Barriers to obstetric fistula treatment in low-income countries: A systematic review

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BARRIERS TO OBSTETRIC FISTULA TREATMENT IN LOW-INCOME COUNTRIES: A SYSTEMATIC REVIEW

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Executive Summary

BACKGROUND

Obstetric fistula is a maternal morbidity condition, which occurs in some low-income countries, caused by prolonged obstructed labor that results in a hole between the vagina and the bladder or rectum through which urine or feces leak. Unrepaired fistula can lead to lifelong ostracism, stigma, and shame.

Obstetric fistula is both preventable and treatable, but women in these countries experience delays in seeking repair due to a number of factors including awareness of their condition as well as the potential for treatment, resources necessary for seeking care, lack of skilled fistula surgeons, and long hospital waiting times.

UNFPA (2012) estimates that 2 to 3.5 million women are currently living with fistula worldwide, with at least 50,000 to 100,000 new cases occurring every year. The true number of women with fistula may actually be higher, as untreated patients who never reach a medical facility are more difficult for researchers to identify, and sampling biases are hard to verify.

This review aims to identify and understand the barriers affecting women’s access to fistula repair, to inform the design of possible interventions that may be effective in addressing these barriers. This work may also identify research gaps surrounding fistula in low-income countries that require targeted formative research before interventions can be designed.

METHODS

A three-stage search protocol was developed using key terms to identify relevant papers. The first stage reviewed titles and abstracts identified from bibliographic databases as well as grey literature searches with explicit inclusion and exclusion criteria. In the second stage, full articles from the first phase were reviewed in parallel by two reviewers who then discussed any discrepancies and agreed on the standardization of the extracted data. The third stage included a qualitative review of references in key articles, expert inquiry, and data extraction from relevant sources. Papers that met the inclusion criteria included interviews, case studies, assessments, or reports that discussed at least one of the three delays in seeking care or an intervention that aimed to reduce the prevalence or incidence of fistula.

A total of 3,921 articles were identified in the electronic database search. Thirty were added from a review of the grey literature, and 21 from the expanded search. A total of 110 studies were included in the systematic review.
RESULTS
The 110 articles were further categorized by nine barriers—psychosocial, cultural, awareness, social, financial, transportation, facility shortages, quality of care and political—which correspond with Thaddeus and Maine’s (1994) Three Delays Model. The articles were further categorized into five types: articles featuring barriers to treatment as their primary focus; articles identifying factors perceived as barriers; articles briefly mentioning barriers; reviews, needs assessments or annual reports; and articles focusing on interventions that aim to remove barriers to treatment. Interventions were analyzed in further detail to ascertain which barriers they targeted and their effectiveness during their study period.

DISCUSSION
From the articles included in this systematic review, it is consistently observed that obstetric fistula is directly linked to poverty, income inequality, gender disparities, discrimination, and poor education. Previous interventions may have achieved increased access to fistula treatment by removing the barriers preventing one or more of the three delays in seeking maternal healthcare. Community-based models identifying women who are disempowered and stigmatized can address the first barrier of limited awareness and knowledge. Transportation and healthcare financing models that successfully refer women with fistula to a surgical center are critical for overcoming the second barrier that prevents women from reaching a medical facility. Provider empathy and respectful care, strong surgical skills, and prioritized registration at facilities ensure that the third delay, appropriate care at a facility, is reduced for women seeking fistula repair services. The number of studies that evaluate interventions is low, however, and study outcomes vary, along with varying effect measurements between studies, making it impossible to aggregate results into a meta-analysis of the effect of interventions on treating women with fistula and removing the barriers to its care.

CONCLUSIONS
While barriers to fistula treatment may be easily identified, reducing their effects is difficult and requires sustained interventions that may target several barriers. There are few scientific studies of fistula prevalence and few studies of population-based strategies to improve fistula treatment. The results presented in this review identify current evidence gaps that must be addressed in research, for generating information for planning and implementing future interventions to improve access to fistula treatment in low-income regions.
Background

GOALS AND RATIONALE FOR CURRENT REVIEW

Obstetric fistula is a maternal morbidity with devastating effects on a woman’s life, persisting in low-income countries but virtually eliminated from the morbidity burden in high- and middle-income countries. UNFPA (2012) estimates 2 to 3.5 million women currently suffer untreated fistula worldwide; and at least 50,000 to 100,000 women develop a fistula every year. There is uncertainty, however, about the prevalence estimate because of the rarity of diagnosis and a lack of high quality studies.

Because women living with fistula are predominantly poor, geographically and socially isolated, and with little political power, identifying these women for accurate prevalence or incidence data is difficult. A recent systematic review found an aggregate prevalence of 0.29 cases per 1,000 women of reproductive age and incidence of 0.09 new cases per 1,000 recently pregnant women each year, suggesting no more than one million women worldwide currently living with fistula (Adler et al. 2013). That study, however, likely missed women who never reached a hospital or who are isolated from their communities. The uncertainty in these estimates and difficulty in measuring the extent of the problem underscore the difficulties in mounting an effective response for fistula’s treatment and prevention.

Obstetric fistula is both preventable and treatable. In recent years, various initiatives have been established to prevent and repair fistula but women experience delays in seeking repair due to a number of factors. Women with fistula may be unaware that repair is possible, or lack the resources to seek care, and may face delays in receiving appropriate treatment due to personnel or facility shortages and poor quality of care (Mukisa and Cole 2013, Obaid and Chong 2004, Bangser 2011, Fiander et al. 2013, Matsamura 2004).

This review aims to identify and understand the delays in receiving treatment and corresponding barriers to accessing fistula treatment, to document interventions that help to overcome barriers, and to specify gaps in the literature that require further research.

DEFINING AND CONCEPTUALIZING OBSTETRIC FISTULA

What is Obstetric Fistula?

