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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



HIDE ▼

▼ Fistula Care Facilities

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

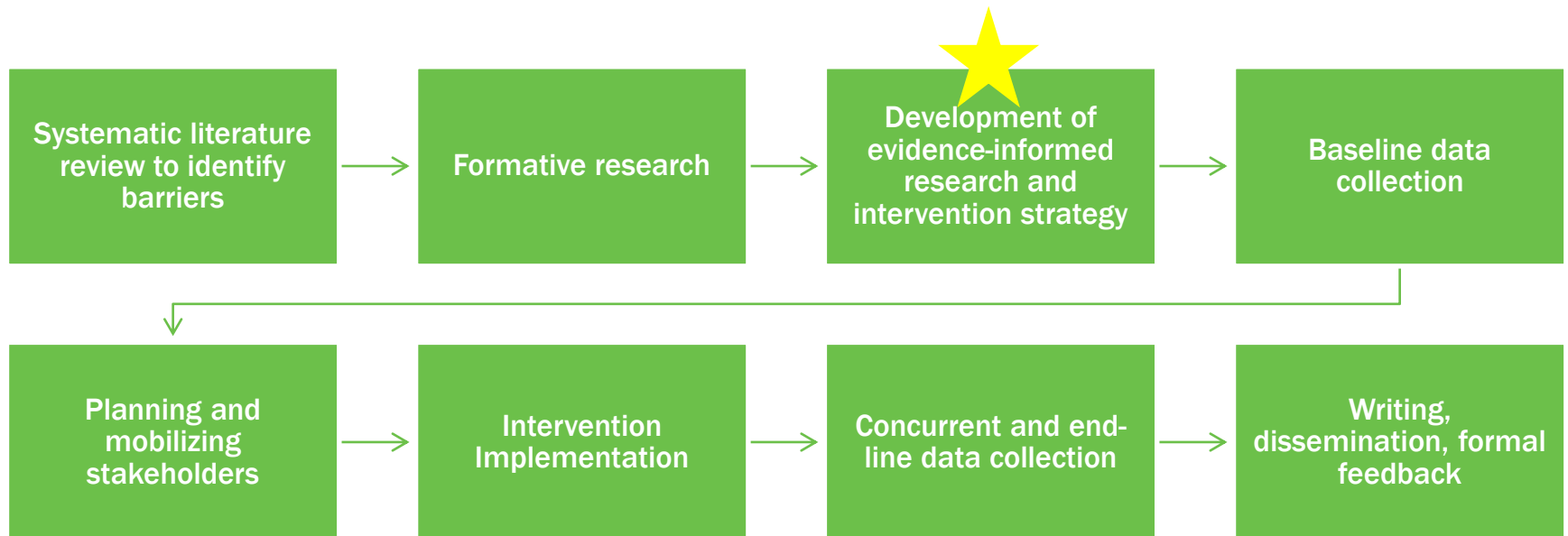
Total Fistula Surgeries ▼

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



- Up to 25 fistula surgeries
- 26 - 50 fistula surgeries
- 51 - 100 fistula surgeries
- 101 - 200 fistula surgeries
- More than 200 fistula surgeries

