FISTULA CARE

Community-Based Screening for Genito-Urinary Fistula in Nigeria: A novel approach

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Prepared by:

Özge Tunçalp, MD PhD
Adamu Isah, MD MPH
Evelyn Landry, MPH
Cynthia K. Stanton, PhD

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FistulaCare

EngenderHealth for a better life

EngenderHealth, 440 Ninth Avenue, New York, NY 10001, USA
Telephone: 212-561-8000, Fax: 212-561-8067, Email: elandry@engenderhealth.org

Fistula Care
c/o EngenderHealth
440 Ninth Avenue
New York, NY 10001 U.S.A.
Telephone: 212-561-8000
Fax: 212-561-8067
e-mail: info@fistulacare.org
www.fistulacare.org

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Table of Contents

Background

Obstetric fistula is one of the most debilitating maternal health morbidities associated with enormous medical and psychological burden. Obstetric fistula is a complication that arises from obstructed or prolonged labor resulting in a hole or opening in the birth canal. This condition develops when the blood supply to the tissues of the vagina, bladder, and/or rectum is cut off by prolonged obstructed labor without prompt medical care. As a result of unrelieved obstructed labor, the bladder, urethra, or rectum and the vaginal wall are compressed between the fetal head and the maternal pubis. This compression and loss of blood supply produces necrosis of the compressed tissues resulting in uncontrolled leakage of urine from the bladder through the vagina, in the case of vesico-vaginal fistula (VVF) and leakage of stool from the vagina, in the case of recto-vaginal fistula (RVF).

The woman is left with chronic incontinence, which results in social problems such as rejection, shame, and stigma as well as economic problems. Genito-urinary fistula can also result from sexual violence or complications from pelvic surgery. It is a condition that has been essentially eradicated in high income countries, due primarily to improved access to and quality of obstetric care. In poor countries, however, fistula continues to have devastating effects on the physical, social, and economic lives of thousands of women[1].

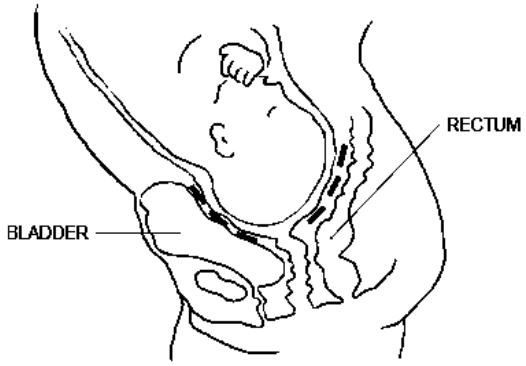

Figure 1: How a fistula may develop
During prolonged labor, the compression of soft tissues (as indicated by the dotted line) between the baby's head and the woman's pelvis cuts off blood flow to the bladder or rectum. As a result, tissue dies, leaving a hole, or fistula.
(Courtesy of UNFPA, Campaign to End Fistula)

The true prevalence and incidence of obstetric fistula remains difficult to determine for several reasons: lack of large-scale, prospective, population-based studies examining pregnancy outcomes (in order to measure incidence); few large-sample population-based studies of fistula prevalence; and, where studies of fistula incidence and prevalence have been conducted, inaccurate measurement, resulting either from problems related to questionnaire design (inappropriate contingency questions or lack of specificity in the definition of fistula), or underreporting of fistula symptoms by women (due to the stigma associated with the condition). In Nigeria, the condition was predominantly thought to be a disease of the northern part of Nigeria only, but field experience and recent findings from the 2008 Nigeria Demographic and Health Survey (DHS) has shown otherwise. The DHS

[1] Johnson, Kiersten, and Amber Peterman. 2008. Incontinence Data from the Demographic and Health Surveys: Comparative Analysis of a Proxy Measurement of Vaginal Fistula and Recommendations for Future Population-Based Data Collection. DHS Analytical Studies No. 17. Calverton, Maryland, USA: Macro International Inc.

shows that estimated prevalence of fistula symptoms in the southern zones ranges between 0.2% and 0.5% percent and in the northern zones the range is between 0.3% and 0.8%. The underlying factors which contribute to obstetric fistula --dearth of skilled birth attendants, poverty, poor health seeking behavior, poor referral systems, poor transportation network, inadequate facilities providing comprehensive obstetric care services—exist in all the geopolitical zones of the country, and are not a problem of just one region. A recent study conducted by Fistula Care shows that fistula in fact affects women across age groups and parities[2]. To effectively plan for the treatment and repair of fistula cases, the Ministry of Health and its international partners require credible estimates of the backlog of existing cases requiring care.

In order to respond to this need, in collaboration with Stanton-Hill Research LLC, EngenderHealth designed a study to quantify the backlog of obstetric fistula cases within select LGAs of Kebbi and Cross River States via community based screenings in these LGAs.

Objectives

1- To quantify the backlog of cases within two local government areas (LGAs) in Kebbi and Cross River States via community based screenings.
2- To explore the feasibility of reporting minimum estimates of prevalence and incidence of fistula a) at the individual district (LGA-local government authority) level and b) extrapolated to the state-level.
3- To assess the questions in the Demographic Health Survey (DHS) fistula module by comparing women's self-reported fistula symptoms to results from the medical assessment.
4- To document the methodology, which may be able to be used by other districts or States to estimate the backlog of cases for program planning purposes.

This report summarizes the study methodology, results and conclusions including recommendations based on lessons learnt.

[2] Barone et al. 2012. Determinants of Fistula Repair Post-Operative Outcomes: A Prospective Cohort Study. *Obstetrics & Gynecology*; 120 (3):524-31

Methodology

EngenderHealth support for Genito-Urinary Fistula Surgery in Nigeria

For nearly a decade, EngenderHealth has partnered with institutions and surgical teams to facilitate more than 25,000 fistula repair surgeries, transforming the lives of women and their families in 15 countries across Africa and Asia. These surgeries have been possible with support from USAID and other generous donors. Currently, Fistula Care, managed by EngenderHealth and supported by USAID, supports fistula treatment and prevention activities in 10 countries in partnership with other international organizations, local nongovernmental organizations, faith-based organizations, ministries of health (including public sector clinics), and national working groups among others. The largest number of Fistula Care-supported treatment sites is in Nigeria (n=10).

