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# Reducing barriers to accessing fistula repair: Establishing a baseline in Ebonyi

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# REDUCING BARRIERS TO ACCESSING FISTULA REPAIR: ESTABLISHING A BASELINE IN EBONYI

## BACKGROUND

Obstetric fistula (OF) is preventable and surgically treatable, but women who lack access to quality maternal healthcare often live with OF for many years. For every 1,000 births, it has been estimated that 2.11 women develop fistula in Nigeria<sup>1</sup> and despite the establishment of national fistula centers across Nigeria, the majority of women with OF remain unrepaired.

As a partner on the Fistula Care *Plus* (FC+) project, the Population Council is conducting implementation research that tests solutions to treatment barriers. Formative research in Nigeria's Ebonyi State found that a lack of knowledge among lower level providers and women and families of how the condition occurs, where treatment is available, and the signs and symptoms of OF, as well as transportation costs, affect women's access to screening and repair.

## IMPLEMENTATION RESEARCH

The research aim is to understand whether a comprehensive information, screening, and referral intervention can reduce transportation, communications, and financial barriers to accessing preventive care, detection, and treatment of fistula in Ebonyi State.

The intervention model follows a "3-1-1" pattern:

- **Three** channels for fistula messages and screening so women can learn about their fistula status:
  - Mass media and interactive voice response (mobile phones)
  - Community outreach agents
  - Primary health care workers
- **One** screening algorithm for detecting fistula condition
- **One** enabler: transport voucher for suspected fistula cases to the fistula repair center.



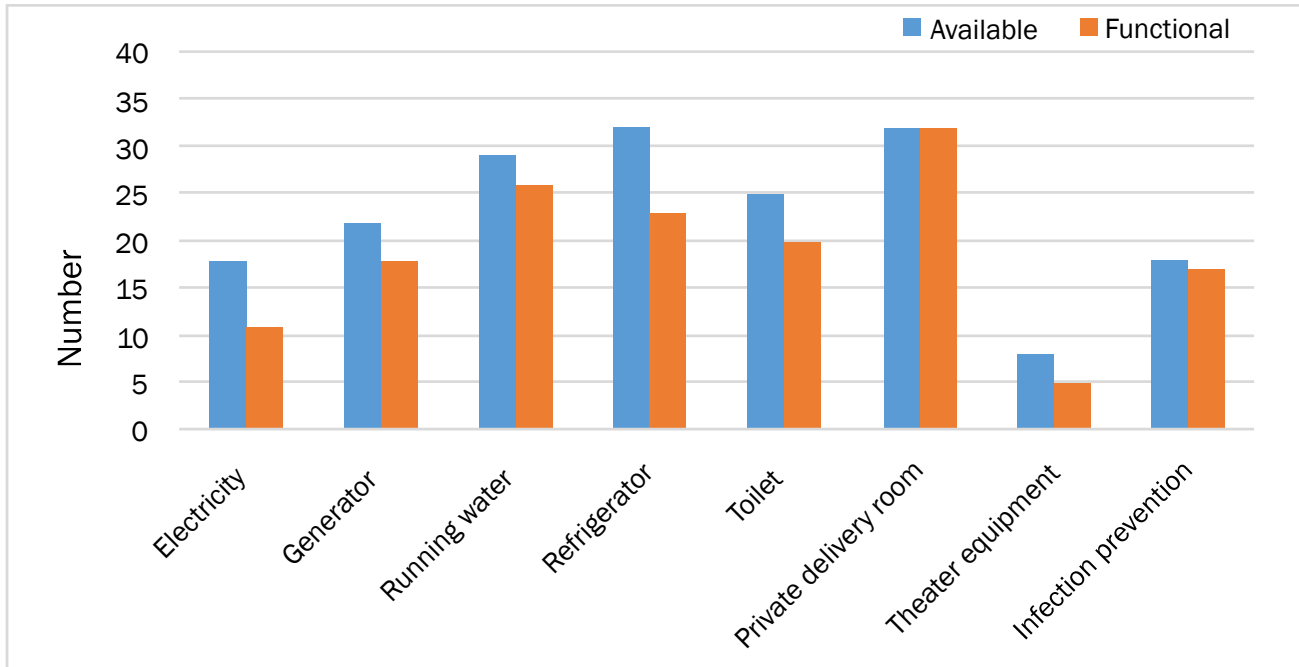
<sup>1</sup> Ijaiya MA, Rahman AG, Aboyeji AP, Olatinwo AW, Esuga SA, Ogah OK, Raji HO, Adebara IO, Akintobi AO, Adeniran AS, Adewole AA. Vesico vaginal fistula: a review of Nigerian experience. *West Afr J Med.* 2010; 29(5):293- 8.

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**FIGURE 1. Capacity of PHC Facilities (n=39)**



## BASELINE DATA COLLECTION

In Ebonyi, Population Council collected baseline data from both intervention and comparison local government areas (LGAs). Researchers conducted 39 facility assessments of primary health centers (PHCs) and one facility assessment of the fistula center to assess health systems capacity; 117 PHC provider surveys that assessed their knowledge, attitudes, and perceptions of barriers, and operational challenges that influence how women access care for fistula; and 91 surveys with women who had received fistula repair about the barriers and enablers they experienced. A subset of 30 post-repair women interviews and four focus group discussions - held separately with men and women residing in selected communities- also further explored barriers and enablers to accessing care. All tools covered transport and referral barriers, as well as psycho-social, cultural, facility shortages, awareness of service options, quality of care, social, political, and financial barriers to accessing care.