The World Health Organization (2006) defines obstetric fistula as an “abnormal opening between a woman’s vagina and bladder and/or rectum through which her urine and/or feces continually leak.” Pressure from a baby’s head during prolonged or obstructed labor restricts blood flow and damages tissues between the vagina and the bladder or rectum. Although obstetric fistula is caused by prolonged and obstructed labor, it is rooted in poverty, predominantly affecting marginalized women who lack access to quality obstetric care, who typically are of lower socio-economic status, with lower levels of education, in rural areas, without prenatal care, and married at younger ages (Zheng and Anderson 2009).
Childbirth care is affected by a variety of factors including access, socio-economic resources, and culture. Obstetric care may be geographically or financially unavailable, home delivery may be common and preferred over facilities, while timely referral systems for emergency obstetric care may be lacking, and girls and women may lack decision-making power and agency for seeking care. Many barriers preventing care for pregnant women and during labor are mirrored in women with fistula unable to access care. A poor, rural, pregnant woman may be unable to afford transportation for birth in a medical facility, and may be similarly unable to access transportation to a facility if she develops a fistula during delivery.

In addition to incontinence and other health problems with direct associations, fistula can lead to lifelong social and psychological problems involving ostracism, stigma, and shame (Blum 2012, Jones 2007, Yeakey et al. 2009). Women may be isolated from their family and community, divorced, or unable to work or participate in community events because of their condition. Community members may blame women living with fistula for their condition, viewing it as punishment for sin or a venereal disease or curse. Consequently, fistula is also associated with psychosocial problems such as depression and anxiety, which may further contribute to inability to seek treatment. Fistula is also associated with sexual, fertility, and future childbearing concerns (Yeakey et al. 2009, Wall et al. 2005, Arrowsmith et al. 1996).

Surgical treatment of fistula is generally reported to be successful, although there is limited long-term evaluation on urinary continence or subsequent quality of life (Creanga et al. 2007). In low-income countries, women have less access to appropriate surgical care for repair due to the low availability of health facilities with repair services and lack of surgical training for fistula repair. In addition to these supply side barriers to repair, a variety of demand side factors affect women’s care seeking for fistula repair: great distances to health facilities, high cost of travel to facilities, and high costs of services. In addition, women may not be aware that treatment is available, or they may lack decision power and attitudes for seeking care. Furthermore, due to the large backlog of women requiring repair and limited available surgeons and personnel, women may experience long waits (Velez et al. 2007, Wall et al. 2005, Ramsey et al. 2007, Browning and Patel 2004).

**Conceptual Frameworks**

Thaddeus and Maine’s (1994) Three Delays Model provides the theoretical context for understanding the barriers to accessing obstetric fistula care. Delay is understood as comprising three phases. Phase I is a delay in deciding to seek care by an individual, family, or both, and includes factors associated with decision making, women’s status, illness characteristics, distances from facilities, financial and opportunity costs, previous health system experiences, and perceived quality of care. Phase II is delay in reaching an adequate care facility, with physical accessibility including facility distribution, travel time, availability and cost, and road conditions. Phase III comprises delay in receiving adequate care at a facility, including the adequacy of the referral system, and shortages of supplies, equipment, and trained personnel, as well as competence of available personnel. For this review, we adapted this model for delays to fistula treatment (Figure 1).
OBJECTIVES

The primary objective of this systematic review is to identify and understand the barriers preventing women from accessing fistula repair at all three phases of delay, as presented by Thaddeus and Maine (1994), to inform the design of possible interventions that may be effective in addressing these barriers. This work may also identify gaps in knowledge that require targeted formative research before interventions can be designed.
Methods

IDENTIFYING AND DESCRIBING STUDIES

Search of Bibliographic Databases

Bibliographic database searches used specified key terms to identify studies for potential inclusion in the review. Databases searched include: PubMed; POPLINE; ELDIS; InterScience (WILEY); ScienceDirect; Cochrane EPOC; World Health Organization Library Information System (WHOLIS); The Database of Abstracts of Reviews of Effectiveness; Web of Science; Library of Congress; Library, Information Science and Technology (LISTA); and Bioline International. Key terms used were:

“vaginal fistula” OR “vesicovaginal fistula” OR “rectovaginal fistula” OR “obstructed labor” OR “prolonged labor” OR “obstetric fistula”

AND

“treatment” OR “repair” OR “access to care” OR “poverty” OR “financial barrier*” OR “transport*” OR “cultural barrier*” OR “economic barrier*”

Articles identified in database searches were imported to Mendeley for review.

Phase I Inclusion and Exclusion Criteria

In Phase I, abstracts of all studies identified in database searches were reviewed to determine whether they should be included, or excluded, in the next review phase. The following inclusion and exclusion criteria were utilized:

**Topic:** Articles were only included for further review if they discussed obstetric fistula and potential barriers to treatment. Articles focusing on fistula associated with other causes such as cancer, radiation, or Crohn’s disease were excluded, as were articles not mentioning fistula. Articles exclusively discussing risk factors for developing fistula were also excluded. Articles were included if they discussed lack of high quality care, prevalence of fistula, treatment seeking for fistula, reasons for successful or unsuccessful treatment, need for multiple surgeries, cultural factors, or other issues that may be perceived as treatment barriers.

**Language:** To be included for further review, studies were required to be in English, or have an English abstract available.

**Population:** Only articles focusing on populations in low-income countries were included.

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1 Asterisk denotes inclusion of all “MeSH” terms during database searches
**Time frame:** Only articles published from 1980 to the present were included for further review. 1980 was established as the terminal date to be as comprehensive as possible without focusing on studies that may include outdated information.

**Type of study:** Types of studies included for further review comprised case reports, comparative studies, journal articles, meta analyses, reviews, and systematic reviews.