In 2008, the South East Regional VVF Center[3] conducted screenings in 13 LGAs in Ebonyi State, [4] and building upon that experience, this new study has been planned. Currently 10 facilities in ten states across northern and southeastern states in Nigeria conduct diagnostic screenings and conduct fistula repair surgeries with support from Fistula Care. . This study was incorporated into these on-going activities in two states (Kebbi and Cross River States) and included the addition of a set of pre-screening questions to fulfill the objectives of this study.

Tool Development and Ethical Approval

Study tools such as informed consent, pre-screening questionnaire, diagnostic and referral forms were developed with input from EngenderHealth. The pre-screening questionnaire covered data on demographic variables, including but not limited to: date of birth, age, religion, marital status, highest degree of education, community which they live in, number of live births, abortions and stillbirths. In line with our Objective #3, this questionnaire also included questions from the latest Nigeria DHS fistula module (2008) to collect more information on the condition reported by women and we verified the self-report of fistula-like symptoms by the medical exam. There were also communication questions related to the outreach efforts and possible barriers to attend the screening. Following the Kebbi exercise we slightly modified the questionnaire as described below:

1) Additional questions were included under communication to better understand whether the community messages were properly understood or not: It was emphasized that these questions were to test the clarity of the community messages, not women's knowledge in general about fistula..

[3] This center was renamed the National Obstetric Fistula Center, Abakaliki in May 20111 when it became a designated federal center.

[4] Fistula Care. 2012. *Community-Based Screening for Obstetric Fistula in Ebonyi State, Nigeria..* New York: EngenderHealth/Fistula Care.

2) During the Kebbi state exercise, we found that uterine prolapse was a common diagnosis. For the Cross River exercise we added the degree of prolapse under the Diagnostic Form.

The complete questionnaires for Kebbi and Cross River can be found in Appendices 1 and 2, respectively.

The study protocol was reviewed and approved by Western IRB in the USA and National Health Research Ethics Committee in Nigeria.

Screening Sites

The screening sites were selected based on coverage (north and south), close relationships with the communities and availability of the fistula surgery facilities. Two states were selected.

1) Kebbi State: This state is situated in the Northwest region with a majority Muslim population. EngenderHealth has been active in this state for a long time, including supporting a fistula center through Fistula Care since 2007. Two local government areas (LGA) further identified were Argungu and Augie.
2) Cross River State: This state is situated in the South-south region with a majority Christian population. Fistula Care's work is relatively new in this State with an operating fistula center since 2011. Two LGAs further identified were Bekwarra and Yala.

The facilities where the screenings took place were assessed for their readiness and Fistula Care provided the materials needed during the examinations.

Pre-Screening

Community Outreach

Fistula Care works in close relationship with local community-based organizations (CBOs) and has strong connections to the communities, which are deemed essential for such a screening exercise. Four weeks before the initiation of the screenings, outreach efforts were coordinated, which included advocacy and collaboration with the traditional leaders, village heads, LGA government staff, health educators and religious leaders. Box 1 summarizes the messages used in both of the states. It should be noted that the officials in Kebbi state provided transportation for the screenings, whereas this was not the case for screenings in Cross River state.

BOX 1: Community Messages used Pre-Screening

Message 1: The continuous leakage of urine or feces or both through woman's private part is called a fistula.
Message 2: This condition can be completely treated through surgical operation in the hospital.
Message 3: The women who are identified with this condition at the screening will be operated free of charge.
Message 4: Women with other forms of leakage not related to fistula will be referred to other hospitals to get treatment, where they shall bear the cost of transportation and operations.

Selection of Health Care Providers and Training

Experienced female nurse-midwives were trained on diagnosis and documentation of fistula before the screening by Dr. Adamu Isah, Deputy Country Project Manager for Fistula Care and a fistula surgeon. This was an important part of our methodology as we wanted to show that screenings did not need to be conducted by fistula surgeons and/or obstetricians-gynecologists. In addition we wanted to assess this approach to address cultural sensitivities in the predominately Muslim communities in Kebbi State where female providers may be more acceptable. Also Dr. Tunçalp travelled to Nigeria to conduct training for the field research team and to oversee the first week of the community screening study for both states. The same team of research assistants and nurse-midwives have participated in all of the screenings to ensure continuity and comparability with minor modifications:

1) One research assistant could not come to the Cross River State screening exercise and was replaced by a new one.
2) Due to the addition of "degree of prolapse" on the diagnostic tool, Dr. Patience Odusolu, an obstetrician, assisted the nurse-midwives the first two days of the Cross Rivers state screening exercise.

The detailed field reports from Kebbi and Cross River state exercises have been previously submitted to EngenderHealth and are available upon request.

Participants

The study included women (including pregnant women) who presented for fistula screenings at study facilities based on their perceived fistula-like symptoms. Although it is rare, women may become pregnant with a fistula, therefore we did not exclude pregnant women. There were no exclusion criteria. On two occasions, we conducted five scheduled screening days for each site, for a total of 20 days.

Screening Procedures and Data Collection

While the women were waiting to be screened our research assistants invited the women to a private room to go over the consent form to participate in the study, and among those

who consented, administered the pre-screening questionnaire. Results of the clinical exam were recorded by the nurse-midwife on the clinical examination form. Finally, since the definitive diagnosis of the presence of a genito-urinary fistula is most reliable when obtained during the time of examination under anesthesia, diagnostic information will once again be collected immediately prior to surgery, when the patient is examined under anesthesia.

All of the women who showed up at the screening with fistula-like symptoms got a physical examination by the medical team to assess their condition and to make an initial diagnosis on whether they have an obstetric fistula, incontinence and/or uterine prolapse or some other condition. The women with fistula were scheduled for surgery within 2-6 months, depending on the caseload and surgeon availability, which will be provided for free through Fistula Care. Women with incontinence, uterine prolapse and other conditions were referred to local hospitals with the capacity to treat these conditions. For all consented women, we received the result of the medical assessment and their results following fistula surgery, where necessary.