Implementation research process



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**

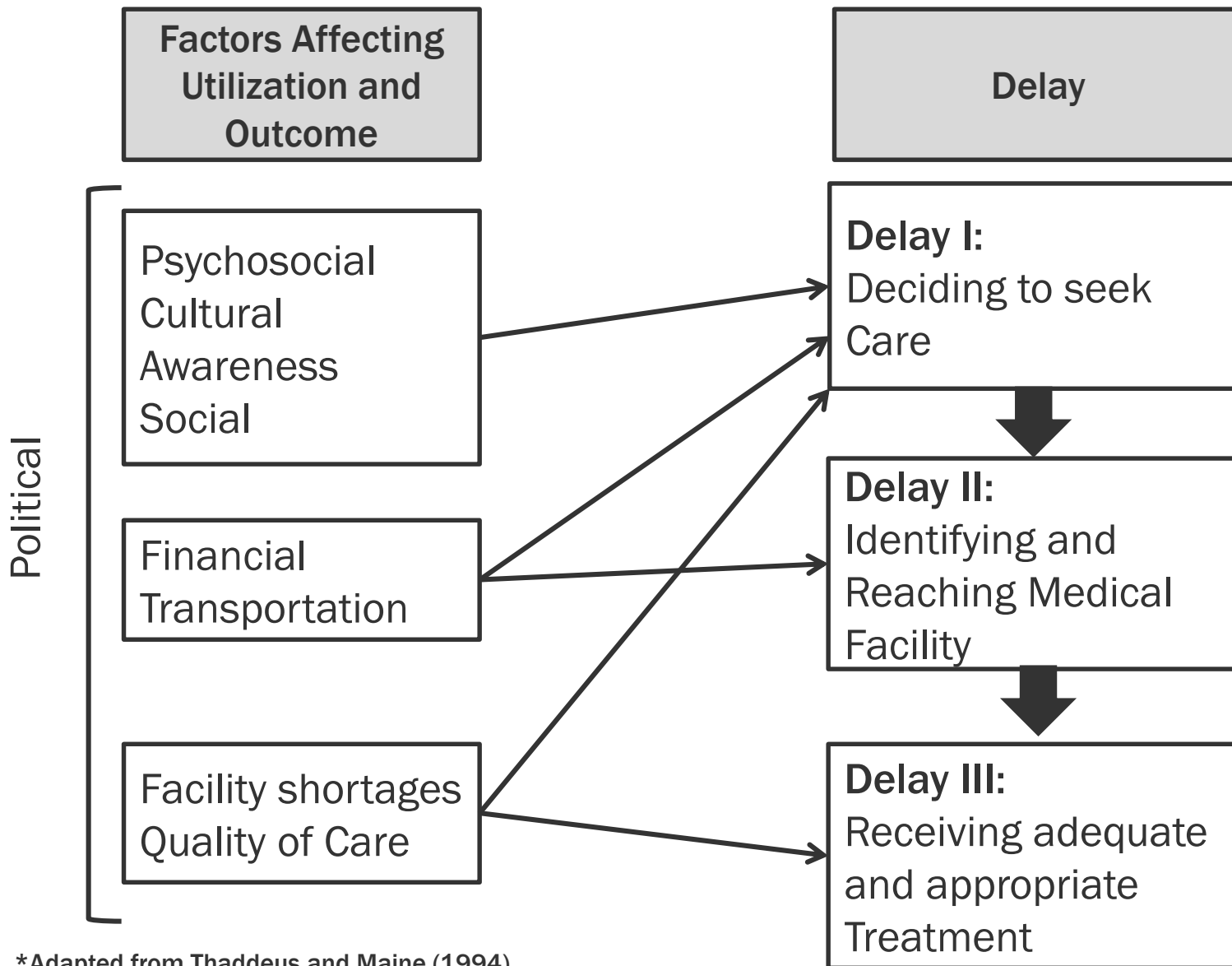


Meet Almaz,

Almaz is 15 years old and has been married for one year. She is about nine months pregnant...



Three Delays Model to Fistula Treatment



*Adapted from Thaddeus and Maine (1994)

Psychosocial

Barriers

- Loss of dignity,
- Depression
- Anxiety

Enablers

- Feeling loved and cared for

“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.”

Cultural

Barriers

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

Enablers

- Community responsibility
- Husband support

“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)

“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?”

Social

Barriers

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

Enablers

- Spousal and familial support
- Encourage participation in social activity

“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

“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.”

Transportation

Barriers

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

Enablers

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

“...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.”