## BASELINE FINDINGS

**Facility Assessment.** Except for three faith-based facilities, all PHC facilities are publicly owned. Over half of the providers are nurse/midwives or community health extension workers and there are half as many junior community health extension workers and community health

officers as there are doctors. Facility representatives report varied infrastructural capacity across the overall sample (Figure 1). Facility referral mechanisms for suspected fistula cases are very poor. Only about 7.7% of facilities have ambulances; 15.4% of transport arrangements are made by fistula patients and relatives.

**PHC Providers.** PHC providers – predominately community health extension workers – have limited knowledge of prevention and treatment of fistula. Only 39-42% of providers spontaneously mentioned prolonged and obstructed labor as labor and delivery complications, no providers correctly identified leaking urine/feces as postnatal danger signs, and 32.5% correctly identified foul-smelling discharge as a postnatal danger sign. About 33.4% of the providers reported having seen prolonged or obstructed labor among their clients. Though only one referral was captured across the 39 PHC facility assessments, 33% providers report referring women with fistula to repair centers. Of those, only 23% counselled the referred client. This counseling rate is less than the already low proportion of providers who know that OF clients should be counseled and referred (35.9%).

Providers understand some of the barriers women face when trying to access fistula repair. In Ebonyi State, the three most frequently mentioned barriers by the 88 surveyed providers were 1) Not having money for fistula care (76.9%), 2) The cost of transportation (47.9%), and 3) Not knowing where to go for fistula care (43.5%).

**TABLE 1. Fistula repair client survey in Ebonyi (n=91)**

Fistula experience indicator	Frequency (%)
Clients began leaking post-delivery (obstetric fistula)	76 (84.4)
OF cases following normal delivery	29 (24.4)
Average amount of time clients live with fistula (of any sort)	Mean: 2.0 years; Range: 1-5
Average number of attempts to seek fistula treatment	Mean: 1.4 times; Range: 1-3
Clients who have previously sought treatment for fistula	25 (27.5)

**Fistula repair clients.** Of the 81 women surveyed post-repair, 30.6% were between 15 and 29 years of age, 73.6% were married, and 95.6% were Christian and 3.3% were Muslim. About 87% had any formal public education and nearly 60% ever worked for an income. Table 1 shows that on average, women live with fistula for two years, though some live with the condition for up to five years. About a quarter (27.5%) previously sought treatment for their fistula. On average, these women have sought formal and traditional care at least once.

**Barriers.** The stigma and shame associated with uncontrollably leaking in public leads to psychological barriers to care-seeking for the majority of women. Findings showed that 88.8% of women were embarrassed and 67.4% felt isolated because of their condition. They also reported social barriers, such as not having someone to support them in reaching/seeking repair sites (17.1%) – this provides insight into the cultural and gender dynamics around family and intimate partner roles. Women do not know that fistula is a condition that can be treated (57.3%) and not knowing where to go for fistula repair (81.4%).

Despite free elements of fistula operations in Nigeria, the transport cost and perceived costs constrain access to repair in Ebonyi. Abandoned women, those living with spouses and families, and those unable to work because of their condition, all experience financial strain because competing costs in resource-poor households often deter or delay access to transport to/from repair centers. Our sample shows that many women felt they do not have money to pay for the needed medical care (59.1%) and felt the cost of transportation to repair sites and accommodation was too high (64.4%).

Other barriers included fear of pain/discomfort during travel to facilities (54.0%) and of bad treatment by providers at the fistula center (21.6%). Some women had been told by providers that their fistula would heal itself

(21.6%), while others had been told by providers in the past that their fistula was untreatable (16.1%).

**Enablers.** Enablers of accessing the fistula center are complex, but center around effective media advertising of fistula centers, timely referral by PHC providers, and the social support women have from their families – particularly relatives in increasing awareness around fistula and facilitating transport to the facility.

*“It was from the radio that I had the announcement about the center that people who have this problem should visit fistula center for repair.”* (IDI, repaired woman, 16 years)

Free repair services at fistula centers and perceived quality of care women received at first contact with the providers facilitated access by restoring confidence and hope and motivate care-seeking decisions.

*“We were afraid of the amount of money to be paid at the hospital, but to our amazement when we came here and saw the doctors, they told us that money is not the problem but [it’s important] to save life first.”* (IDI, repaired woman, 17 years)

## CONCLUSION

Baseline data reveal the necessity of a comprehensive intervention to address fistula treatment barriers in Ebonyi. Not only do PHC providers lack adequate knowledge of fistula, referral and counseling, but women and community members report that access barriers to fistula centers bring persistent logistical, financial, awareness, and social challenges. These findings inform the intervention, which builds on existing enablers in Ebonyi, such as media communication and social/transport support, and aims to promote greater access to fistula repair in the state.