Data Analysis and Data Monitoring

Instead of paper and pen data collection, we utilized the free program Epidata to enter the answers of the women during the interviews. This program allows implementation of alerts, error messages and skip patterns, and reduces the likelihood of entry errors as well as missing information. At the end of each day, the data from the medical form with the diagnosis filled out by the medical team were also entered into EpiData by the research assistants. After data entry, the Epidata files were double checked by Fistula Care's Monitoring and Evaluation officer (for the Nigeria project) to further ensure data quality. Then, all of these records were electronically sent to the co-investigators. These EpiData files were transferred to Stata by the co-investigators for data analysis. All the data analyses were conducted using Stata Version 12.

Additional Data Collection – Fistula Registries

In addition, to obtain historical estimates of the number of women repaired in the LGAs targeted for screening, limited data were abstracted from patient registers at local fistula repair centers. The following key variables were abstracted, where available, by Fistula Care's Monitoring and Evaluation Officer: patient id, age, duration of fistula, and LGA of provenance. Data were abstracted for all patient records between 2007-2011 in Kebbi and 2011-2012 in Cross River center.

Results

A 5-day screening was conducted in each selected LGA facility for both Kebbi and Cross River states for a total of 20 days of data collection. Overall, a total of 286 women attended these screenings: 88 in Kebbi State sites (July 9-20, 2012) and 180 in Cross River sites (November 27-December 7, 2012).

Table 1 summarizes the background characteristics of the clients attending the screenings. In terms of socio-demographic characteristics, clients from Cross River state were older, more likely to be widowed and with higher education. In both of the states, almost all of the clients lived in the LGA where the screenings were conducted. In terms of fistula-like symptoms, 56.8% of the women in Kebbi State exercise reported ever having fistula-like symptoms compared with 16% of women in Cross River state exercise.

Table 1: Background Characteristics of the Clients Attending Screenings in Kebbi State and Cross River State (N=286)

	Kebbi State (N=88) n (%)	Cross River State (N=180) n (%)	TOTAL (N=268) n (%)
Age			
Median (25%, 75%)	30 (23,40)	39.5 (28, 55)	35 (26, 50)
Religion			
Christian	0 (0)	179 (99.4)	179 (66.8)
Muslim	88 (100)	1 (0.6)	89 (33.2)
Marital Status			
Married/Cohabitating	54 (61.4)	98 (54.4)	152 (56.7)
Divorced/Separated	19 (21.6)	25 (13.9)	44 (16.4)
Widowed	13 (14.7)	47 (26.1)	60 (22.4)
Single	2 (2.3)	10 (5.6)	12 (4.5)
Education			
None	80 (90.9)	101 (56.1)	181 (67.5)
Primary	5 (5.7)	47 (26.1)	52 (19.4)
Secondary	3 (3.4)	21 (11.7)	24 (9.0)
More than secondary	0 (0)	11 (6.1)	11 (4.1)
LGA			
Argungu	39 (44.3)	n/a	39 (14.5)
Augie	48 (54.5)	n/a	48 (17.9)
Other-Kebbi	1 (1.2)	n/a	1 (0.37)
Bekwarra	n/a	82 (45.6)	82 (30.6)
Yala	n/a	92 (51.1)	92 (34.3)
Other-Cross River	n/a	6 (3.3)	6 (2.2)
Ever had fistula-like symptoms			
No	38 (43.2)	151 (83.9)	189 (70.5)
Yes	50 (56.8)	29 (16.1)	79 (29.5)

Fistula-like symptoms and related characteristics

The fistula-like symptoms were explored further among the women who responded positively to the qualifying question (i.e., ever had fistula-like symptoms; 50 women in Kebbi State and 29 women in Cross River State). *Table 2* summarizes the results from this section, which utilized the DHS module.

In both states, one third of women report having the symptoms between 1-5 years, with the majority reporting them after delivery, specifically after a difficult labor and delivery at home. Approximately 90% of the women in Kebbi report arriving at the facility after more than 12 hours of labor, whereas 26% in Cross River report arriving at the facility in less than 12 hours. The clients in Kebbi State report a higher percentage of C-section than those in Cross River, 44% and 20%, respectively. The majority of women report having a stillbirth as an outcome, 84% and 74% in Kebbi and Cross River states, respectively.

We also asked questions on treatment seeking and majority of the women in both of the states sought treatment from health care providers. Success rates after the latest treatment was low, only one woman in the Kebbi State exercise and three women in the Cross River State exercise reported no more leakage at all.

Table 2: Fistula-like symptoms and related characteristics reported by the clients attending Screenings in Kebbi State and Cross River State (N=79)

	Kebbi State (N=50) n(%)	Cross River State (N=29) n(%)	TOTAL* n(%)
Duration of the symptoms			
Within the last 12 months	12 (24.0)	3 (10.3)	15 (19.0)
1-5 years	15 (30.0)	10 (34.5)	25 (31.7)
More than 5 years	23 (46)	16 (55.2)	39 (49.3)
Precipitating Event			
After delivery	37 (80.4)	19 (73.1)	56 (77.8)
After some kind of illness	5 (10.9)	4 (15.4)	9 (12.5)
Spontaneous/Congenital	2 (4.3)	1 (3.8)	3 (4.2)
During pregnancy	2 (4.3)	0 (0.0)	2 (2.8)
After an operation	0 (0.0)	1 (3.8)	1 (1.4)
Don't Know	0 (0.0)	1(3.8)	1(1.4)
Delivery			
Normal labor/delivery	4 (10.8)	2 (10.5)	6 (10.7)
Difficult labor/delivery	33 (89.2)	17 (89.5)	50 (89.3)
Delivery Location			
Home	10 (27.0)	4 (21.1)	14 (25.0)
Hospital	27 (73.0)	15 (78.9)	42 (75.0)
Arrival time at the facility			
<12 hours	3 (11.1)	4 (26.7)	7 (16.7)
12-24 hours	13 (48.2)	5 (33.3)	18 (42.9)