**Search of Publishers’ Pages**


These journals were selected for further review based on a combination of a frequency of appearances in our database search and relatively high impact factors. Publishers’ pages were searched using the same key terms used in the database searches.

**Search of Organization and Network Websites**

Several organizational and network websites were searched for additional studies or reports. Websites of interest were identified using Google searches of fistula campaigns and organizations, as well as expert recommendations.

Websites of EngenderHealth, Human Rights Watch, Fistula Care, Comprehensive Community Based Rehabilitation in Tanzania (CCBRT), Women’s Dignity Project, United Nations Population Fund (UNFPA), Campaign to End Fistula, United States Agency for International Development (USAID), Department for International Development (DfID), Marie Stopes International, Population Council, Results for Development, World Health Organization (WHO), Worldwide Fistula Fund, and Fistula Foundation were included in this web search.

**Phase II Inclusion and Exclusion**

After identifying studies from bibliographic database searches, publishers’ pages, and organization and network websites, we proceeded to Phase II with inclusion and exclusion criteria. Two researchers separately reviewed and included only articles that met our criteria. Articles were read in their entirety and included or excluded using the following criteria:

**Barriers to treatment:** Articles were excluded if there were no discussions of factors that may be perceived as barriers to obstetric fistula treatment.

**Treatment delays:** To be included in Phase II, articles were required to examine at least one outcome addressing one of the three delays to care presented by Thaddeus and Maine (1994) (delay in the decision to seek care, delay in arrival at a health facility, or delay in the provision of adequate care).

For each article included in Phase II, the researchers entered article information into a data extraction form (Appendix A) and saved each entry in an Excel spreadsheet. Data entered into the extraction form included information on the article’s title, authors, publication date,
journal or source, study design, country, length of study, population of interest, setting or sampling frame, comparison group (if applicable), intervention (if applicable), outcomes and barriers identified, and additional notes.

After their separate, parallel screenings of the articles, the two researchers discussed any discrepancies and made a final, collaborative judgment of inclusion or exclusion of the articles in question.

**Expert Recommendations**

Additional articles were sent from the International Research Advisory Group Meeting led by Fistula Care Plus in Boston in July 2014. Eleven articles were sent; four had already been identified in the electronic database search, resulting in seven additional expert recommendations. Of those seven resultant articles, four were duplicates already identified in the electronic database searches.

**French Database Search**

The same bibliographic databases searched in English were also searched in French, using the key terms:

“fistule vaginale” OR “lésions iatrogènes” OR “incontinence urinaire” OR “fistule vésico-vaginale” OR "fistule recto-vaginale” OR “dystocia” OR “travail prolongé” OR “fistule obstétricale” OR “après traitement chirurgical"

AND

“traitement” OR “réparation” OR “accès aux soins” OR “barrière financière*” OR "pauvreté" OR "transport" OR "barrière culturelle*" OR "barrière économique*" OR “intégration sociale”

Due to the low number of French articles found using database searches, Phase II inclusion and exclusion criteria were immediately used to determine which articles to include in the review.
SEARCH RESULTS

The search was conducted from June through July 2014. A total of 3,921 citations were identified from the electronic database search. An additional 30 were added from a review of the grey literature. Figure 2 outlines the process used to determine which studies would be included in the review. A total of 110 articles were included.

Figure 2: Flow diagram of identification of studies
METHODS FOR SYNTHESIS

Categorizing Studies

Once articles included in the review were compiled in Excel, our researchers categorized them by the extent to which they discussed barriers to fistula treatment:

1. Barriers are a study’s primary focus
2. Article identifies factors that reviewers perceived as barriers
3. Barriers are mentioned briefly in introduction or discussion but are not an article’s primary focus
4. Reviews, needs assessments, or annual reports with some mention of barriers
5. Interventions aiming to remove barriers to fistula treatment

Categorizing Barriers

Based on the frequency of barrier themes identified in the articles included in this review, we categorized barriers into nine groups, and the studies mentioning each of these nine barriers were then tallied (and presented in Box 1 on the following page):

1. Psychosocial
2. Transportation
3. Cultural
4. Facility shortages
5. Awareness
6. Quality of Care
7. Social
8. Political
9. Financial

Confidence in Findings Assessment (CFA) for Interventions

The 12 studies of interventions removing barriers to treatment were analyzed to assess the extent to which barriers were reduced. Due to the range of different study outcomes and various study designs identified in this review, it was important to assess the quality of studies included and the confidence in the study findings for effective recommendations from the literature. In other systematic reviews, the purpose in assessing quality is to reduce the risk of bias in aggregating study results using the CONSORT checklist (Schulz et al. 2010) and the Newcastle-Ottawa Scale, although there are methodological concerns with NOS (Stang 2010). As in Meyer et al. (2011), our reviewers developed a “Confidence in Findings Assessment” (CFA) tool, although our version of the CFA did not draw from the Newcastle-Ottawa scale. In our qualitative assessment of study designs, participant selection, quality of comparison, and outcome measurement, each reviewer scored each study as high, medium, or low confidence overall. Studies with a reasonable counterfactual and strong description of the intervention were rated as high confidence. Articles describing study outcomes but without sufficient information on outcome attribution to the intervention were assigned medium confidence. Articles without a comparison group and a weak design were rated as low confidence (Table 6, Appendix D).
Results

TYPES OF BARRIERS AND CATEGORIZATION

Categorization and frequency of barriers

The barriers identified in the 110 articles were grouped into nine categories (see Table 1 in Appendix B for an outline of the categories with bulleted descriptions from the articles). Box 1 outlines the frequency of articles that mentioned each barrier; articles often mentioned more than one barrier.

