

Empowering women by promoting direct access to obstetric fistula information and services

Vandana Tripathi | November 14, 2016



What is genital fistula?

- A genital fistula is an abnormal opening in the female genital tract that causes uncontrollable, constant leakage of urine and/or feces
- Fistula can be obstetric, iatrogenic, traumatic, or due to other causes

Fistula Care *Plus* overview

Goal: To strengthen health system capacity for fistula prevention, detection, treatment, and reintegration in priority countries

Timeframe: 2013-2018

Funding: USAID

Countries: Bangladesh, Democratic Republic of Congo, Niger, Nigeria, Togo, Uganda



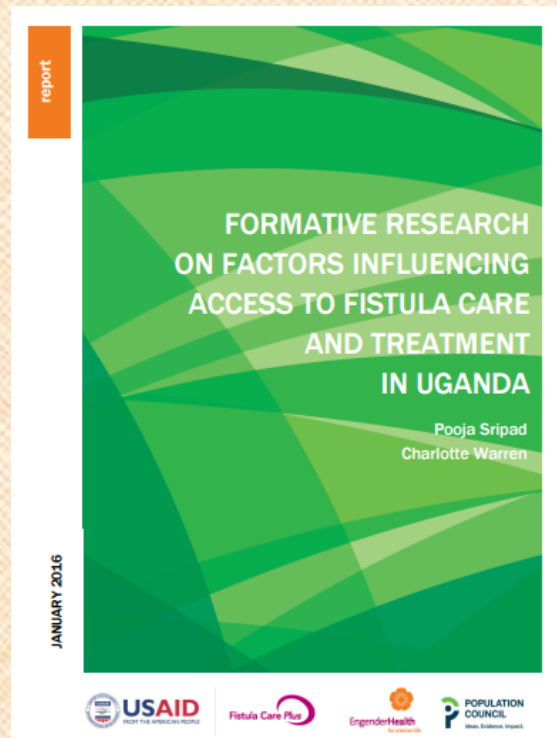
Objective 3: Reduced transportation, communications, and financial barriers to accessing preventive care, detection, treatment, and reintegration support

Problem

- We believe there are women with fistula who have not yet reached fistula services and are not well-served by current outreach and/or service delivery models
 - Comparing estimates of fistula burden (e.g., modeling, surveys) with number of women served annually at fistula treatment sites
- Questions:
 - Who and where are these unserved women?
 - What barriers do they face in seeking, reaching, and receiving fistula care?
 - What interventions, enablers, and/or supports would address these barriers?
 - Many assumptions, theories, beliefs – little evidence

FC+ research partnership with Population Council

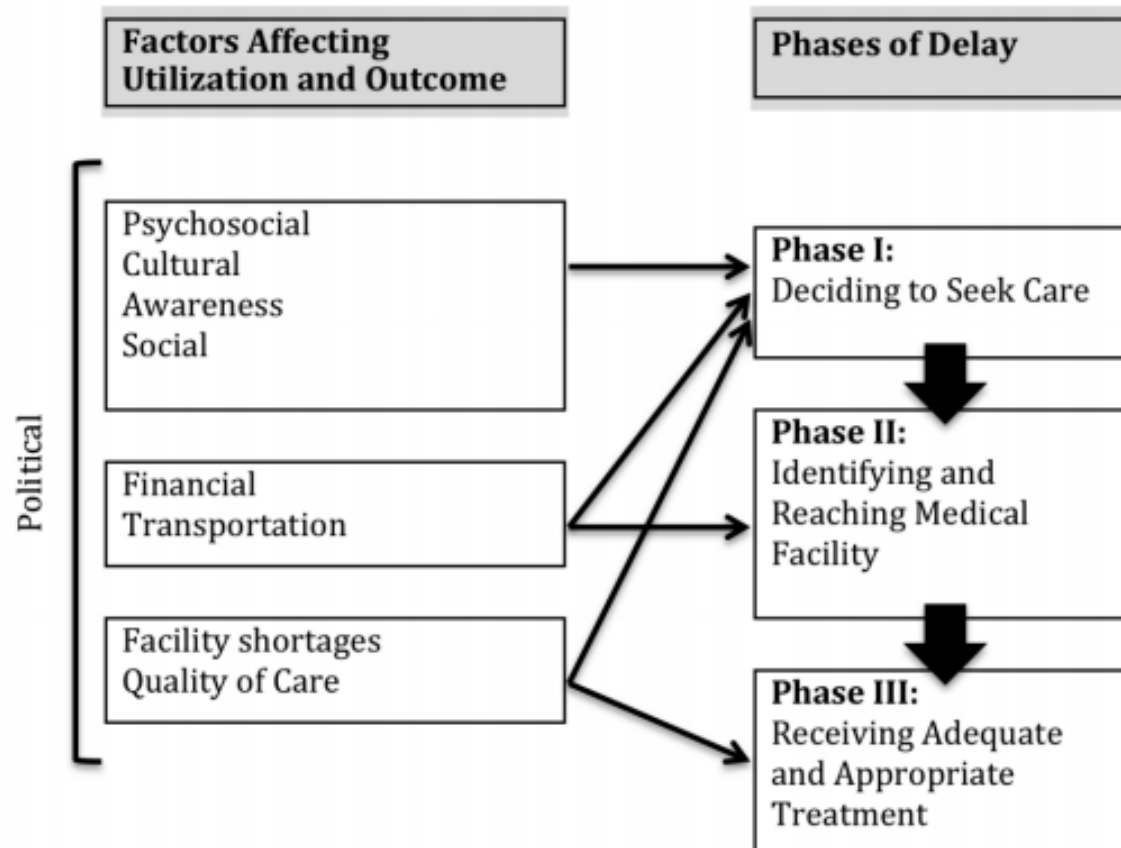
- Part I: Systematic literature review (2014/2015)
- Part II: Formative research in Nigeria and Uganda (2015)
- Part III: Intervention study in Nigeria and Uganda (2016 onward)



