



ISSUES IN PUBLIC HEALTH RESPONSE

The Campaign to End Fistula: What have we learned? Findings of facility and community needs assessments

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KEYWORDS

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Abstract

Objective: To present a summary of the findings of the fistula needs assessments that have been conducted through the Campaign to End Fistula in 25 countries in Africa and Asia to expand knowledge on the issue related to causes and impact, country capacity to manage the problem and clinical and programmatic gaps. *Method:* The methodology of the assessments was qualitative and quantitative, and included focus group discussions; in-depth interviews/narratives; key informant interviews; and review of medical records, with slight variations by country. *Results:* Analysis of 20 of these assessments provides insight into the capacities, gaps, and perspectives specific to each country regarding fistula prevention and treatment and the social reintegration of treated women. *Conclusion:* Needs assessment findings have been key tools to spark action and guide the implementation of national programs to eliminate obstetric fistulas throughout Africa and Asia. © 2007 International Federation of Gynecology and Obstetrics. Published by Elsevier Ireland Ltd. All rights reserved.

1. Introduction

Obstetric fistula (OF) is a devastating condition for millions of women in developing countries—with severe consequences for their families and communities—that has remained relatively overlooked. This neglect is evidenced by the paucity of information on the extent of the problem, its underlying causes, treatment capacity, and patients' experience. Launched by the United Nations Population Fund (UNFPA) and partners in 2003, the Campaign to End Fistula is now

drawing attention, commitment, and resources to eliminate OF worldwide.

One of the critical components of the Campaign is to assess the situation regarding OF in each country, including the country's capacity to manage the problem and the clinical and programmatic gaps that need to be remedied. Needs assessments have been completed in the 25 following countries: Bangladesh, Benin, Burkina Faso, Cameroon, Central African Republic, Chad, Democratic Republic of Congo, Djibouti, Equatorial Guinea, Eritrea, Ghana, Kenya, Malawi, Mali, Mauritania, Mozambique, Niger, Nigeria, Rwanda, Sierra Leone, Somalia, Sudan, Tanzania, Uganda, and Zambia. Now that the needs assessments are completed, a clearer understanding of OF, of the affected women, and of the efforts needed to tackle this public health problem is emerging.

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2. The cost of giving birth

For each of the half million women who die in pregnancy and childbirth each year, approximately 20 to 50 experience morbidities which, if left untreated, can cause lifelong pain and humiliation [1]. Inaccessible quality maternal health care, along with a host of socio-cultural and economic factors, make pregnancy- and childbirth-related morbidity the second leading cause of lost years of healthy life among women of reproductive age in developing countries (Personal communication, World Health Organization [WHO], 2004).

Obstetric fistula is considered among the most severe of these morbidities. It is suspected that most of the estimated 2 million women living with fistulas are from Africa, parts of Asia, and the Arab region [2].

Extrapolations based on WHO burden of disease estimates suggest a potential annual incidence of 50,000 to 100,000 new cases each year [3], but some health providers have proposed that the incidence may be as high as 2 to 5 cases per 1000 deliveries in areas that lack access to emergency obstetric care [4]. Accurate population-based data, however, are almost non-existent, reflecting the fact that women with fistulas have been systematically overlooked.

3. The Campaign to End Fistula

While many individual efforts to manage OF have been underway worldwide for decades, governments, donors, and health professionals often did not recognize the condition as a public health problem until recently. In response to emerging evidence of the devastating impact of fistula on women and the social fabric, UNFPA with myriad partners launched the Campaign to End Fistula in 2003. The Campaign aims to make fistulas as rare in developing countries as they are in industrialized countries today, and to highlight the broader issues of maternal health, reproductive health and rights, and gender equity.

The Campaign includes more than 40 countries throughout sub-Saharan Africa, Asia, and the Arab region. At the national level, the Campaign is working to prevent fistulas from occurring, treat women who are affected, and help them reintegrate into society. Each Campaign country carries out 3 programmatic phases at its own pace. It first conducts a needs assessment to gauge the national situation regarding OF; in response to the findings, key national stakeholders develop a national fistula elimination strategy or plan; and then, all implement the strategy as part of their broader reproductive health and safe motherhood programs.