	Kebbi State (N=50) n(%)	Cross River State (N=29) n(%)	TOTAL* n(%)
>24 hours	10 (37.0)	6 (40.0)	16 (38.1)
Don't Know	1 (3.7)	0 (0)	1 (2.3)
C-Section			
No	12 (44.4)	3 (20)	15 (35.7)
Yes	15 (55.6)	12 (80)	27 (64.3)
Stillbirth			
No	6 (16.2)	5 (26.3)	11 (19.6)
Yes	31 (83.8)	14 (73.7)	45 (80.4)
Treatment Seeking			
No	10 (20.0)	9 (31.0)	19 (24.1)
Yes	40 (80.0)	20 (69)	60 (75.9)
Last Treatment Sought From			
Health care provider	30 (75)	18 (90.0)	48 (80.0)
Untrained providers	10 (25)	2 (10)	12 (20.0)
Success after the latest treatment			
Yes, no more leakage at all	1 (2.5)	3 (15.0)	4 (6.7)
Yes, but still some leakage	19 (47.5)	4 (20.0)	23 (38.3)
Still have problem	20 (50.0)	13 (65.0)	33 55.0)

*Denominators may change depending on the question as certain questions.

Communication and Access to Screenings

The questionnaire also had a list of questions focusing on the reception of the communication messages and access to the screenings. *Table 3* summarizes the related findings. It should be noted that after the Kebbi State exercise, we added a set of specific questions on the correct understanding of specific messages used in the communities during the outreach activities; therefore we only have data from the Cross River State exercise.

As can be observed, the penetration of the messages was mixed. The free-of-charge fistula surgeries were heard the least frequently (56%), whereas the message related to the other forms of leakage being referred to other facilities bearing the costs were most frequently heard (83%).

The channels that the women heard about the screenings differed between the two states. In Kebbi state exercise, almost half of the women heard about the screenings from the village heads, which was negligible in Cross River. Community organizations, town criers and churches were the main channels in the Cross River exercise.

Transportation was another issue where the two state exercises differed. In Kebbi state almost 60% of the women came by car, whereas in Cross River state women used more than one vehicle, with a combination of motorcycle, car and foot.

In terms of accompaniment to the screenings, 85% of the women in Cross River state were by themselves, whereas only 52% of the women in Kebbi state came alone; the majority coming with a family member (11% with a husband) or a friend.

Table 3: Communication and Access to the Screenings in Kebbi State and Cross River State (N=268)

	Kebbi State (N=88) n(%)	Cross River State (N=180) n(%)	TOTAL (N=180) N (%)
Messaging			
The continuous leakage of urine or feces or both through woman's private part is called a fistula.	n/a	56 (65.9)	56 (65.9)
This condition can be completely treated through surgical operation in the hospital.	n/a	63 (74.1)	63 (74.1)
The women who are identified with this condition at the screening will be operated free of charge.	n/a	48 (56.5)	48 (56.5)
Women with other forms of leakage not related to fistula will be referred to other hospitals to get treatment, where they shall bear the cost of transportation and operations.	n/a	71 (83.5)	71 (83.5)
Hearing about the screenings			
Community organization	5 (5.7)	34 (18.9)	39 (14.5)
Radio spots	1 (1.1)	1 (0.6)	2 (0.7)
Family	19 (21.6)	17 (9.4)	36 (13.4)
Acquaintance/friend	8 (9.1)	7 (3.9)	15 (5.6)
Town crier	3 (3.4)	57 (31.7)	60 (22.4)
Village head	40 (45.4)	1 (0.6)	41 (15.3)
Church related staff	0 (0)	40 (22.2)	40 (14.9)
Health care staff	9 (10.2)	18 (10.0)	27 (10.1)
Other	3 (3.4)	5 (2.8)	8 (3.0)
Transportation to the screenings			
On foot	5 (5.7)	52 (28.9)	57 (21.3)
Motorcycle	24 (27.3)	81 (45.0)	105 (39.2)
Car	52 (59.1)	38 (21.1)	90 (33.6)
Taxi/Public Moto	7 (7.9)	8 (4.4)	15 (5.6)
Other	0 (0.0)	1 (0.6)	1 (0.4)

	Kebbi State (N=88) n(%)	Cross River State (N=180) n(%)	TOTAL (N=180) N (%)
Accompaniment to the screenings			
Alone	46 (52.3)	153 (85.0)	199 (74.2)
Husband	10 (11.4)	4 (2.2)	14 (5.2)
Mother/Father	7 (7.9)	4 (2.2)	11 (4.1)
Sister/Brother	4 (4.5)	7 (3.9)	11 (4.1)
Friend/Acquaintance	11 (12.5)	3 (1.7)	14 (5.2)
Other family	10 (11.4)	9 (5.0)	19 (7.1)

Medical Screening and Verification of the DHS Fistula Question

Table 4 summarizes the results of the medical examination. In the Kebbi state exercise, 26 women (29.4%) were diagnosed with a form of fistula, whereas only 12 women (6.7%) were diagnosed in Cross River. Cyctocele/rectocele is the most common diagnosis in Kebbi State (39.8%) and is the second most common diagnosis in Cross River state (5.6%), followed by uterine prolapse. However, in terms of absolute numbers, only 31 women in Cross River state were diagnosed with some form of uro-gynecological problem, whereas all 88 women in Kebbi state had one.

Table 4: Medical examination diagnoses in Kebbi State and Cross River State Screenings (N=268)

	Kebbi State (N=88) n(%)	Cross River State (N=180) n(%)	TOTAL (N=268) n(%)
Urinary fistula	23 (26)	10 (5.6)	33 (12.3)
Rectovaginal fistula	3 (3.4)	2 (1.1)	5 (1.9)
Stress Incontinence	6 (6.8)	2 (1.1)	8 (3.0)
Cyctocele/Rectocele	35 (39.8)	10 (5.6)	45 (16.8)
Uterine prolapse	21 (23.9)	7 (3.9)	28 (10.5)
Other (non urogyn related)	0 (0.0)	149 (82.8)	149 (55.6)

Prevalence of fistula (urinary and rectal) was 14% (n=38) in the medical screening. In order to verify the reporting of the fistula-like symptoms with the actual diagnosis of fistula, we have calculated women reporting current fistula-like symptoms in the questionnaire and compared it to the women medically diagnosed with fistula at the screening.

