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
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
• 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
**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.

<table>
<thead>
<tr>
<th></th>
<th>Kano</th>
<th>Ebonyi</th>
<th>Hoima</th>
<th>Masaka</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IDIs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Women affected by fistula</td>
<td>8</td>
<td>9</td>
<td>20</td>
<td>15</td>
<td>52</td>
</tr>
<tr>
<td>Spouses &amp; other family members</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Providers at camps, facility &amp; district managers</td>
<td>4</td>
<td>7</td>
<td>14</td>
<td>13</td>
<td>38</td>
</tr>
<tr>
<td><strong>FGDs</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-repair clients</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Community stakeholders – women</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Community stakeholders – men</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
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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

SOURCE: Warren et al., Global Health Mini-University, March 4, 2016
Response to formative research findings: Screening & referral package

- Target barriers:

<table>
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<tr>
<th>Population</th>
<th>Low awareness</th>
<th>High cost</th>
<th>High stigma</th>
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<tbody>
<tr>
<td>Health system</td>
<td>Low awareness</td>
<td>Provider gate-keeping</td>
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</table>

- 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**
• 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
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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