4. Methods

In 2003, EngenderHealth and UNFPA conducted the first large-scale mapping exercise in 9 African countries to build the body of knowledge on fistulas [4]. This was followed by similar exercises in other countries in Africa, Asia, and the Arab regions. While the initial 9 countries were studied together, the exercises that followed were conducted separately in the different countries and initiated at the national level. By the end of 2005, fistula needs assessments were completed for 25 countries and further assessments were conducted for almost all of the initial 9 countries. The assessments were intended to raise awareness on

OF and to draw information for advocacy and programming purposes. Most of the needs assessment reports can be found at www.fistulanetwork.org. Others can be obtained by request to fistulacampaign@unfpa.org. The present article examines and summarizes the findings from 20 of the countries [4–22].

Based on a 9-question survey instrument, the methodological approach of the needs assessments was both qualitative and quantitative, with variations between countries to reflect the national context. The needs assessments that followed the initial 9-country assessment typically were broader in scope and depth. Table 1 provides an overview of the coverage and different methods utilized for each assessment. All assessments were conducted with approval from the different Ministries of Health.

Typically, the assessments included a background document review and interviews with key informants such as policy makers, service providers, affected women, community members, and community-based and non-governmental organizations. The interviews were conducted using structured and semistructured questionnaires.

In a number of countries, qualitative assessment methods were applied to determine the socio-cultural factors contributing to OF incidence and influencing its consequences. These methods included focus group discussions, in-depth interviews/narratives, and key informant interviews. Most reports noted that respondents were informed about the study and included their written consent.

Medical aspects of the surveys addressed issues of availability, service provision, and utilization of obstetric services. In each country health facilities were visited, mostly national, regional, and district hospitals, but sometimes local health centers as well. Existing records were also reviewed in most countries to obtain trends, evaluate the magnitude of the problem, and estimate the resources used to treat women with fistulas.

The initial 9-country assessment was conducted by a team from EngenderHealth consisting of 1 physician and 1 program staff member. For ensuing assessments, teams included some or all of the following: Ministry of Health staff, epidemiologists, public health consultants, urologists or obstetrician/gynecologists, midwives, and anthropologists. Most assessments were designed and overseen by committees headed by the Ministry of Health.

5. Findings

This analysis focuses on findings regarding the substantive areas of prevention, treatment, and patient reintegration from 20 of the countries. Because of national variations in methods and scope, comparing findings between countries was not feasible. Instead, this article presents a summary of findings across countries to give a broad perspective of the situation and facilitate access to key information from the reports.

5.1. Prevention

In a number of the assessments, the prevention component was based mainly on data from existing studies and data related to fistula occurrence such as contraceptive prevalence, access to emergency obstetric care, maternal mortality ratios, and mean age at marriage and during the index

Table 1 Overview of methods utilized

Assessment	Coverage	Site visits	Register review	Interviews with						Focus groups			Community survey
				Policy makers	Health personnel	Fistula patients	Relatives	TBAs	NGOs	Fistula patients	Women	Men	
9-country assessment ^a	Rapid national; selected site visits	X	X	X	X	X				X			
Bangladesh 2003 ^b	National; 6 unions for community survey	X		X	X	X	X	X					X
Burkina Faso 2004	National	X	X		X	X							
Burkina Faso (socio-cultural) 2004	2 districts in each of 3 health regions				X	X				X	X		
Cameroon 2004	2 provinces		X	X	X	X	X	X			X	X	
Central African Republic 2005	8 districts in 6 health regions		X		X	X					X	X	
DR Congo 2005	6 provinces	X		X	X	X							
Equatorial Guinea 2005	National				X	X		X					X
Eritrea 2003 ^c	National					X					X	X	
Eritrea 2005	NA					X	X						
Kenya 2004	5 districts	X		X	X				X		X	X	
Malawi 2005	National	X	X		X	X							
Mali 2003	National record review; 6 zones for interviews		X		X	X			X				X
Mauritania 2004	3 willayas	X			X	X							
Nigeria 2003	National	X		X	X				X				
Somalia 2005	Selected sites in Somaliland and Puntland	X		X	X				X				
Tanzania 2002 ^d	National												
Uganda 2003	National	X	X	X	X	X			X				
Zambia 2004	National	X	X			X					X		