For this calculation three questions in the DHS module were used: ever had fistula like symptoms, seeking care and outcome of care. Women reporting CURRENT fistula-like symptoms are calculated by subtracting the women reporting getting treatment with

success (no leakage) from the women reporting ever having fistula-like symptoms. The prevalence among our study population was 28% (n=75). Verification assessment [5]shows that the question has 92% sensitivity, 83% specificity with 47% positive predictive value and 98% negative predictive value (*Table 5*). We also re-calculated excluding all the women in Cross River state with non-gynecological ailments. This time, sensitivity was 50%, specificity 94%, positive predictive value 92% and negative predictive value 57% (results not shown). Given that for project purposes, sensitivity is more important than positive predictive value, this change did not improve reporting.

Table 5: Reporting of current fistula-like symptoms versus fistula diagnosis

	Medical Screening for Fistula		
Current fistula-like symptoms reported	**No**	**Yes**	**Total**
No	190	3	193
Yes	40	35	75
Total	230	38	268

Provenance and Exploring Prevalence Estimation

As part of this study, we also explored the feasibility of estimating minimum estimates of prevalence at the individual district level and further extrapolation to the state-level. In order to do that, we collected data from the registries in the fistula repair centers.

We collected basic data on the following groups (N=630).

1) 499 fistula cases operated at Kebbi Center in Birnin Kebbi between 2007 and 2011
2) 93 fistula cases operated at Ogoja Center in Cross River
3) 38 new fistula cases diagnosed in both of the screening states in 2012. Tentative operation times for the last group will be the first half of 2013

[5] Sensitivity and specificity are measures of accuracy detected by a diagnostic test; that is, sensitivity is the percentage of all true cases of a condition, which were identified by a diagnostic test (in this case, a screening question). Likewise, specificity is the percentage of all true non-cases, which were identified as such by the same diagnostic test. Sensitivity and specificity estimates reflect accuracy relative to the truth (ie, here, the clinical truth). Positive and negative predictive value estimates reflect accuracy relative to the diagnostic test; that is, among all positive responses from the diagnostic test (ie, screening question), what percent are true clinically-defined cases. Likewise, negative predictive value represents the percentage of all negative responses from the diagnostic test that are true clinically-defined non-cases. Thus, the primary difference between sensitivity/specificity and positive and negative predictive value is the denominator, which changes the interpretation of the indicator.

Table 6 summarizes where these patients live (based on data availability at the registers and the majority of the women come from the highlighted LGAs.)

The majority of the 545 women for whom we have information on place of delivery delivered at a facility (83.5% vs. 16.5%). Furthermore, the majority of the 446 women for whom we have information on the duration of leakage had it for less than one year (68.3%).

Table 6: Provenance data for the fistula patients (2007-2012)

Kebbi State (N=409)	**n (%)**	**Cross River State (N=101)**	**n (%)**
Aliero	10 (2.4)	Abi	2 (2.0)
Arewa	21 (5.1)	Bekwarra	21 (20.8)
Argungu	51 (12.5)	Boki	9 (8.9)
Augie	26 (6.4)	Etung	2 (2.0)
Bagudo	34 (8.3)	Ikom	8 (7.9)
Birnin Kebbi	37 (9.1)	Mbube east	1 (1.0)
Bunza	14 (3.4)	Obanliku	9 (8.9)
Dandi	8 (2.0)	Obubra	5 (4.9)
Dansadau	1 (0.2)	Obudu	7 (6.9)
Fakai	10 (2.4)	Ogoja	14 (13.9)
Gulbe	1 (0.2)	Yala	23 (22.8)
Gulma	1 (0.2)		
Gwandu	23 (5.6)		
Jega	29 (7.1)	Abuja (N=1)	
Kalgo	18 (4.4)	Gwagwalada	
Kebbe	1 (0.2)		
Koko Besse	25 (6.1)	Akwa Ibom(N=1)	
Maiyama	16 (3.9)	Calabar	
Ngaski	4 (1.0)		
Sakaba	8 (1.9)		
Sangelu	1 (0.2)		
Shanga	7 (1.7)		
Suru	17 (4.2)		
Wasagu/Danko	11 (2.7)		
Yauri	11 (2.7)		
Zuru	24 (5.9)		

Our analysis plan was to incorporate the facility register data with the screening exercise data and utilize the CBO data in Kebbi state to identify a correction factor in terms of women who were already identified in the communities by the CBOs but who did not come to the screenings. In Cross River state, we would estimate the minimum point prevalence estimate. Two factors limited our analyses:

1- In Kebbi state, CBOs did not have a list of women in the communities with fistula-like symptoms that they were able to share with us.
2- In Cross River state, as will be discussed in the conclusions, we were faced with challenges in messaging and transportation, which led us to conclude that we did not receive as many women with fistula-like symptoms in our screenings as possible.

In light of these results, we have concluded that these data and calculations would not support the estimation of prevalence in LGAs or further extrapolation for the states.

CONCLUSIONS

Our results show that this methodology, which was built on the exercise conducted in Ebonyi State in Nigeria, proves to be a feasible approach for identifying backlog of women needing surgery in the LGAs where the screenings were conducted. The methodology involves community outreach followed by screening by nurse-midwives at lower level facilities. According to our results, with the assumption that everyone with fistula came within the two LGAs where the screenings took place, the backlog is 26 clients in Kebbi state sites (Augie and Argungu) and 12 clients in Cross River state sites (Bekwarra and Yala). Moreover, this exercise identified related morbidities such as cyctocele/rectocele (35 clients and 10 clients in Kebbi and Cross River respectively) as well as uterine prolapse (21 clients and 7 clients in Kebbi and Cross River respectively).

During this exercise, we had also verified the fistula questions used in the DHS. Our analysis showed that the DHS fistula question when used for screening purposes among women with perceived fistula symptoms has 92% sensitivity, 83% specificity with 47% positive predictive value and 98% negative predictive value[6].