Systematic review findings

- 9 key barriers identified
- Limited assessment of interventions to address barriers
- Barriers organized into conceptual framework based on three delays model

Figure 1: Three Delays Model to Fistula Treatment



Formative research - Design

- Objective: To understand barriers to fistula care and enabling factors for alleviating these barriers, particularly from the perspective of women with fistula, family members and other community stakeholders
- Location: Ebonyi & Kano States, Nigeria; Hoima & Masaka Districts, Uganda
- Method/Sample: In-depth interviews and focus group discussions with purposively sampled respondents

	Kano	Ebonyi	Hoima	Masaka	Total
IDIs					
Women affected by fistula	8	9	20	15	52
Spouses & other family members	4	2	6	5	17
Providers at camps, facility & district managers	4	7	14	13	38
FGDs					
Post-repair clients	1	1	2	2	6
Community stakeholders – women	1	1	1	1	4
Community stakeholders – men	1	1	1	1	4

Formative research – Key findings, Nigeria (1)

- Widespread lack of awareness about fistula's causes and treatment among women with fistula, their family members, and general public
 - Stigma may prevent women from participating in community events, and/or prevent them from discussing symptoms with participants
 - Media (e.g., radio) strategies may directly reach women not served by community-based, in-person approaches
- Care-seeking decisions are not made exclusively or even primarily by women with fistula
 - “Gatekeepers” abound!
 - Parents often have a positive role in care-seeking, providing financial/psychosocial support

Formative research – Key findings, Nigeria (2)

