A conversation with Kate Grant and Lindsey Pollaczek, February 16, 2018

Participants

- Kate Grant – Chief Executive Officer, Fistula Foundation
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- Josh Rosenberg – Senior Research Analyst, GiveWell
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Note: These notes were compiled by GiveWell and give an overview of the major points made by Ms. Grant and Ms. Pollaczek.

Summary

GiveWell spoke with Fistula Foundation (https://www.fistulafoundation.org) as part of its investigation into giving opportunities to cause additional fistula repair surgeries. Conversation topics included the Foundation's operating model, how it would use additional funds, and the monitoring and evaluation of its programs.

Operating model

Fistula Foundation adopts two main approaches to increase fistula surgeries, with its choice depending largely on time, funding, and geographical concerns.

- **Individual hospitals.** The Foundation partners with established hospitals that already have a trained surgeon to pay for the provision of surgeries. This model can be very efficient when all that is required is additional funds to carry out more surgeries, and is the only option in places with major security concerns, such as Afghanistan and the Democratic Republic of the Congo. However, this model cannot reach women outside the hospitals' discrete catchment areas, and in any case most hospitals lack the required capacity to bring hard-to-reach women into care.
- **Whole countries.** In some countries, the Foundation provides the necessary training and resources to conduct high-quality surgeries and to bring hard-to-reach women into care to a network of hospitals across the country. This approach is generally more effective at increasing fistula surgeries but is also more resource-intensive.

Ms. Pollaczek has been leading the Kenya program for the past four years, based in Nairobi. Over the last 18 months Ms. Pollaczek has turned her focus to Zambia, the newest program with a whole-country focus.

In addition, the Foundation occasionally supports surgery "camps" where a large number of treatments are done in a short visit. One of these will take place soon in the Nuba Mountains in South Sudan, where the inhabitants are generally very poor and lack access to obstetric care. However, this model is the Foundation's least

preferred model because it does not provide support for any subsequent complications.

Room for more funding

Fistula Foundation's revenue and surgery numbers have tripled over the last five years, reaching $9.5 million and 6,600 respectively in 2017. The Foundation believes it could absorb significantly more funding to cause additional fistula surgeries.

Fistula Foundation would spend approximately 90% of any additional funding on its countrywide treatment programs, expanding the Kenya and Zambia programs, and/or establishing similar programs in places such as Angola, Madagascar, and Northern Nigeria. Whole-country programs require significant funding. For example, the Foundation's Kenya program costs around $1.2 million per year, not including the additional resources the Foundation invested to build the network of providers.

The remaining ~10% of additional funding would fund additional surgeries through partnerships with individual hospitals.

Monitoring and evaluation

Data quality

Impact evaluation is hampered by the lack of high-quality data on both the prevalence of fistula and the availability of treatment. The Global Fistula Map (www.globalfistulamap.org) shows the number of fistula surgeries, fistula surgeons, and facilities that provide fistula surgery identified by Fistula Foundation, the United Nations Population Fund (UNFPA), Direct Relief, EngenderHealth, and Women and Health Alliance International. However, this data is often outdated or incompletely reported. Annual variation in the number of surgeries resulting from extraneous factors such as weather or elections also makes the data difficult to interpret.

In 2007, the Foundation and other groups worked with Johns Hopkins University on a multi-country study designed to rigorously examine fistula prevalence and treatment outcomes over a six-month period. However, due to a funding shortfall the study ultimately only obtained limited data from Bangladesh.

Establishing whether surgeries would have occurred without Fistula Foundation's intervention

The UNFPA launched a campaign in 2003 to end fistula and it has become the *de facto* coordinator of these efforts. The UNFPA holds annual meetings on the topic and has placed representatives in many sub-Saharan African and Southeast Asian countries in order to lead national campaigns. As part of this campaign, in 2014 the UNFPA gathered baseline data in many countries, including Kenya, where it found that approximately 1,000 surgeries were performed annually.

Based on this baseline research and its ongoing data collection, the Foundation believes that the number of surgeons qualified to carry out fistula surgery in Kenya has doubled since the Foundation established its program there. Similarly, the number of fistula surgeries in Zambia has doubled within one year of the Foundation launching its whole-country program. Before the Foundation began working in Zambia, the UNFPA, working with the Ministry of Health, was the sole provider of fistula surgeries in Zambia and it provided them through annual camps.

The Foundation believes these increases in trained fistula surgeons and in surgeries are unlikely to have taken place without its intervention. Fistula surgery requires specialist training and in each country there is only a small community involved in treating fistula, almost all of whom are known to the Foundation. Before supporting a provider the Foundation asks who the surgeon is, where they trained, and who can vouch for their technical skill. It is therefore unlikely that many high-quality surgeries are taking place that the Foundation is unaware of; indeed, it may be the case that surgeons untrained in fistula repair attempt the operation and increase morbidity.

Outcomes

The Foundation also collects data through its partner organizations.

- **Baseline.** Before establishing a partnership it conducts an informal baseline survey, asking how many surgeries the partner currently carries out (which is often zero) and whether there is a need for more. The Foundation then collects ongoing data about how many surgeries occur following its work, which difference it uses to estimate its impact.
- **Surgical success.** Quarterly (or monthly in the case of Kenya) surgical logs record the outcome at the time of discharge as dry (continent), fistula closed but incontinent, or not closed.
- **Follow up.** Subsequent data collection varies among program sites. It is most robust in Kenya, where community-based teams refer women for surgery and then follow up with them one, three, six and 12 months after surgery. During these visits the teams collect information on social outcomes, such as family and peer interaction, as well as continence. The Zambia program is currently implementing a similar monitoring and evaluation strategy. Elsewhere, the Foundation's partner hospitals generally collect data on post-discharge outcomes only if the patient returns with a complication.

Collection of long-term follow-up data is hindered by many factors, including that patients often live in rural areas and are widely dispersed. However, anecdotal evidence suggests that treatment causes positive feedback loops that enable women to reintegrate into their communities.

Training

Fistula Foundation is working with the International Federation of Gynecology and Obstetrics (FIGO) to improve its assessment of the quality of fistula surgery training.

This work recognizes that in some sites surgeons have been trained in fistula repair at a hospital with little patient demand, and therefore have had few opportunities to develop their skills.

Treatment-seeking

Fistula Foundation is of the view that work to generate awareness about fistula, address social stigma, and empower women living in poverty is necessary to ensure women actually access treatment for fistula when it is available.

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