<table>
<thead>
<tr>
<th>Barrier Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td>71</td>
</tr>
<tr>
<td>Facility Shortages</td>
<td>65</td>
</tr>
<tr>
<td>Social</td>
<td>65</td>
</tr>
<tr>
<td>Transportation</td>
<td>62</td>
</tr>
<tr>
<td>Quality of Care</td>
<td>58</td>
</tr>
<tr>
<td>Awareness</td>
<td>57</td>
</tr>
<tr>
<td>Cultural</td>
<td>42</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>30</td>
</tr>
<tr>
<td>Political</td>
<td>12</td>
</tr>
</tbody>
</table>

Box 1: Studies mentioning barrier category

In this section of the report, we describe the barriers mentioned in the surveyed articles in order of their frequency.

Financial

Financial barriers were the most frequently mentioned barriers in this review. Many articles reported that women experience barriers when attempting to access fistula treatment because the procedure is too costly. According to the Fistula Foundation (2014), the approximate average cost to treat obstetric fistula is US$450—including surgery, post-operative care, and physical rehabilitation. This price estimate is based on average costs reported to the Fistula Foundation in 25 countries in sub-Saharan Africa and South Asia. Costs and length of hospitalization can vary by degree of fistula complexity. In response to unaffordable medical costs, some countries have introduced exemption policies to make certain health care services free. Ghana’s Ministry of Health introduced an exemption policy that includes repair of vesico-vaginal and recto-vaginal fistulas. Significant problems with its implementation have been reported, however (Ofori-Adjei 2007).

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2 Corresponds to the number of articles that mention each barrier; many articles mention more than one barrier to care.
Facility shortages

Facility shortages are significant barriers and involve shortages of doctors, trained surgeons, and other personnel in addition to shortages of facilities themselves as well as equipment and supplies. These shortages contribute to the large numbers of women requiring repair, especially in rural areas.

Social

The high number of articles citing social barriers indicates that many women experience varying degrees of social stigma that can prevent them from seeking care. Women who experience fistula report feeling isolated or abandoned by their husbands, families, or communities, without anyone to accompany them to treatment facilities (Mselle et al. 2011, Alju and Esegbona 2011). Social barriers may also contribute to financial barriers; women who are abandoned by their husbands and families may find it more difficult to acquire funds for financing the procedure or transportation costs.

Transportation

Transportation and its costs were repeatedly cited as a barrier to care. A majority of women living with fistula are from remote, rural areas, and most fistula services are in urban centers. Women report that transportation is costly or sometimes non-existent. To overcome this challenge, in Kenya and Tanzania a mobile money service (MPESA)3 helped low-income women both save and prepay for fistula repair costs, and receive money for transportation (Bangser 2011, Finander 2012 and 2103). Even when transportation is available or affordable, women may experience too much pain or discomfort to travel, or may be turned away from public transportation due to their condition.

Quality of care

Perceived poor quality of care is a commonly cited barrier involving multiple facets of care. Although fistula is often surgically treatable, surgery is not always successful, especially when complex and involving both the vagina and rectum (recto-vaginal fistula), or when a woman has significant scar tissue. According to a retrospective review of fistula surgeries over 25 years in Nigeria, 82 percent were cured after one operation, with some women receiving two, three, four, or five surgeries total (Hilton and Ward 1998). Although the totally cured rate in this cohort was 98 percent, it is possible, in similar settings, that many women may be discouraged from multiple fistula surgeries after previous unsuccessful attempts. Even when a fistula is successfully closed, women may experience stress incontinence for several months or years after the surgery. The perception that women may continue to leak even after their “cure” may dissuade some women from choosing to seek care. Rural women who seek care for fistula may also face diagnosis or referral challenges, and long waiting times may delay their appropriate care because of the needs of acute conditions in other patients.

3 MPESA is a mobile money service whereby money can be sent, cashed, and saved via mobile telephone networks
Awareness

Lack of awareness is a frequently mentioned barrier to seeking fistula treatment; many women who suffer from obstetric fistula do not know what fistula is, that their condition is treatable, or where to get treatment. Women with fistula and members of their community may also be misinformed about the causes of fistula. In some communities fistula is believed to be a curse or a punishment from God (Naidu and Donnay 2003, Muleta et al. 2008). Some women living with fistula, and some traditional birth attendants who assist women who develop fistula, believe that doctors caused fistulas during deliveries. When fistula is believed to be inflicted by God, or when fistula is believed to be caused by a doctor’s actions, a woman living with fistula is unlikely to be interested in seeking treatment at a health facility.

Cultural

Cultural factors, which include male societal dominance, may act as barriers to care for some women. In some cultures (e.g. in Nigeria) “a perceived social need for women’s reproductive capacities to be under strict male control” exists (Wall 1998). If women with fistula lack decision-making capabilities or control over household funds, whether facilities or transportation are readily available may not matter, as they may be unable to access treatment regardless. Male dominance influences women’s reproductive and healthcare choices and may also contribute to women’s development of fistula (Odhiambo 2010). Cultural barriers include negative attitudes toward medical clinics or doctors, and reliance upon traditional medicines or home remedies.

Psychosocial

Although psychosocial barriers were not cited as frequently as other barriers, they remain important factors that can influence a woman’s care seeking decisions. Numerous studies reveal that women with obstetric fistula have a disproportionately high prevalence of depression (Goh et al. 2005, Alio et al. 2011, Mselle et al. 2011, Weston et al. 2011, Siddle et al. 2013). In addition to depression, studies report that women living with fistula experience anxiety, loss of dignity, and low self-worth (Wall 1998, Inbaraj 2004, Mselle et al. 2011, Narcisi et al. 2010). Researchers believe that such psychological symptoms can inhibit women’s agency and motivation for seeking treatment.