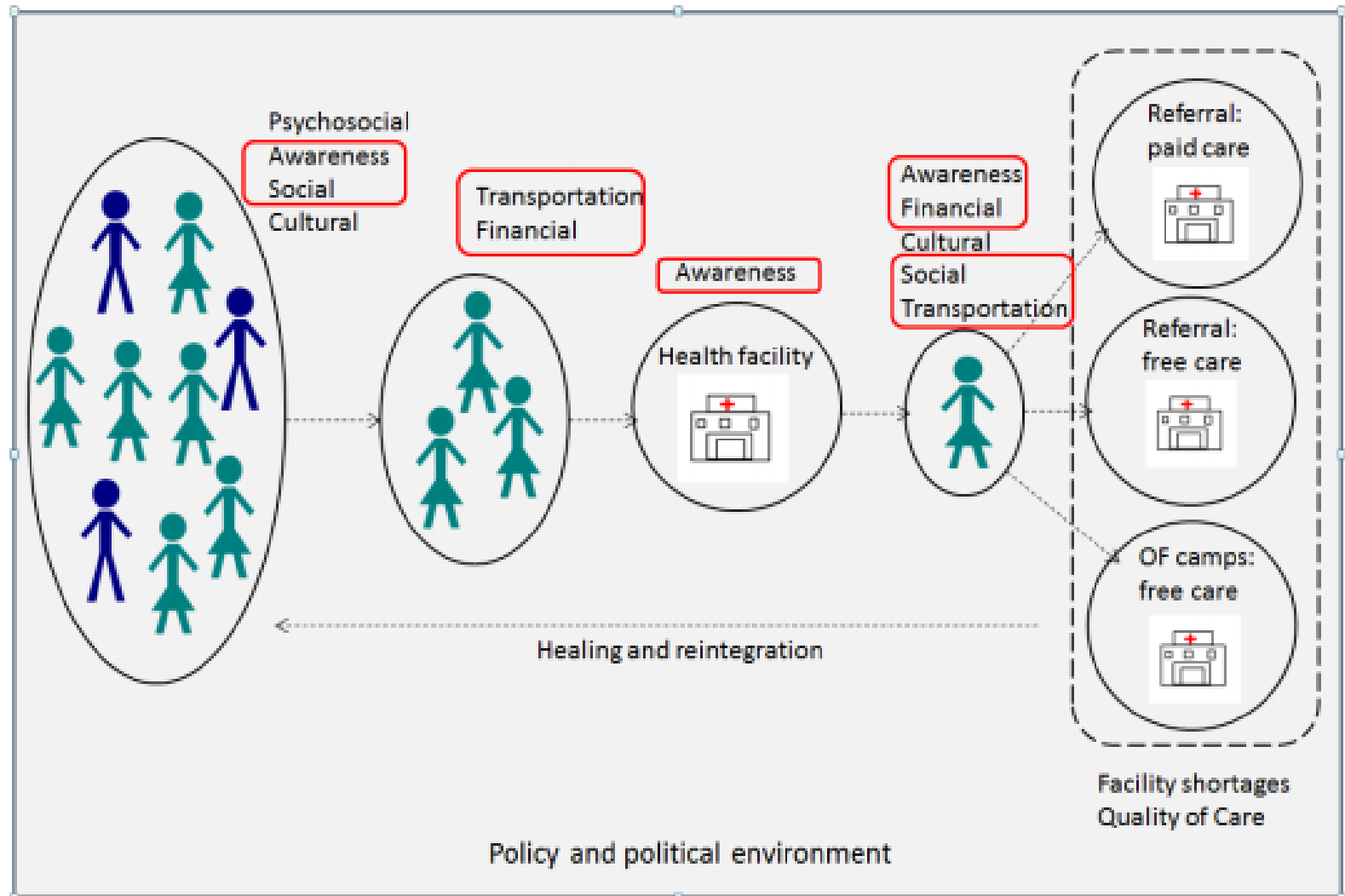
- Knowledge & behavior change needed **within** health system, too
 - Inadequate knowledge at lower-level/local health facilities manifests in passive and active barriers to appropriate fistula care:
 - *Providers are not well informed about fistula or existence of fistula treatment centers; unable to provide correct referrals*
 - *Providers attempt to provide treatment at lower-level facilities without adequate training, knowledge, etc.*
- Research did not uncover instances of women being banned from or discouraged from using transport due to fistula symptoms
 - Drivers were sympathetic to fistula clients' situation

Formative research – Context matters

- Nigeria: South vs. North
 - “Standout” barrier in Ebonyi: Lack of awareness/correct info about treatment
 - “Standout barrier” in Kano: Costs related to transport and care for the patient and accompanying person
- Uganda vs. Nigeria
 - Mobile Money is a viable option for reimbursing transportation costs in Uganda
 - Drivers in Uganda expressed greater concern regarding transporting women with fistula symptoms

Visualizing the impact of identified barriers

Figure 2: Factors affecting fistula repair access



Response to formative research findings: Screening & referral package

- Target barriers:

Population	Low awareness	High cost	High stigma
Health system	Low awareness	Provider gate-keeping	

- Planned intervention: “3-1-1”
 - **Three** channels for fistula messages and screening
 - *Channel 1: Mass media + interactive voice response (IVR)*
 - *Channel 2: Community outreach agents*
 - *Channel 3: PHC health workers*
 - **One** screening algorithm:
 - *4-5 question screening tool*
 - **One** enabler:
 - *Transport voucher for suspected cases → straight to accredited fistula treatment center*

Innovation: Fistula screening hotline

- FC+ and VOTO Mobile have developed a free IVR fistula screening hotline
 - Key screening question: *Do you currently experience constant leakage of urine or feces from your vagina during the day and night even when you are not urinating or trying to urinate?*
- IVR also asks about demographics, etiology, and care seeking
- Community agent follows up with positively screened women, including with free transport voucher to fistula center
- Why IVR? **Not limited by literacy**



