

A conversation with EngenderHealth, May 15, 2019

Participants

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- Dr. Sk Nazmul Huda – Global Activities Manager and Bangladesh Project Manager, Fistula Care *Plus* Project, EngenderHealth
- Dr. Vandana Tripathi – Deputy Project Director, Fistula Care *Plus* Project, EngenderHealth
- Dr. Lauri Romanzi – Project Director, Fistula Care *Plus* Project, EngenderHealth
- Kristin Saucier – Director of Resource Mobilization, EngenderHealth
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Note: These notes were compiled by GiveWell and give an overview of the major points made by Ms. Piracha, Dr. Huda, Dr. Tripathi, Dr. Romanzi, and Ms. Saucier.

Summary

GiveWell spoke with Ms. Piracha, Dr. Huda, Dr. Tripathi, Dr. Romanzi, and Ms. Saucier of EngenderHealth as part of the second round of investigating applicants to the 2019 GiveWell Grants for Global Health and Development in Southeast Asia and Bangladesh (<https://www.givewell.org/research/grants-southeast-asia-bangladesh-2019/application-details>). Conversation topics included determinants of fistula, EngenderHealth's work on prevention and treatment of fistula, its monitoring and evaluation system, and its use of additional funding.

Determinants of fistula

Obstetric fistula—an abnormal opening between the vagina and the bladder or rectum caused by prolonged obstructed labor—can be prevented by addressing determinants at various levels:

- **Distal level** – The distal determinants of fistula include poverty, low social status, gender issues, lack of education, and lack of employment.
- **Intermediate level** – Intermediate determinants include lack of access to care, lack of quality care, and delivering children at home rather than at a facility.
- **Direct level** – The direct determinants of fistula include lack of adequate intervention and general quality of care related to facility management of women in obstructed labor.

While obstetric causes are the most common cause of fistula in most settings, a substantial proportion of fistula is iatrogenic, caused by errors during cesarean section or other pelvic surgery. Fistula can also be traumatic, resulting from sexual violence or accidents, or caused by cancer, infection, or congenital in origin.

EngenderHealth's work on prevention and treatment of fistula

Community-based fistula screening and diagnosis

As part of its USAID-funded *Fistula Care Plus (FC+)* project, EngenderHealth supports the identification and treatment of fistula cases in Bangladesh.

Symptom and history-based checklist

EngenderHealth developed a four-question checklist that community-level fieldworkers, after receiving basic training, are able to use to identify potential cases of fistula.

Screening through EngenderHealth's checklist tool is based on patient history and self-reported symptoms, and is not a clinical confirmation of fistula. Because screening based on self-report can also identify severe incontinence related to causes other than fistula, it is important to follow screening with clinical examination for diagnosis.

Community-based fistula diagnosis event

EngenderHealth developed the community-based fistula diagnosis event (CFDE) system to clinically confirm suspected fistula patients identified by its checklist. A group of approximately 10 nurses and doctors visit remote villages where potential fistula patients have been identified and invite the women to a facility where a structured, four-step examination process can be performed:

- **Station one** – At the first station, patients are registered, provided with refreshments, measured for height and weight, and provided with a waiting number.
- **Station two** – At the second station, two nurses record a detailed account of patient history, which typically takes 45 minutes to one hour.
- **Station three** – At the third station, a doctor determines whether a patient requires an internal exam or dye test and performs the required tests. If a patient is determined to suffer from a condition unrelated to fistula, they either receive treatment during the examination or are referred to another medical provider.
- **Station four** – At the fourth station, patients are provided with a final diagnosis and comprehensive treatment plan, which will include discussion of the counseling to be provided to family members, the arrangements for an individual to accompany the patient to the hospital, the preparations for personal belongings to be managed while the patient is undergoing treatment, the time the patient will spend under hospital care and in recovery, and the process for rehabilitation and community reintegration after treatment.

Schoolgirls for Fistula-Free Bangladesh program

Schoolgirls for Fistula-Free Bangladesh is an FC+ initiative to prevent and treat fistula through the education and empowerment of schoolgirls in ninth and tenth grades. The program is currently operating in seven schools across the country.

Through Schoolgirls for Fistula-Free Bangladesh, each participating schoolgirl receives education on reproductive health, gender equity, marriage, fistula, and other related issues—with the core goal of enabling schoolgirls to prevent fistula and other obstetric morbidities in their lives. Secondly, each schoolgirl is also connected with two pregnant women in their respective community and is encouraged to aid these women in the prevention or treatment of fistula and other pregnancy-related issues. For example, a schoolgirl may identify symptoms in a pregnant woman and direct her to the appropriate place of care.

Although it is difficult for schoolgirls to identify fistula (due to afflicted women often being isolated), 10-12 cases of fistula have been identified through the program.

Monitoring and evaluation

EngenderHealth monitors and evaluates its work on fistula diagnosis and treatment through a customized database built on the District Health Information System 2 (DHIS2) platform, which enables data visualization and tracking trends (e.g. consistent performance issues at specific sites) and is used by many national Ministries of Health. Core indicators are tracked on a quarterly basis for all supported sites.