Abbreviations: TBAs, traditional birth attendants; NGO, non-governmental organizations.

^a Includes Benin, Chad, Malawi, Mali, Mozambique, Niger, Nigeria, Uganda and Zambia.

^b Study included interviews with community members and a focus group discussion with experts.

^c Study included physical examination.

^d Mailed survey to health facilities.

Table 2 Indicators of maternal health care among rural women^a

Country	Indicator	
	Births with skilled attendants	Rate of cesarean deliveries
Bangladesh 2004	11.1	2.2
Benin 2001	70.5	1.6
Burkina Faso 2003	30.9	0.4
Cameroon 2004	45.3	0.7
Central African Republic 1994–1995	23.7	1.6
Chad 2004	7.6	0.1
DR Congo ^b	61	–
Equatorial Guinea ^c	65	–
Eritrea 2002	11.5	0.8
Kenya 2003	34.5	3.0
Malawi 2000	50.5	2.4
Mali 2001	27.4	0.5
Mauritania 2000–2001	29.1	1.5
Mozambique 2003	35.6	0.6
Niger 1998	8.1	0.3
Nigeria 2003	29.3	1.1
Somalia ^d	19.5	–
Tanzania 2004	59.6	2.4
Uganda 2000–2001	33.4	1.9
Zambia 2001–2002	27.1	1.2

^a The source was ORC Macro, 2006, using the MEASURE DHS STATcompiler; the values are given as percentages.

^b Multiple Indicator Cluster Surveys (MICS; UNICEF surveys) 2001.

^c MICS 2000.

^d MICS 1999.

pregnancy (which ended in a fistula). As shown in Table 2, maternal health indicators in rural areas across these countries are highly suggestive of populations with limited access to care. For example, fewer than 1 in 3 births are assisted by a professional attendant in 11 of the 20 countries, and the rates of cesarean deliveries are less than 2% in the rural areas of 13 of the countries. None of the 20 countries report a rural cesarean delivery rate higher than 3%, although the lower limit recommended by WHO is 5%.

The assessments almost universally attributed poverty as the underlying cause of OF because of its relation to poor health, insufficient nutrition, stunted growth, limited access to maternal health care, illiteracy, and a culture of early marriage and pregnancy. A number of countries also analyzed the socio-demographic characteristics of women with OFs. As expected, most of the assessments showed that young, primiparous, illiterate women from rural regions formed the largest group of women with OFs. However, in some countries, high proportions of older, multiparous women also had OFs.

For women who experienced obstetric complications, assessments revealed a host of factors hindering their access to emergency obstetric care, correlating closely with the 3 classic delays, i.e., delay to seek care, to reach a facility, and to receive care at the facility. Table 3 provides an overview of barriers highlighted in the assessments and identified mostly through key informant interviews and focus group discussions.

In a few countries, such as Burkina Faso and Malawi, it was reported that women and their families do not prepare for childbirth owing to the belief that preparations can bring on misfortune [4,7]. Large proportions of women also reported giving birth at home or with a traditional birth attendant (TBA), and in one district in Kenya 70% to 80% of deliveries were assisted by a TBA [14]. As noted in Table 3, a variety of socio-cultural and geographic factors influence where a woman delivers, including a traditional preference for the first birth to occur at the grandparents or husbands' home. Assessments indicated that women's positive perceptions of TBAs and the low cost of their services serve as impediments to seeking facility-based care. Poor provider attitudes toward rural women or those who had no antenatal care also often play a role in dissuading women from seeking their services, as noted by focus group discussants in Zambia:

Nurses get angry and shout at relatives when a woman has been in labour for many days without being brought to hospital... Health workers don't respect the judgment of relatives who take patients to the health centre even when a patient is brought in as a stretcher case. They may insist that she is still very far from delivering [22].