Political

Political barriers were cited least frequently but are an important barrier to consider. Due to competing priorities, fistula repair (and maternal health in general) does not receive the attention and funding it requires. In low-income countries, governments may be overwhelmed with other medical problems (such as malaria or HIV) requiring a significant proportion of their attention and resources. Chronic conditions that do not directly result in death, such as obstetric fistula, are viewed as low priority. Additionally, civil war, political insecurity, and corruption are reported as barriers to seeking fistula repair services.
THE THREE DELAYS TO FISTULA TREATMENT

Figure 1 (on page 5) is an adaptation of the Three Delays Model presented by Thaddeus and Maine (1994). The factors affecting utilization and outcome involve nine barriers to fistula treatment identified in the systematic review.

Psychosocial, cultural, awareness, and social barriers affect the Phase I decision of seeking care. Financial and transportation barriers affect both the decision to seek care and the ability to identify and reach a medical facility. If a woman living with fistula is aware that she is unable to access transportation to a repair center, she may decide not to seek care; if she initially decides to seek care, she may find herself unable to do so if transportation is unavailable or financially unfeasible. Facility shortages and quality of care affect both the decision to seek care, as well as receiving adequate and appropriate treatment. A woman with fistula may be dissuaded from deciding to seek care if she has heard about poor quality of care from other women in her community who have also experienced fistula; if she is able to seek care and reach a medical facility, poor quality of care may prevent her from receiving adequate and appropriate treatment. These eight barriers are affected by the broader political environment, which may itself be a barrier (or facilitator, where supportive policies exist) to treatment.

TYPES OF ARTICLES AND CATEGORIZATION OF BARRIERS

Tables 3 through 6 (Appendix C) present all included articles in five categories based on the extent to which they address barriers to fistula treatment. The five categories include: articles with barriers to treatment as their primary focus; articles identifying factors that their researchers perceive as barriers; articles briefly mentioning barriers; reviews, needs assessments, or annual reports; and articles focusing on interventions that aim to reduce barriers to treatment. Each of the four tables presented in Appendix C include the treatment barriers addressed in each article.

INTERVENTIONS TO ALLEVIATE BARRIERS TO FISTULA CARE

The fifth category includes studies of interventions aiming to reduce barriers to treatment. Expanding on tables 2 through 5 in Appendix C, Appendix D’s Table 6 presents detailed information that may help identify best practices and potential gaps or limitations. The table also assesses the quality of evidence on an intervention’s effectiveness.

Eight studies were rated with high confidence, with their evidence presented clearly indicating that their interventions alleviated barriers identified during their study periods. Most of these studies targeted facility shortages, awareness, or transportation.

Three studies were rated with medium confidence, their evidence suggesting that they may have helped increase access to treatment, but unclear on whether the intervention itself resulted in the outcome, or whether the targeted population would have received treatment in the absence of the intervention.
One study was rated with low confidence: an educational brochure aimed at increasing women’s awareness. Its authors concluded it was an effective means, but it targeted only women already presenting for treatment, and the evidence did not measure its effectiveness in the wider population of all women suffering from fistula. Additionally, other studies report that the majority of women living with fistula are illiterate, and a brochure is likely to be unhelpful in increasing awareness.

**LIMITATIONS OF STUDIES OF INTERVENTIONS**

Several of the studies of interventions faced design limitations, raising questions of whether or not their observed outcomes were truly the result of their intervention or due to other factors. Many studies lacked comparison groups, limiting the ability to attribute any observed effect to their interventions. Only four of the 12 interventions had a comparison group. Three studies used before and after designs (Fiander et al. 2013, Bangser et al. 2011, USAID Aquire project 2007), in Kenya, Tanzania, and Ethiopia. One study in Nigeria tested information heard on the radio with non-listeners.

It was also difficult to ascertain, from the published descriptions of how interventions were implemented, whether their target populations were truly women unable to access treatment in the absence of those interventions. Additionally, despite the apparent success of intervention programs targeting facility shortages in the short term, such as the Fistula Fortnight concept in countries such as Nigeria (Ramsey 2007), it is unclear whether such interventions have lasting effects in removing barriers in the long term.

The literature search found few studies able to plausibly establish causality; many studies were unable to establish temporality between factors identified as barriers and the inability to access care, and between interventions and their reported outcomes. Due to the low number of studies with appropriate comparison groups, unbiased sampling methods, and effective controls for confounding variables, much analysis relied on information presented in interviews, observational studies, and country reports. The small number of scientific studies also prevents a meta-analysis, due to the lack of common outcome measures.

Additionally, many of the observational studies and interviews in this review were at health facilities. Although these studies present some valuable information, their populations of interest were women already presenting for, or receiving, fistula treatment. While it may be beneficial to determine which barriers made it difficult for those women to access care, they ultimately were able to access treatment. It would be better to focus research efforts on women with fistula who cannot access treatment. Identifying women with fistula who are unable to access care is difficult—most of these women are poor, illiterate, rural, lack awareness about their condition, and may be isolated from their communities—one factor why the literature is limited. Community-based studies are costly given the relatively low estimated fistula prevalence of approximately 1.57 obstetric fistula cases per 1,000 women in sub-Saharan Africa and South Asia (Adler et al. 2013)—even though this figure is likely an underestimate.


**Discussion**

**IMPLICATION OF FINDINGS**

This review identifies several interventions with the aim of reducing barriers to fistula treatment. While this is encouraging, stronger monitoring and evaluation mechanisms are necessary for assessing the extent to which such interventions contribute to or accelerate access to fistula treatment. It is likely these interventions have played some part in treatment improvements, but without rigorous evaluations using experimental or quasi-experimental study designs, it is not possible to quantify their impact with validity. Generally, sampling was facility-based, with a lack of baseline data and plausible comparison groups.