This approach is a good use of financial and human resources as the health care staff consists of nurse-midwives rather than obstetrician-gynaecologists and the screenings are conducted at lower-level facilities. However important lessons were learnt that could be used to refine this approach for future use in states and governments planning services for their populations.

For this approach to be successful, it is essential to have community participation and ownership by the community leaders as well as government officials. This can be easily observed looking at the two different state exercises. In Kebbi state, government officials provided transportation throughout the screening exercises and also village heads were more active in disseminating the messages. In contrast, in Cross River, despite multiple requests and continuing communication, local government did not provide transportation support for the screening activity. Coupled with the wide geographic distribution of

[6] Note, these estimates of sensitivity, specificity and positive/negative predictive value do not represent the *validity* of DHS fistula module questions as the assessment was restricted to women with perceived fistula-like symptoms and not to a sample of women of reproductive age.

hamlets in Cross River, the access for women with fistula-like symptoms was hindered. At this point, it should be noted that EngenderHealth has been active in Kebbi State even before the Fistula Care project started, which underlines the strong community and administrative relationships. Moreover, Fistula Care activities in Cross River state started less than two years ago, where the project first focused on capacity for the services before engaging with the communities and creating demand.

Recommendation: Transportation should be an essential element of community-based fistula screening programs.

Another factor, which needs to be highlighted, is the importance of messaging and the readiness to manage local factors. Unlike in Hausa (spoken in Kebbi state), there is not one word for fistula in the languages spoken in the Cross River state. This led to community partners using "reproductive health problems" to describe the reason for the screenings rather than "fistula". As can be observed in our data, this message was further diluted and majority of the women showed up at the screening with other ailments, whereas in Kebbi state all of the 88 women had some form of uro-gynecological problems ranging from fistula to urinary incontinence. Even though the number of women coming to the facilities for the screenings was below our expectations in both of the states, the exercise in Kebbi was more successful in terms of identifying the backlog of fistula patients needing surgery.

Recommendation: Stronger ties with communities and better messaging strategies are crucial for success in identifying fistula cases in community-based fistula programs.

Our study also raises a question regarding how to manage other uro-gynecological problems such as uterine prolapse as well as post-surgery leakages. For example, all of the eight women diagnosed with "urinary incontinence" in the medical screening were post-surgery patients (and prolapse was the second most common diagnosis). Women who present with uterine prolapse (and are not fistula patients) are currently not covered under the mandate of Fistula Care; however if a woman presents with fistula and has prolapse, the surgery to correct the prolapse is covered by the project[7]. Fistula Care has prepared a concept paper on the implications of integrating uterine prolapse repair (and possibly other pelvic floor disorders) with fistula repair services for USAID's consideration[8]. Women who have had fistula repair surgery and have remaining urinary incontinence can receive continuing care and treatment through Fistula Care; women are advised to do pelvic floor exercises; some may require a second surgery if the fistula is not quite closed to eliminate the incontinence. In order to effectively determine the reasons for the remaining incontinence we need to better understand why it is happening in order to prescribe the appropriate treatment. EngenderHealth has prepared a concept paper for further research on this issue but has yet to find the funding to implement the study. Integration of treatment for pelvic floor disorders into fistula services has resource and training implications.

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[7] Fistula Care began collecting this information in October 2009; to date in Nigeria 317 uterine prolapse repairs have been conducted among 6,186 fistula repair surgeries (5%).

[8] Fistula Care. 2011. Programming Considerations for Integrating Uterine Prolapse and Fistula Services. Submitted to USAID as part of the 2011 management review.

Recommendation: Future fistula programs (including training programs for surgeons) should consider providing care for women afflicted by related uro-gynecological problems such as uterine prolapse and identify appropriate treatment regimens for women with post-surgery leakages.

Analysis of the registry data from the fistula repair centers in both states shows that women who are identified in the screenings are more likely to have had fistula for a longer period of time (1-5 years versus less than one year), which underlines the importance of the community-based approach in terms of reaching a different population than the ones reached by the surgery efforts at the fistula repair centers.

The original plan of comparing lists of specific women identified by CBOs as having fistula-type symptoms against the list of women who present at fistula screenings (and are identified as a fistula case) remains a worthwhile exercise, where possible, for estimating the backlog of fistula cases.

Follow-up Actions

- Fistula Care Nigeria will be following up the referrals in both states to ensure that the women with fistula received further evaluation and surgery. Moreover, the team will follow up on the referrals due to other uro-gynecological problems. The results from this exercise will also be incorporated into the results of this study.

- To share this approach and lessons learnt with a wider audience we are willing to draft a manuscript to be submitted to a peer-reviewed journal. We are envisioning this manuscript as a programmatic paper on introducing community-based screening of fistula as a feasible approach to identify potential backlog of women needing surgery in Nigeria and similar contexts. The paper will also underline the lessons learnt. Possible journals for submission are International Journal of Gynaecology and Obstetrics, BMC Pregnancy and Childbirth, Tropical Medicine and International Health.

APPENDICES

Appendix 1: Pre-screening Questionnaire Kebbi State
Appendix 2: Pre-screening Questionnaire Cross River State

PRE-SCREENING INTERVIEW (KEBBI, NIGERIA)

	SCREENING ID NUMBER	☐☐☐☐	
#	**QUESTIONS**		**SKIP**
	BACKGROUND INFORMATION		
1.	What is your age?	☐☐	
2.	Which religion do you belong to?	Christian……0 Muslim……1 Other……2 If Other, please specify_____	
3.	What is your marital status?	Married/Cohabitating……0 Divorced/Separated……1 Widowed……2 Single……3	
4.	What is the highest degree of formal education that you attained? *(Not including Islamic/Arabic education)*	None……0 Primary……1 Secondary……2 More than Secondary……3 Don't Know/Missing……9	
5.	Which community do you currently live in?	_____	
6.	Which LGA do you currently live in?	Argungu……0 Augie……1 Aleiro……2 Arewa-Dandi……3 Bagudo ……4 Birnin Kebbi ……5 Bunza ……6 Dandi ……7 Fakai ……8 Gwandu ……9 Jega ……10 Kalgo ……11 Koko/Besse ……12 Maiyama ……13 Ngaski ……14 Sakaba……15 Shanga ……16 Suru ……17 Wasagu/Danko ……18 Yauri ……19 Zuru……20 IF OTHER, please specify the STATE……21 _____	
7.	How would you describe where you live? *(RA responds based on the prior answers)*	Urban……0 Rural……1 Don't know……9	
	REPRODUCTIVE HEALTH		
8.	Now I would like to ask about all the births you have had during your life. Have you ever given birth before?	NO……0 YES……1	If NO, skip #12
9.	How many sons or daughters to whom you have given birth are alive?	SONS ☐ DAUGHTERS ☐	
10.	Have you ever given birth to a boy or a girl who was born alive but later died?	NO……0 YES……1	If NO, skip to #12