Table 3 shows that women exercise limited decision-making regarding their own health care at the time of delivery. In both Bangladesh and Burkina Faso, it was noted that mothers-in-law, husbands, and other family members sometimes barred women from utilizing services that they had requested [5,7].

Long distances, poor roads, lack of transportation, lack of emergency referral mechanisms, and financial difficulties also were noted in almost all countries as substantial barriers. For instance, in Mali, the assessment reported that 85% of women in rural areas lived at least 30 km away from the nearest hospital [4]. Women living with fistulas in Mauritania reported having traveled an average of 150 km to access emergency obstetric care [17].

In many countries, even when a decision to seek facility-based care was made, women encountered a lack of trained providers and shortages in critical supplies and equipment. In Malawi, for example, as much as 56% of deliveries are conducted at a health facility but some of the personnel performing deliveries are not trained to provide this service. At the health center level, previous research found that the hospital cleaner attended up to 37% of deliveries [15].

5.2. Treatment

The needs assessments uncovered many obstacles to accessing fistula treatment, resulting in large backlogs. In Kenya, there is an estimated 3000 new fistula cases each year, with only 7.5% currently treated [15]. In Burkina Faso, women were reported to wait as long as 60 months for treatment, and records revealed that some of those who reached the facilities never received treatment [6]. In Bangladesh, most of the women interviewed had been living with their fistulas for more than 10 years [5]. Reasons for the backlog were a lack of specialized repair centers and trained staff, financial and geographic inaccessibility of repair, and low awareness about treatment options.

Table 3 Barriers to preventive care

Country ^a	Health system barriers	Other barriers
Bangladesh	Shortage of skilled attendants	Low awareness; decisions made by mothers-in-law/relatives; delivery by untrained TBAs
Benin	Limited hospitals in some regions	NA
Burkina Faso	Cost; distance to health facility; quality of care	Preference for home delivery; birth preparation perceived as cause of negative delivery outcomes; low male involvement
Cameroon	Cost; access; EmOC functions unavailable; insufficient coverage of EmOC	Previous good experience with home delivery/TBA; husband's refusal of male providers
Central African Republic	Low skills in obstetric care; staffing shortages	Illiteracy; misinformation in the community
Chad	Staffing shortages, particularly female; cost; care provided by low-level staff	Preference for home delivery; cost and difficulty of transportation
DR Congo	Availability of EmOC	Transportation difficulties
Equatorial Guinea	Shortage of midwives; low functioning of primary health care	Home or health post deliveries without skilled attendance; poor road conditions; limited transportation
Eritrea	Weak emergency referral	Preference for home delivery especially for first birth; lack of transportation; decisions made by female relatives
Kenya	Some basic EmOC functions not available at hospitals and health centers; lack of partograph use, weak referral systems, low access to skilled attendance	Misinformation about delivery process, rugged physical landscape, preference for TBAs
Malawi	Staffing shortages; quality of care; supply shortages	Preference for home delivery, especially for first birth; limited transportation options; decisions made by uncle or husband
Mali	Midwives based in urban areas; non-functional community health centers	Decisions made by mothers-in-law/relatives
Mauritania	Long distances between facilities; limited availability of cesarean sections	Poor roads, lack of transportation
Mozambique	Weak referral systems; quality of care	Rough terrain; long distances and waiting homes not preferred
Niger	Lack of providers in rural settings	Limited mobility for women; preference for home delivery, especially for first birth; harmful traditional delivery practices
Nigeria	Shortage of female health workers; supply shortages; cost	Preference for home delivery, especially for first birth; limited mobility of women; operative delivery seen as a failure; religious and traditional practices
Somalia	EmOC functions not available; competing health priorities; staffing shortages due to brain drain and public and private sector competition; lack of equipment and supplies	Reliance on prayer to relieve obstruction; reluctance to leave home during and after delivery because of religious practices; limited decision-making ability of women; limited access for nomadic populations, refugees, and internally displaced persons
Tanzania	NA	NA
Uganda	Inconsistent quality of care; cultural preferences regarding delivery position	Preference for home delivery related to privacy and fear of operative delivery; women who are not delivered vaginally considered inferior or bewitched; decisions made by husbands; transportation arrangements and cost
Zambia	Staffing shortages; migration of nurses; availability of consumables; distance to clinics; health worker attitudes	Traditional methods utilized before seeking medical care; waiting homes too small and overcrowded