Interventions targeting demand side barriers—psychosocial, awareness, social, and cultural—are also lacking. Interventions more frequently targeted financial barriers; this is understandable considering financial barriers were the most frequently reported barriers to care. To address financial barriers, many countries in Africa, and globally, are introducing user fee exemption policies to improve access to care and, consequently, improve maternal outcomes. Recent work from FEMHealth (2014), however, reports that the impacts of these policies are not well understood; they have found a range of both positive and negative outcomes in different contexts. This recent research highlights the importance of context, culture, and political frameworks in addition to the implementation of interventions and policies themselves.

This review identifies a shortage of studies focusing on identifying barriers to fistula treatment. Only two studies in this review had such an aim, but many studies identify factors that researchers perceived as treatment barriers. This review also reveals a lack of prevalence studies that could quantify the extent of the problem of untreated obstetric fistula. This gap in the literature could reflect both a logistical challenge in identifying relatively few cases, and an ethical challenge in justifying the cost of case identification, while offering practical solutions to women identified as a result of the research, especially in regions where there are few surgical options for repair.

Overall, more commitment is needed to address the barriers to care affecting women living with fistula. Solutions need a holistic approach and cannot focus on just one barrier—such as awareness or financial access—while neglecting psychosocial and cultural factors. Solutions must have a long term focus to ensure that initiatives contribute to an overall environmental shift, encouraging integration of fistula case identification and surgical care within comprehensive maternal health outreach and service delivery that will also contribute to obstetric fistula prevention, ultimately removing the need for fistula care services.
STRENGTHS AND LIMITATIONS OF THE RESEARCH APPROACH

There are several strengths to using the approach and methods employed during this systematic review. The review was comprehensive: Almost 4,000 articles spanning more than 30 years were screened for inclusion. The articles reviewed include a broad range of different sources, including academic journals, case studies, country reports, needs assessments, and descriptions of campaign efforts. Articles addressing fistula in many low-income countries were reviewed in both English and French. As a result of the wide range of countries included in this review, identified barriers can be considered applicable for potential studies and interventions in low-income regions where women remain at risk of fistula.

Additionally, the categorization of articles made it possible to demonstrate the degree to which articles addressed barriers to fistula treatment. Presenting review results in this way permits an exploration of the literature on fistula treatment barriers while also exploring the literature on related fistula topics, which helped contextualize the findings on barriers.

Despite its strengths, the systematic review of barriers to fistula treatment faces some limitations. Because fistula affects some of the most marginalized and powerless women in low-income countries, fistula is under researched, with few population-based studies, particularly studies of interventions to overcome delays in seeking fistula treatment. This review was limited to articles published either in English or French, and may have missed relevant articles in other languages.

Certain factors identified as barriers in the review may be context specific and country dependent. For example, certain cultural barriers, including male control of household resources and wife seclusion, may only be applicable in certain regions. Similarly, the extent to which a factor identified as a barrier truly prevents a woman with fistula from seeking treatment is dependent on the woman’s education, age, marital status, and community, and related factors.
Conclusions

This review indicates, while barriers to fistula treatment may be easily identified, their alleviation is difficult and requires a sustainable and multi-faceted intervention targeting several barriers simultaneously. Rigorous studies of the determinants, prevalence, and distribution of fistula are lacking, in addition to studies documenting barriers to fistula treatment. The results presented in this review identify current evidence gaps that must be addressed by rigorous research so valid information can be generated to plan and implement future interventions for improving access to fistula treatment in low-income countries.

RECOMMENDATIONS FOR FURTHER RESEARCH

Based on this review, our recommendations for further research require studies systematically documenting implementation of interventions for removing supply and demand side barriers, and rigorously evaluating the effectiveness of their outcomes through quasi-experimental or experimental designs. Such studies may include the implementation of interventions that appeared effective in removing barriers to fistula treatment but which need evidence with greater validity, such as transportation schemes or radio messages. Future intervention studies must include plausible counterfactuals to better attribute their study outcomes to the interventions.

Additionally, population screening tools enabling health systems to systematically identify women with untreated fistula are needed to help inform women about their condition and treatment options. Such tools would also allow health systems to more precisely estimate their obstetric fistula burdens. Community-based research, instead of facility-based studies, is crucial for finding women with obstetric fistula who are unable to reach facilities, and thus are unable to access treatment. Combining fistula case identification, through community outreach, with rigorous surveillance methods for measuring prevalence would be a cost-efficient strategy for achieving two aims in one intervention.

Future interventions should test strategies for reducing stigma and improving community support to empower women living with fistula with the knowledge and means for seeking treatment.
References


www.thelancet.com/journals/lancet/article/PIIS0140-6736%2806%2969476-2/fulltext#article_upsell


United Nations Population Fund South Sudan. 2012. Obstetric fistula campaign in South Sudan. UNFPA.


# Appendix A

## Data Extraction Form

Fistula Project 2014.  
* Required

**Title**

**Authors**

**Publication Date**

**Journal/Source**
- AJOG  
- BJOB  
- BMCP  
- EAMJ  
- IJO  
- IUPEP  
- JOG  
- JWH  
- The Lancet  
- OG  
- SS&M  
- Health Policy and Planning  
- Other:

**Study Design**
- Cohort  
- Case Control  
- Cross Sectional  
- Ecological
☐ Clinical Trial
☐ Case Study
☐ Interview
☐ Report
☐ Other: 

Country *

Length of Study

Population of interest
Age, location sampled from, socioeconomic status, have fistula or not, treated or untreated

Setting/sampling frame
sampled from a health facility or household (general population)?

Control/comparison group
Yes or no? Who? E.g. comparing treated women to untreated women
Intervention
Yes or no? Describe.