11.	How many boys or girls have died like this?	Boys dead ☐ Girls dead ☐	
12.	Have you ever lost a pregnancy? It might be spontaneously or when you or someone else had to do something to end the pregnancy.	NO……0 YES……1	If NO, skip to #14
13.	How many pregnancies have you lost in your lifetime?	☐	
14.	Some women have stillbirths, that is, they give birth in late pregnancy to a dead child. Have you ever had a stillbirth?	NO……0 YES……1	If NO, skip to #16
15.	How many stillbirths have you had in your lifetime?	☐	
	FISTULA-LIKE SYMPTOMS (DHS) Sometimes a woman can have a problem such that she experiences a constant leakage of urine or stool from her vagina during the day and night. This problem usually occurs after a difficult childbirth, but may also occur after a sexual assault or after a pelvic surgery. This is called vesicovaginal fistula (VVF).		
16.	Have you ever experienced a constant leakage of urine or stool from your vagina during the day and night?	NO……0 YES……1	IF NO, skip to #31
17.	Did this problem occur within the last 12 months?	NO……0 YES……1	IF YES, skip to #19
18.	What year did this problem occur?	☐☐☐☐	
19.	Did this problem occur after a delivery?	NO……0 YES……1	If YES, skip to #20
b.	Did this problem occur after an operation in your pelvic area? (pelvic surgery)	NO……0 YES……1	If YES, skip to #26
c.	Did this problem occur after some other event?	NO……0 YES……1 If OTHER, please specify_____2	
	RA CONFIRMATION QUESTION FOR THE TOOL: Problem after delivery?	NO……0 YES……1	If NO, skip to #26
20.	Did this problem occur after a normal labor and delivery, or after a very difficult labor and delivery?	Normal Labor/Delivery……0 Very Difficult Delivery……1	
21.	Where did the delivery take place?	Home……0 Facility……1	If HOME, skip to #24
22.	How long after the labor pains began did you go to the facility?	<12 hours……0 12-24 hours……1 >24 hours……2 I don't know……9	
23.	Did you get a cesarean section at the facility?	NO……0 YES……1	
24.	Was this baby born alive?	NO……0 YES……1	
25.	After which delivery did this occur?	Delivery Number ☐	
26.	How many days after (ANSWER TO QUESTION #19) did the leakage start?	Number of days after the precipitating event ☐ (Enter 99, if more than 99 days)	
27.	Have you sought treatment for this condition?	NO……0 YES……1	If YES, skip to #29

28.	Why have you not sought treatment? *(Multiple options available)*	Did not know how it could be fixed……0 Do not know where to go……1 Too expensive……2 Too far……3 Poor quality of care……4 Could not get permission……5 Embarrassment……6 If Other, please specify_____ _____7	
	RA CONFIRMATION QUESTION FOR THE TOOL: Treatment sought?	NO……0 YES……1	If NO, skip to #31
29.	From whom did you last seek treatment?	Health Professional Doctor/Clinical Officer……0 Nurse/Midwife……1 Patient Attendant……2 Other Person Untrained village doctor……3 Traditional Birth Attendants (TBA)……4 If Other, please specify_____5	
30.	Did the treatment stop the problem?	YES, No more leakage at all……0 YES, But still some leakage……1 NO, Still have problem……2	
31.	Are there any (other) women in your household who suffer from vesicovaginal fistula/obstetric fistula?	NO……0 YES……1	
32.	How many (other) women in your household suffer from vesicovaginal fistula/obstetric fistula?	Number ☐☐ Don't Know……99	If NO, skip to #34
33.	Did she/they come or are they planning to come to the screening?	NO……0 YES……1 Don't Know……9	
	COMMUNICATION		
34.	How did you hear about the screening today?	The community organization……0 The radio spots……1 Family……2 Acquaintance/Friend……3 Town Crier……4 Fistula patients……5 If Other, please specify_____6	
35.	How did you get to the clinic today? *(Multiple options available)*	On foot……0 By bicycle……1 By motorcycle……2 By car……3 By taxi/public moto……4 By train……5 By cart……6 By using animals such as donkey, camel etc..7 If Other, please specify_____8	
36.	Did you come to the screening by yourself?	NO……0 YES……1	If YES, skip to the END
37.	Who accompanied you to the screening?	Husband……0 Mother/Father……1 Sister/Brother……2 Friend/Acquaintance……3 If Other, please specify_____4	
THANK YOU VERY MUCH FOR YOUR TIME. NOW, I'LL TAKE YOU BACK TO THE WAITING AREA.			