Abbreviations: DR Congo, Democratic Republic of Congo; EmOC, emergency obstetric care; NA, not available; TBA, traditional birth attendant.

^a In countries where 2 studies were conducted, findings from both are included in the table.

Human resources and basic infrastructure at facilities were found to be generally inadequate. In 7 of the 20 countries, 5 or fewer physicians were performing fistula repairs. These data do not take into account the competency of those currently performing the repairs nor the regularity with which they provide the service. Of 47 physicians interviewed in Uganda, only 4 physicians had participated in a structured fistula training program [21]. Similarly, in a country as large as

Mozambique, only 3 physicians are known to have the necessary skills and actually provide fistula repairs [4]; and in Burkina Faso, permanent repair surgeons are not available on staff at the 2 university hospitals nor at the 5 regional hospitals [6].

Very few training opportunities were available other than informal on-the-job guidance. The incentives for surgeons to train in fistula repair remain low because of the potentially

high failure rate of repair, low salary, stigma associated with the condition, and lack of opportunities for training and work. Crises in human resources also result in a shortage of physicians to train. In some contexts, as in Chad, women prefer female health providers but they are in short supply [4]. In Kenya there were acute staff shortages, with actual staffing often less than 50% of recommended levels. For example, one hospital had 200 nurses but required 300 [14].

Although fistula repair does not typically require many specialized instruments, most treatment facilities were found to be lacking even the most basic equipment and supplies. In Tanzania, for instance, 19 of the hospitals currently doing repairs reported shortages. In some cases, visiting surgeons bring supplies with them. Hospitals doing repairs with resident surgeons, however, require a regular supply of consumables and basic equipment [6]. Even where equipment was available, it was often found to be in very poor condition, as evidenced in Nigeria where a great number of facilities were providing repair throughout the country, but no operating theaters were fully equipped. Equipment was either absent or dilapidated, and the majority of theaters lacked special instruments needed for fistula repair [18].

As Table 4 illustrates, the number of women treated annually differed greatly by country. The annual caseloads are estimates based on weekly, monthly, or annual treatment figures provided in the assessments. Within countries the caseloads varied between facilities, with often 1 or 2 facilities providing most of the repairs. For example, the Tanzania assessments show that 6 facilities are performing nearly two-

thirds of all repairs; and similarly, close to half of all repairs in Nigeria are performed at 2 centers in the northern region [18,20].

Although patients very rarely had to cover the entire cost of the repair, the cost varied across and within countries. Because the governments provided partial subsidies or cost exemptions at many public hospitals, and mission or private hospitals receive external financial support, fistula treatment was commonly free of charge at these facilities. The remaining costs, however, were often prohibitive, especially transportation costs.

Geographic access also poses a barrier to treatment. Many women are forced to endure long and difficult journeys from their home villages to reach fistula repair services. The story told by a 32-year-old Eritrean woman who has lived with a fistula for 17 years exemplifies this disheartening experience:

I heard about it on the radio. I came by bus from Gash Baraka. I left my home at 5 AM on the first day and made it to Barentu by 4 PM that day. I left from Barentu at 5 AM the next morning and arrived in Massawa at 6 PM. I have been waiting here since Friday night. I came alone and left my children at home [13].