Outcomes *
Barriers identified, outcome of intervention (improve service utilization, improve quality of fistula repair, improve community-based detection and referral of fistula)

Other details or Notes *

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### Table 1: Categorization of barriers to treatment of fistula

<table>
<thead>
<tr>
<th>Category</th>
<th>Barriers</th>
</tr>
</thead>
</table>
| **Psychosocial** | - depression  
                   | - loss of dignity and self-worth  
                   | - anxiety  |
| **Cultural**    | - societal male dominance  
                   | - domestic responsibility  
                   | - practice of wife seclusion  
                   | - male control of money  
                   | - requiring permission from husbands to seek care  
                   | - other forms of gender power imbalance  
                   | - negative attitudes about medical clinics or doctors  
                   | - restrictions on female mobility  
                   | - reliance on traditional medicine and home remedies  
                   | - belief that hospitals are places where people go to die  
                   | - unwilling to be referred to clinics or hospitals because they  
                   | - were nervous about learning their HIV status  |
| **Awareness**   | - unaware that fistula is treatable  
                   | - lack of information about fistula  
                   | - perception that fistula was caused by a doctor  
                   | - lack of community awareness on ability to treat fistula  
                   | - fear of surgery  
                   | - not knowing where to go for treatment  
                   | - belief that fistula is a punishment from god  |
| **Social**      | - isolation  
                   | - abandonment or divorce from husband  
                   | - women are unable to find someone who would accompany them  
                   | - loss of, or lack of, social support  
                   | - too embarrassed to go to a hospital because of own smell  
                   | - relatives hide the presence of a family member with fistula  |
| **Financial**   | - cost of procedure is unaffordable  
                   | - poverty and cannot afford care  
                   | - lost job and cannot afford care  |
| **Transportation** | - cost of travel and accommodation is high  
                   | - lack of transportation  
                   | - pain and discomfort  
                   | - perineal nerve damage affecting the ability to walk, or foot-drop, and other physical mobility issues  
                   | - surgeons are far away and repairs are rarely at local hospitals  
                   | - living in a rural location without nearby health services  
                   | - most hospitals capable of performing repairs are in urban areas  |
### Facility Shortages (trained personnel and equipment)
- shortage of health workers
- insufficient repair resources
- lack of specialized surgeons
- no electricity at hospital
- lack of doctors
- lack of doctors and nurses
- limited availability of operating rooms and equipment
- administrative delays and clinical mismanagement
- few facilities providing repairs
- shortage of female health providers

### Quality of Care
- told by health workers that it would repair itself
- past unsuccessful repairs
- incontinence even after successful repair
- fistula patients require longer hospitalization than general surgery patients
- multiple referrals
- diagnosis challenges
- inadequate training for fistula repair
- verbal and physical abuse from doctors and nurses
- poor quality of care
- fistula patients seen as a low priority
- limited knowledge of fistula among health workers
- poor communication, or miscommunication, from health workers
- long wait times

### Political
- fistula not recognized as a public health problem
- underfunding of fistula programs
- corruption
- civil war and/or political insecurity
- governments are overwhelmed by other priorities
- limited political commitment to maternal health
## Appendix C

### Table 2: Barriers as Primary Focus

<table>
<thead>
<tr>
<th>Location and Time Frame</th>
<th>Barriers Identified</th>
<th>References</th>
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</thead>
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<tr>
<td>Eritrea (Nov – Dec 2004)</td>
<td>Awareness, Transportation, Quality of Care, Social, Financial</td>
<td>Turan et al. 2007</td>
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</table>

### Table 3: Identified Factors Perceived as Barriers

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<th>Location and Time Frame</th>
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<tr>
<td>African &amp; Asian Countries</td>
<td>Transportation</td>
<td>Adler et al. 2013</td>
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<td>Benin</td>
<td>Awareness, Financial, Cultural</td>
<td>Nathan et al. 2009</td>
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<td>Countries not specified</td>
<td>Facility Shortages, Quality of Care, Social, Financial, Transportation</td>
<td>Wall 2007</td>
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<td>Low-income countries</td>
<td>Social, Cultural</td>
<td>Roush et al. 2012</td>
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<td>Low-income countries</td>
<td>Transportation, Financial, Quality of Care, Facility Shortages, Social, Cultural</td>
<td>Thaddeus &amp; Maine, 1994</td>
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<td>Location and Time Frame</td>
<td>Barriers Identified</td>
<td>References</td>
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<td>----------------------------------------------------------</td>
<td>-----------------------------</td>
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<td>Transportation, Financial, Cultural, Social</td>
<td>Muleta et al. 2007</td>
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<tr>
<td>Ethiopia (Feb – Apr 2005)</td>
<td>Psychosocial</td>
<td>Browning et al. 2007</td>
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<td>Ethiopia (Dec 2008 – Sep 2009)</td>
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<td>Goh et al. 2013</td>
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<td>Ghana &amp; Rwanda</td>
<td>Quality of Care, Financial</td>
<td>Lassey 2007</td>
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<td>Jordan (1972 – 1996)</td>
<td>Quality of Care</td>
<td>Amr 1998</td>
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<td>Psychosocial, Social, Financial, Awareness, Transportation, Quality of Care, Cultural</td>
<td>Weston et al. 2011</td>
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<td>Kenya (2 months)</td>
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<td>Khisa &amp; Nyamongo 2012</td>
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<td>Transportation, Social, Facility Shortages, Quality of Care, Awareness, Cultural</td>
<td>Yeakey et al. 2011</td>
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<td>Kalilani-Phiri et al. 2010</td>
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<td>Yeakey et al. 2009</td>
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<td>Cam et al. 2010</td>
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<td>Umoiyoho et al. 2012</td>
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<td>Mukisa &amp; Cole 2013</td>
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Table 4: Barriers Briefly Mentioned

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<td>Hardee et al. 2012</td>
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<td>McFadden, et al. 2011</td>
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<td>Tanzania</td>
<td>Facility Shortages, Transportation, Awareness, Financial, Quality of Care</td>
<td>Obaid &amp; Chong 2004</td>
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<td>Facility shortages, Awareness</td>
<td>Bangser et al. 1999</td>
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<td>Togo</td>
<td>Financial, Transportation, Quality of Care</td>
<td>Anoukoum et al. 2010</td>
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<td>Uganda</td>
<td>Awareness, Social, Transportation, Financial, Facility Shortages</td>
<td>Matsamura 2004</td>
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**Table 5: Reviews, Needs Assessments, or Annual Reports**