PRE-SCREENING INTERVIEW (CROSS RIVER, NIGERIA)

	SCREENING ID NUMBER	☐☐☐☐	
#	**QUESTIONS**		**SKIP**
	BACKGROUND INFORMATION		
38.	What is your age?	☐☐	
39.	Which religion do you belong to?	Christian……0 Muslim……1 Other……2 If Other, please specify_____	
40.	What is your marital status?	Married/Cohabitating……0 Divorced/Separated……1 Widowed……2 Single……3	
41.	What is the highest degree of formal education that you attained? *(Not including Islamic/Arabic education)*	None……0 Primary……1 Secondary……2 More than Secondary……3 Don't Know/Missing……9	
42.	Which community do you currently live in?	_____	
43.	Which LGA do you currently live in?	Bekwarra……0 Yala……1 Abi……2 Akamkpa……3 Akpabuyo……4 Bakassi……5 Biase……6 Boki……7 Calabar Municipal……8 Calabar South……9 Etung……10 Ikom……11 Obanliku……12 Obubra……13 Obudu……14 Odukpani……15 Ogoja……16 Yakurr……17 IF OTHER, please specify the STATE……18 _____	
44.	How would you describe where you live? *(RA responds based on the prior answers)*	Urban……0 Rural……1 Don't know……9	
	REPRODUCTIVE HEALTH		
45.	Now I would like to ask about all the births you have had during your life. Have you ever given birth before?	NO……0 YES……1	If NO, skip #12
46.	How many sons or daughters to whom you have given birth are alive?	SONS ☐ DAUGHTERS ☐	
47.	Have you ever given birth to a boy or a girl who was born alive but later died?	NO……0 YES……1	If NO, skip to #12

48.	How many boys or girls have died like this?	Boys dead ☐ Girls dead ☐	
49.	Have you ever lost a pregnancy? It might be spontaneously or when you or someone else had to do something to end the pregnancy.	NO……0 YES……1	If NO, skip to #14
50.	How many pregnancies have you lost in your lifetime?	☐	
51.	Some women have stillbirths, that is, they give birth in late pregnancy to a dead child. Have you ever had a stillbirth?	NO……0 YES……1	If NO, skip to #16
52.	How many stillbirths have you had in your lifetime?	☐	
	FISTULA-LIKE SYMPTOMS (DHS) Sometimes a woman can have a problem such that she experiences a constant leakage of urine or stool from her vagina during the day and night. This problem usually occurs after a difficult childbirth, but may also occur after a sexual assault or after a pelvic surgery. This is called vesicovaginal fistula (VVF).		
53.	Have you ever experienced a constant leakage of urine or stool from your vagina during the day and night?	NO……0 YES……1	IF NO, skip to #31
54.	Did this problem occur within the last 12 months?	NO……0 YES……1	IF YES, skip to #19
55.	What year did this problem occur?	☐☐☐☐	
56.	Did this problem occur after a delivery?	NO……0 YES……1	If YES, skip to #20
b.	Did this problem occur after an operation in your pelvic area? (pelvic surgery)	NO……0 YES……1	If YES, skip to #26
c.	Did this problem occur after some other event?	NO……0 YES……1 If OTHER, please specify_____2	
	RA CONFIRMATION QUESTION FOR THE TOOL: Problem after delivery?	NO……0 YES……1	If NO, skip to #26
57.	Did this problem occur after a normal labor and delivery, or after a very difficult labor and delivery?	Normal Labor/Delivery……0 Very Difficult Delivery……1	
58.	Where did the delivery take place?	Home……0 Facility……1	If HOME, skip to #24
59.	How long after the labor pains began did you go to the facility?	<12 hours……0 12-24 hours……1 >24 hours……2 I don't know……9	
60.	Did you get a cesarean section at the facility?	NO……0 YES……1	
61.	Was this baby born alive?	NO……0 YES……1	
62.	After which delivery did this occur?	Delivery Number ☐	
63.	How many days after (ANSWER TO QUESTION #19) did the leakage start?	Number of days after the precipitating event ☐ (Enter 99, if more than 99 days)	
64.	Have you sought treatment for this condition?	NO……0 YES……1	If YES, skip to #29

65.	Why have you not sought treatment? *(Multiple options available)*	Did not know how it could be fixed……0 Do not know where to go……1 Too expensive……2 Too far……3 Poor quality of care……4 Could not get permission……5 Embarrassment……6 If Other, please specify_____ _____7	
	RA CONFIRMATION QUESTION FOR THE TOOL: Treatment sought?	NO……0 YES……1	If NO, skip to #31
66.	From whom did you last seek treatment?	Health Professional Doctor/Clinical Officer……0 Nurse/Midwife……1 Patient Attendant……2 Other Person Untrained village doctor……3 Traditional Birth Attendants (TBA)……4 If Other, please specify_____5	
67.	Did the treatment stop the problem?	YES, No more leakage at all……0 YES, But still some leakage……1 NO, Still have problem……2	
68.	Are there any (other) women in your household who suffer from vesicovaginal fistula/obstetric fistula?	NO……0 YES……1	
69.	How many (other) women in your household suffer from vesicovaginal fistula/obstetric fistula?	Number ☐☐ Don't Know……99	If NO, skip to #34
70.	Did she/they come or are they planning to come to the screening?	NO……0 YES……1 Don't Know……9	
	COMMUNICATION		
71.	How did you hear about the screening today?	The community organization……0 The radio spots……1 Family……2 Acquaintance/Friend……3 Town Crier……4 Fistula patients……5 If Other, please specify_____6	
	Please let me know if you remember hearing any of the following messages (between questions 35-38):		
72.	The continuous leakage of urine or feces or both through woman's private part is called a fistula.	NO……0 YES……1 Don't Know……9	
73.	This condition can be completely treated through surgical operation in the hospital.	NO……0 YES……1 Don't Know……9	
74.	The women who are identified with this condition at the screening will be operated free of charge.	NO……0 YES……1 Don't Know……9	
75.	Women with other forms of leakage not related to fistula will be referred to other hospitals to get treatment, where they shall bear the cost of transportation and operations.	NO……0 YES……1 Don't Know……9	

76.	How did you get to the clinic today? *(Multiple options available)*	On foot……0 By bicycle……1 By motorcycle……2 By car……3 By taxi/public moto……4 By train……5 By cart……6 By using animals such as donkey, camel etc..7 If Other, please specify_____8	
77.	Did you come to the screening by yourself?	NO……0 YES……1	If YES, skip to the END
78.	Who accompanied you to the screening?	Husband……0 Mother/Father……1 Sister/Brother……2 Friend/Acquaintance……3 If Other, please specify_____4	
THANK YOU VERY MUCH FOR YOUR TIME. NOW, I'LL TAKE YOU BACK TO THE WAITING AREA.			

Name of the interviewer:

Date of the interview:

day	month	year