Some women also cross borders to receive treatment when access to services will be easier or to ensure anonymity. And women also seek traditional remedies when they are not aware that surgical treatment exists, are too poor to consider it, or are afraid of travelling to urban centres for care. The assessment in Burkina Faso, for instance, noted that traditional remedies were often the first recourse, and that care at health facilities was only sought when these failed [7]; and in Benin, the assessment noted that women may consult a local healer, who typically tries to remove their "curse" [4].

5.3. Community perceptions and socio-economic consequences of fistulas

As shown in Table 5, the needs assessments revealed that a large majority of community members had little knowledge of anything about fistulas, which were commonly believed to be caused by adultery, sorcery, or evil spirits. In Burkina Faso, for example, there are widespread beliefs that fistulas occur in women who offend someone or are unfaithful [7]. In some countries, as in Cameroon, sexually transmitted infections were also attributed as a cause of fistula [8]. Regardless, communities and women themselves often have a fatalistic attitude toward the condition. As stated by a focus group member in Zambia, "Nothing is done but to accept what has happened because life is full of blessings and curses" [22].

The socio-economic consequences of fistulas on the lives of the women who have them and their families were found to be dramatic. Because of the odor and stigma associated with the condition, women with fistulas often isolate themselves from their families and communities or are abandoned by their husbands. The social and physical effects often render women unable to work or participate in community life and can cause them anxiety, depression, and other adverse psychosocial effects.

While, overall, the assessments reported rejection of the affected women from their communities, there were some notable exceptions—such as in the areas studied in Cameroon

Table 4 Key quantitative findings on fistula treatment

Country	No. of medical personnel performing surgery	No. of facilities providing treatment	No. of women treated annually
Bangladesh 2003	6–12	6	123
Benin 2002	5 ^a	3	43
Burkina Faso 2004	NA	20	49
Cameroon 2004	NA	NA	NA
Central African Republic 2005	NA	9	86
Chad 2002	2	2	190
Democratic Republic of Congo 2005	12	101	NA
Equatorial Guinea 2005	NA	2	NA
Eritrea 2003	3	3	NA
Kenya 2004	NA	6	225
Malawi 2005	12	6	148
Mali 2003	24	2	566
Mauritania 2004	NA	2	NA
Mozambique 2003	3	3	169
Niger 2003	5	10	275
Nigeria 2003	52	30	4140
Somalia 2005	2	5	50
Tanzania 2002	12	50	712
Uganda 2003	47 ^a	16	323
Zambia 2004	4	5 ^a	175

^a The total includes visiting and national surgeons.

Table 5 Key qualitative findings on consequences of fistula

Country	Community perceptions	Socioeconomic consequences
Bangladesh 2002	Belief that a woman's infidelity is responsible for difficult labor	Sometimes abandoned by their husbands or forced to accept that husbands marry other women. Some women disdained by health workers who considered them "unclean"
Burkina Faso 2004	Perceived as punishment for wrongdoing although a minority of mostly younger women are aware that the condition is associated with a difficult delivery	Moral and financial support often provided by birth family; however women reported feelings of shame, rejection and bitterness along with obsessive thoughts about cleanliness
Cameroon 2004	Causes identified included difficult delivery, sexually transmitted infections, rape, sorcery, infidelity or evil spirits. Aware that fistula is a condition that causes suffering for women.	Large proportion remain with their husbands, but also receive support from their birth parents in the case of marital separation or divorce; if a woman has children already, her spouse is less likely to reject her
Eritrea 2003	Most were aware of the causes although some still perceive fistula as being "God's will"	Affected women live under trees or in tents in isolation; many relatives take the woman to an unknown town to live because she has brought shame to the family
Kenya 2004	Completely unaware of the causes of fistula; some communities do not link fistula to childbirth complications but rather that "she is not woman enough"; others reported adultery or witchcraft as the cause	Community members often sympathized with the women, but the women self-isolated; in other areas, husbands would return their wives and demand a refund of bride price
Zambia 2004	Unaware of the causes of fistula; belief that traditional herbs can relieve obstructed labor. Some attribute a difficult labor to a husband's infidelity during a pregnancy.	There were reports of both men who supported their wives and others who divorced or abandoned them