Policy and political environment

Barriers

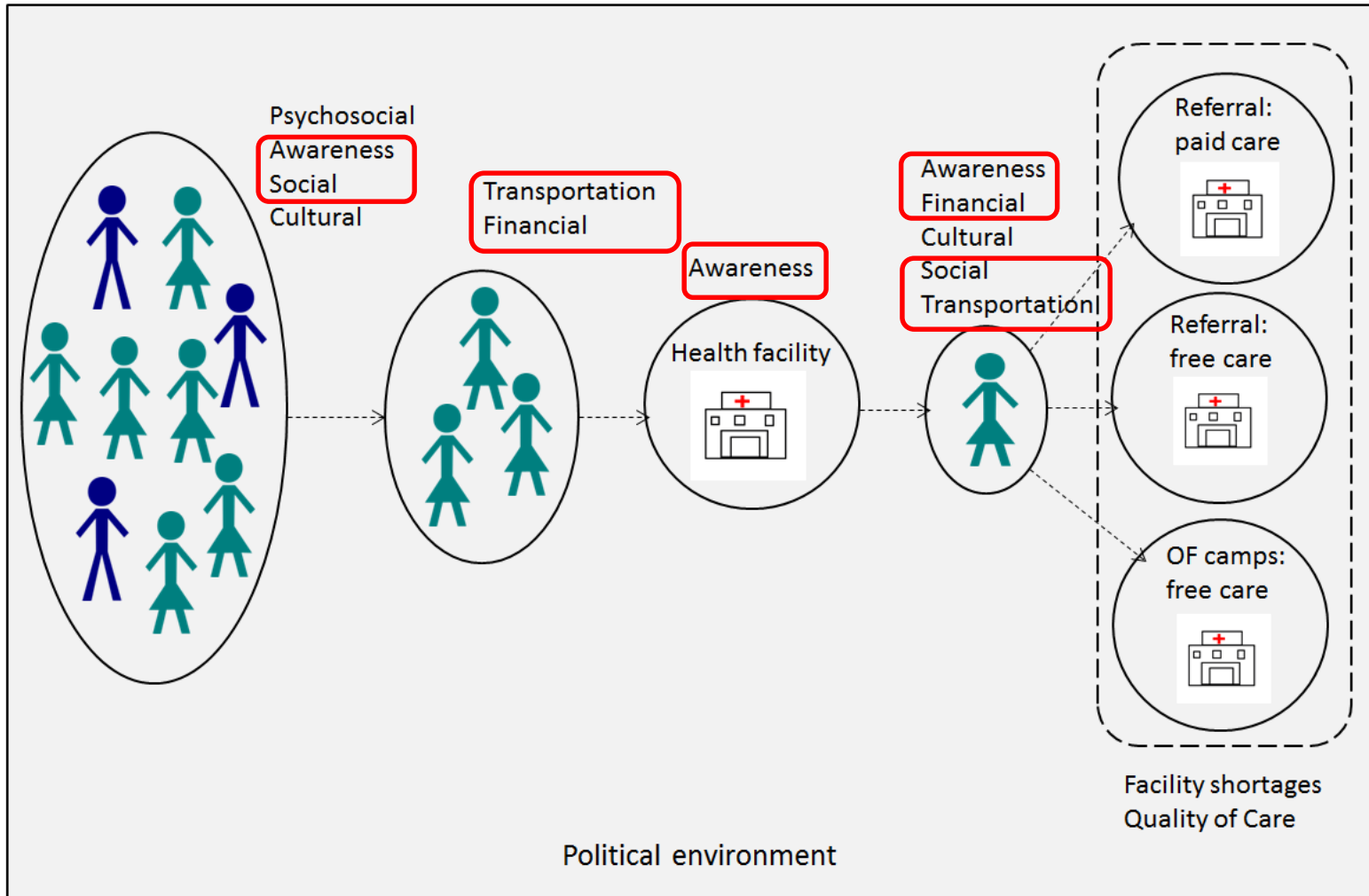
- Health systems
- Provider incentive and education structures
- Young people lack access

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 first target repairs



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??