31%
  - 51 - 100: 16%
  - 101 - 200: 15%
  - More than 200: 12%
Implementation research process

1. Systematic literature review to identify barriers
2. Formative research
3. Development of evidence-informed research and intervention strategy
4. Baseline data collection
5. Planning and mobilizing stakeholders
6. Intervention implementation
7. Concurrent and end-line data collection
8. Writing, dissemination, formal feedback

Concurrent data analysis and feedback between evaluators and implementers
In your group, discuss and write out:

1. **Barriers** to Fistula care
2. **Enablers** to getting care
3. **Interventions/Solutions** to increase access to care

Meet Almaz,

Almaz is 15 years old and has been married for one year. She is about nine months pregnant...
Three Delays Model to Fistula Treatment

Factors Affecting Utilization and Outcome

Delay

Delay I: Deciding to seek Care

Delay II: Identifying and Reaching Medical Facility

Delay III: Receiving adequate and appropriate Treatment

Political

Psychosocial
Cultural
Awareness
Social

Financial
Transportation

Facility shortages
Quality of Care

*Adapted from Thaddeus and Maine (1994)
Psychosocial

**Barriers**
- Loss of dignity,
- Depression
- Anxiety

**Enablers**
- Feeling loved and cared for

Cultural

**Barriers**
- Gendered households
- Restricted female mobility
- Early marriage and/or pregnancy

**Enablers**
- Community responsibility
- Husband support

“She suffered isolation since she could not socialize, she was so depressed that at times she could plan to throw herself to a nearby well.”

“They (sisters) are the ones who decide what happens in our family...they will tell you that if you disturb their brother, they will make life miserable for you because he is the bread winner...you can’t really do much.”
### Awareness

**Barriers**
- Insufficient knowledge
- Misconceptions including belief in witchcraft

**Enablers**
- Community education
- Use of communication channels (radio, churches, VHTs)

### Social

**Barriers**
- Isolation and stigma
- Negative spousal, familial, and community responses

**Enablers**
- Spousal and familial support
- Encourage participation in social activity

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“I think it’s a projection from the witches kingdom because why will this happen to me considering the fact that this is my first pregnancy?”

“My husband hates me so much since this problem started. He said all I want is for him to be spending. My husband was not supportive at all. In fact I am like a widow...he banned me from entering his provision store. He has married another wife who enters there with him.”
Financial

**Barriers**
- Lack/loss of job due to condition
- Poverty

**Enablers**
- Mobilization of funds for various stages of care access (savings, loans, wages)
- Free care

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“It was just the lack of money that hindered me from seeking care for eight years, we were looking for traditional treatment because of lack of money to come here....yes no money to come here. My husband hadn’t, and his father hadn’t, my father had to sell some things for us to come here.”
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Transportation

**Barriers**
- Distance to care center
- Cost of transport
- Discomfort during transport

**Enablers**
- Transport refunds
- Outreach vans/taxis/ambulances
- Family/community facilitated

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“...some lack means of transport to reach there [treatment centers]. Some getting vehicles is hard, roads are impassable and may be costs are very high. It depends on where the patients stay because some live deep in villages.”
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Policy and political environment

Barriers
• Health systems
• Provider incentive and education structures
• Young people lack access

Enablers
• Support OF interventions
• Incorporate OF into other relevant policy areas
• Women’s empowerment

“Some health workers who misbehave towards women should be punished.... let government put laws that will help the patients to enjoy the services and also the practitioners to do their worker faithfully.”
Barriers to fistula repair

Intervention target areas:
- Psychosocial Awareness
- Social Cultural Awareness
- Transportation Financial
- Awareness Financial Cultural Social Transportation

Political environment:
- Referral: paid care
- Referral: free care
- OF camps: free care
- Facility shortages Quality of Care
Some key interventions

• Community and provider awareness
• Financial support for transport
• Social support/counseling
Fistula Care *Plus* Intervention Design

- **Objective:**
  To reduce awareness, social, financial, and transportation barriers to accessing fistula repair in Nigeria and Uganda

- **Targeted intervention design**
  - Population/community
  - Health centers
  - Contextually operationalized

- **Mixed methods evaluation**
Our planned interventions:

• Population/community
  – Referral system
  – Screening tool and payment mechanism

• Health center
  – Referral system, increased knowledge of health providers, and vouchers
  – Train providers to counsel, refer, and ensure patient well-being post operation
Summary

• Obstetric fistula is a concern in low- and middle-income countries and represents a silent suffering of poor women

• Barriers to, and enablers of, care in 9 generalized types

• Integrated approach needed

• FC+ consortium implementation research underway
Questions??