and 3 of the 4 districts studied in Kenya, where the assessments reported much higher levels of community support [8,14]. In Bangladesh, there was discrepancy between the groups interviewed. Health providers reported that women were typically neglected by their husbands whereas, among the younger women, many of those interviewed felt that their husbands were sympathetic to their condition. These young women, however, were upset that they could not be more "useful" [5].

5.4. Reintegration

An OF is a devastating physical injury with numerous severe emotional and social consequences. Owing to the stigma associated with OFs, patients are in great need of counseling during the preoperative and postoperative periods. Overall, the assessments found great shortfalls in the provision of reintegration services, including family planning, psychosocial counseling, and capacity-building activities. In most cases rehabilitation care was not available in any consistent manner, nor was follow-up undertaken after discharge. In Niger, treated women still may not be able to return to their husbands, and most lack the basic skills they need for employment [4]. In Malawi, after repair, patients are not referred for social services. The health workers indicated that there was no need for referral because once the patient was dry, she would be accepted back [15]. The assessments discovered that a number of health facilities, along with community-based and national organizations, were working to develop reintegration and counseling programs, but were in need of financial support.

6. Conclusion

Obstetric fistula assessments have provided insight into capacities, gaps, and perspectives concerning the prevention and treatment of the condition, as well as into the broader community and policy context of OF and the reintegration of treated women. Presented as a summary, some of the distinct variations between countries are masked. However, country-specific programming information, such as constraints at facilities and the identification of key institutions and individuals already working in these areas, has been critical. The findings have allowed countries to identify existing capacities and expertise and to design national programs that build on these existing strengths.

In Campaign countries, assessment findings represent not only a vital resource for programming but also a powerful advocacy tool for mobilizing political will and community involvement. While many of the findings are not surprising, in most countries the assessments represent the first national research on the issue. The process of conducting the assessment itself also played a part in raising awareness and building commitment around a largely unknown issue. Interviews with key informants, such as policy makers and health professionals, as well as the dissemination of the findings in workshops following the finalization of the studies, contributed to increasing knowledge and awareness. In countries where the government and a committee of stakeholders were involved in the design and oversight of the study, national ownership and commitment were built early in the process, facilitating efforts to place OF on the health agenda.

The rapid initial assessments were useful in triggering action, but their scope and depth were often insufficient for programming purposes. They were acknowledged as too medically focused and deficient in important socio-cultural data. More quantitative information was needed to establish baselines for indicators to measure progress within the countries. Consequently, the assessments that followed have increased the depth of investigation, particularly regarding quantitative data and socio-cultural aspects. Since mid-2004 most countries have elected to include socio-cultural components, either as part of the national assessment or through additional studies. All 9 of the initial countries elected to conduct further assessments, 8 of which are completed.

The needs assessments have been and continue to be a crucial first step in the global Campaign to End Fistula. At the same time, it has been acknowledged that much more research is needed. Partners in the Campaign to End Fistula have begun to identify methods for better understanding the burden of the disease—its incidence and prevalence as well as its economic and social consequences—and to promote other areas of research for evidence-based clinical practice and programming.

What the assessments have revealed is that where women lack education, financial independence, decision-making power, and access to obstetric care, OF incidence appears to be unacceptably high. They revealed shortcomings in women's access to fistula prevention, treatment, and rehabilitation services, but also identified dedicated individuals and organizations hard at work to address the issue. The socio-cultural findings, which bring forward the voices of women living with fistulas, are helping to highlight the continued gaps between reproductive health needs and services, as well as gender and socio-economic inequities.

Conflict of interest

The authors are currently or have previously been employed by UNFPA. UNFPA launched the Campaign to End Fistula and supported many of the needs assessments.

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