Collection of long-term data

Fistula repair sites supported by FC+ maintain individual patient files, which include data on condition at discharge, and invites patients to return to facilities for a follow-up visit. Neither FC+ nor most supported sites can systematically and consistently track long-term outcomes due to the remoteness of the locations where patients reside. However, in some settings, FC+ is working with government partners to devise a strategy for collection of long-term patient data, which would include the development of a community-based fistula registry. Additionally, FC+ and its predecessor project (Fistula Care) have supported site-specific studies of long-term outcomes, including fistula recurrence and post-repair pregnancies.

Some countries have managed to track long-term fistula surgery outcomes in a very small sample of patients.

Use of additional funding

If it received \$250,000 in additional funding through the 2019 GiveWell Grants for Global Health and Development in Southeast Asia and Bangladesh, EngenderHealth would allocate approximately 50% of the funding to community-based fistula and prolapse screening and diagnosis events in the Rohingya refugee camp of Cox's Bazar, approximately 30% of the funding to an expansion of the Schoolgirls for

Fistula-Free Bangladesh program, and 20% of the funding to a workshop in Cox's Bazar on reproductive health and rights for refugees.

The FC+ project is active through March 2021. However, EngenderHealth is unable to use its FC+ funding for the three aforementioned activities in Bangladesh. Proposed work in the Rohingya refugee camp of Cox's Bazar is disqualified because of a requirement that USAID-awarded funds impact Bangladeshi citizens. Additionally, given the priority deliverables and benchmarks in the FC+ workplan, there is insufficient project funding to expand the Schoolgirls for Fistula-Free Bangladesh program.

Community-based fistula and prolapse diagnosis events in the Rohingya refugee camp of Cox's Bazar

With additional funding, EngenderHealth would train the fieldworkers of community-based organizations currently operating in the Rohingya camp of Cox's Bazar to administer its four-question checklist to refugees in the camp. For each 20-40 patients identified by fieldworkers, one community-based fistula and prolapse diagnosis event will be hosted within the camp—for a total of two events.

EngenderHealth expects that fistula is more common among refugee populations due to a lack of access to facility-based delivery and other quality health services. It has conservatively estimated that the proposed events in Cox's Bazar would result in the clinical confirmation and treatment of 50 fistula and prolapse cases, although it believes that over 100 cases may ultimately be identified. Similar to its current work, funding for the program in Cox's Bazar would cover the full cost of treatment (e.g. diagnosis, transport to hospital, surgery, counseling, rehabilitation).

Potential emphasis on non-surgical treatment

Pessaries, prosthetic devices available in various shapes and sizes, reduce the symptoms and improve the overall health of prolapse patients. A pessary can be used as a permanent non-surgical treatment for prolapse or as an interim treatment while a patient awaits surgery (typically a waiting period of six months to one year). Fistula can sometimes be non-surgically treated with a catheter, although the opening must be fresh and small in size.

EngenderHealth believes that non-surgical treatment, specifically for prolapse, may be particularly suitable for the refugee camp setting—as close follow-up of patients would be feasible.

Monitoring and evaluation

For the proposed program in Cox's Bazar, EngenderHealth would continue tracking the same indicators measured in the FC+ project (e.g. surgical outcomes). However, it is also interested in attempting to routinely and more accurately collect follow-up patient data three months, six months, and one year after patient discharge. Long-term follow-up may be more feasible and would be particularly important in the refugee camp setting, where women are at higher risk of developing health-related complications.

The specific design and timeframe for follow-up will depend on how long patients remain in the refugee camp as well as the input of other organizations working in the camp, which EngenderHealth would like to partner with.

Other organizations working on fistula in the Rohingya refugee camp of Cox's Bazar

EngenderHealth is currently aware of at least two other organizations, Humani Terra and Women And Health Alliance International, providing fistula services to women in the Rohingya refugee camp of Cox's Bazar. Humani Terra, headquartered in Marseilles, France, is implementing various maternal health interventions in the camp, including significant work on fistula. Based on conversations between the two organizations over the past few years, EngenderHealth believes that Humani Terra would welcome a strong partner with expertise in fistula and prolapse to address women's full needs for these services.

As part of its proposed work in Cox's Bazar, EngenderHealth would undertake a more complete landscape analysis of organizations in the camp working on fistula.

Expansion of the Schoolgirls for Fistula-Free Bangladesh program

EngenderHealth would like to use funding from GiveWell to expand the Schoolgirls for Fistula-Free Bangladesh program to two additional schools.

Workshop in Cox's Bazar on reproductive health and rights for refugees

EngenderHealth would use a portion of additional funding to conduct one to two workshops, in collaboration with the Bangladeshi Ministry of Health and Family Welfare (MOHFW), on the sexual and reproductive health and rights of refugees in Cox's Bazar. The target audience for these workshops would be the myriad organizations providing various services to the refugee camp, and EngenderHealth's hope is that the MOHFW will be able to influence these organizations to incorporate reproductive health services in their respective work. Specific positive outcomes could include:

- **Increased distribution of family planning products** – Organizations working in Cox's Bazar could distribute family planning products (e.g. condoms, birth control pills) supplied by the government. EngenderHealth could facilitate basic training for fieldworkers as well as a space for distribution.
- **Increased collaboration to provide clinical family planning services** – With a deeper understanding of the organizational landscape in Cox's Bazar, NGOs could better coordinate and manage the provision of clinical family planning services (e.g. injectable contraceptives, intrauterine devices, vasectomies, tube ligations).

All GiveWell conversations are available at
<http://www.givewell.org/research/conversations>