Photo credit: VOTO Mobile

Fistula screening & referral: Other key activities

- Train PHC providers & community agents to build their capacity to conduct fistula screening and refer patients at the community & facility levels
- Partner with transportation associations and sensitize drivers
- Advertise fistula hotline using radio messages and communications materials at PHCs and other community venues

Fistula Care Plus
Fistula Screening Job Aide for PHC Workers & Community Agents

Screener Name: _____
Patient ID: _____
Date: _____

This tool is for PHC workers and community agents to screen women for fistula and collect information related to their condition before referral to a treatment facility for diagnostic clinical examination.

Q1: How old were you at your last birthday?	
<input type="checkbox"/> a) 10-14	<input type="checkbox"/> d) 25-39
<input type="checkbox"/> b) 15-19	<input type="checkbox"/> e) 40+
<input type="checkbox"/> c) 20-14	
Q2: Do you currently experience constant leakage of urine or feces from your vaginas during the day and night even when you are not urinating/trying?	
<input type="checkbox"/> a) Yes	<input type="checkbox"/> b) No
<p>If Q2 answer is YES, patient screens positively. Please collect the below information on the patient and then refer them for diagnostic clinical examination at fistula treatment facility.</p> <p>If Q2 answer is NO, patient screens negatively. End form and review patient symptoms for alternative diagnoses.</p>	
Q3: Did this problem (LEAKAGE OF URINE AND/OR FECES) start...	
<input type="checkbox"/> a) After you delivered a live or stillborn baby	<input type="checkbox"/> c) After a sexual assault, attack, or other injury
<input type="checkbox"/> b) After abdominal or pelvic surgery while you were not pregnant	<input type="checkbox"/> d) None of the above
Q4: Did this delivery (after which leaking started) happen normally, did they pull the baby out, or did they cut you/do an operation?	
<input type="checkbox"/> a) Normal delivery	<input type="checkbox"/> c) C-section (delivery through the tummy)
<input type="checkbox"/> b) Assisted vaginal delivery	
Q5: Have you ever sought treatment for this problem?	
<input type="checkbox"/> a) Yes	<input type="checkbox"/> b) No
Q6: From whom did you seek treatment most recently?	
<input type="checkbox"/> a) Health professional (such as doctor, midwife or nurse)	<input type="checkbox"/> c) Traditional birth attendant or other provider
<input type="checkbox"/> b) Community or village health worker	<input type="checkbox"/> d) Other: _____
Q7: Did the treatment involve surgery?	
<input type="checkbox"/> a) Yes	<input type="checkbox"/> b) No
Q8: Who has most recently helped you in seeking treatment?	
<input type="checkbox"/> a) Husband	<input type="checkbox"/> c) Own family (such as mother, father, sister)
<input type="checkbox"/> b) Husband's family (such as mother-in-law)	<input type="checkbox"/> d) Other person
Q9: Why have you not sought treatment? Please select the most significant of the following answer choices.	
<input type="checkbox"/> a) Did not know that treatment is possible or where to go	<input type="checkbox"/> d) Social barriers (such lack of permission, embarrassment, isolation)
<input type="checkbox"/> b) Cost of travel or treatment	<input type="checkbox"/> e) Concerns about quality of care at the treatment facility
<input type="checkbox"/> c) Distance of treatment	<input type="checkbox"/> f) Other

If Q3 is b, c or d, skip to Q5

If Q5 is No, skip to Q9

Population Council evaluation of screening & referral package

- Quasi-experimental design
- Data collection includes:
 - Health facility assessments at fistula center and PHCs including inventory checklists and record review
 - Quantitative interviews/questionnaires with providers at PHC facilities
 - Qualitative focus group discussions (FGDs) with men and women living in catchment areas
 - Qualitative in-depth interviews (IDIs) with women following repair at fistula centers
 - IDIs with key informants including senior health managers, provider, and community-based referral agents
- Barrier index: A tool to measure barriers faced by women accessing fistula services will be developed and validated

Promoting resilience and overcoming barriers: Lessons learned for/from fistula care

- A resilient system of fistula care is:
 - Informed about, realistic about, and responsive to barriers
 - Holistic, working inside and outside the health facility
 - Attentive to the ways that women ‘fall through the cracks’ as they move across the continuum from home to effective care

THANK YOU!

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