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<th>Location and Time Frame</th>
<th>Barriers Identified</th>
<th>References</th>
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<td>Waiz et al. 2003</td>
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<td>UNFPA 2003</td>
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<td>Location and Time Frame</td>
<td>Barriers Identified</td>
<td>References</td>
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<td>Transportation, Facility Shortages</td>
<td>Bangser &amp; Haile-Mariam 2010</td>
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<td>Social, Psychosocial, Cultural, Awareness, Financial, Facility Shortages, Quality of Care, Political</td>
<td>Odhiambo 2010</td>
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<td>Sierra Leone &amp; Tanzania</td>
<td>Political, Awareness, Transportation, Social, Facility Shortages</td>
<td>Slinger et al. 2013</td>
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<td>Mehta &amp; Bangser 2006</td>
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## Appendix D

### Table 6: Interventions to alleviate barriers to fistula care

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<th>Study Population</th>
<th>Comparison Group</th>
<th>Demand-side Interventions</th>
<th>Supply-side Interventions</th>
<th>Barrier Targeted</th>
<th>Outcomes</th>
<th>CFA Grade</th>
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<tbody>
<tr>
<td>1. Bangser 2011</td>
<td>Kenya &amp; Tanzania (Jul 2009 – Nov 2010)</td>
<td>Women in Tanzania and Kenya</td>
<td>Pre-intervention fistula repairs</td>
<td>Kenya: M-PESA is a mobile application that helps low-income women save and prepay for fistula repair costs. Public education campaigns on radio station regarding fistula, and a hotline. Tanzania: hotline established for patients to get information about treatment</td>
<td>Tanzania: Fistula repair surgery provider CCBRT and UNFPA added 20 beds to existing building for women awaiting fistula repair; CCBRT paid for transport costs for patients via M-PESA</td>
<td>Financial; Transportation; Awareness; Facility Shortages</td>
<td>Kenya: Increase in fistula patients from 15 to 40 per month. Hotline received nearly 600 calls from Jan – Oct 2010. 230 women funded for fistula repair (including transport and follow-up). Tanzania: CCBRT hotline received more than 20 calls per day. 54 ambassadors referred 120 women for fistula repair from Jan – Nov 2010. 60% increase in patients after M-PESA</td>
<td>High</td>
</tr>
<tr>
<td>2. Bangser et al. 1999</td>
<td>Tanzania (Mar 1997 – Nov 1998)</td>
<td>Women with untreated fistula in Mwanza Tanzania</td>
<td>None</td>
<td>Radio messages about fistula treatment at BMC</td>
<td>Training 1 doctor and 2 nurses from BMC at Addis Ababa Fistula Hospital; on-site workshops for 70 health workers in Mwanza</td>
<td>Facility shortages; Awareness</td>
<td>None mentioned</td>
<td>Low</td>
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<td></td>
<td>Study Authors</td>
<td>Country</td>
<td>Setting</td>
<td>Methodology</td>
<td>Outcome</td>
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<td>3.</td>
<td>Baptiste et al. 2010</td>
<td>Nigeria (Jun 2006 – Feb 2007)</td>
<td>Women and men in northern Nigeria: Kaduna and Kano States</td>
<td>Non-listeners to radio drama</td>
<td>70-episode, research-based radio serial drama called Gugar Goge (Tell it to me Straight), depicting the life of a 12-year-old girl with OF; broadcast over radio stations; discusses how women can access fistula treatment</td>
<td>High</td>
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<td>92% of the population heard at least one episode and 82% reported listening weekly; increase in health care services and fistula services; 32% of male listeners strongly agreed that &quot;a woman with fistula should be part of the community like everyone else,&quot; compared with 18% of male non-listeners</td>
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<td>4.</td>
<td>Fiander &amp; Vanneste 2012</td>
<td>Tanzania (1 year)</td>
<td>Patients at CCBRT for fistula repair</td>
<td>Year before</td>
<td>CCBRT set up transportMYpatient using M-PESA; CCBRT visited 4 regions in 2010 to spread awareness about transportMYpatient</td>
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<td>Financial; Transportation 65% increase in the number of fistula repairs performed in 2010 compared with 2009</td>
<td>High</td>
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<td>5.</td>
<td>Fiander et al. 2013</td>
<td>Tanzania (2009 – 2011)</td>
<td>Women arriving at CCBRT via the transportMYpatient initiative</td>
<td>Pre-intervention</td>
<td>CCBRT introduced transportMYpatient to overcome travel costs; uses mobile banking to cover transport costs for patients with fistula; Identifies women using ambassador network</td>
<td>Transportation</td>
<td>Increase in number of fistula repairs post-intervention from 170 to 339. Transported 166 patients in 2011, accounting for 49% of total repairs</td>
<td>High</td>
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<td>6.</td>
<td>Gerten et al. 2009</td>
<td>Nigeria (Jul 2007)</td>
<td>Women awaiting or recently undergone VVF surgery</td>
<td>None</td>
<td>Educational brochure for patients</td>
<td>Awareness</td>
<td>Women felt that the information they learned from the brochure was helpful</td>
<td>Low</td>
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<tr>
<td>No.</td>
<td>Authors et al.</td>
<td>Location</td>
<td>Target Population</td>
<td>Providers Trained</td>
<td>Treatment and Support</td>
<td>Facility Shortages</td>
<td>Awareness</td>
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<td>7.</td>
<td>Iliyasu et al. 2007</td>
<td>Nigeria (Feb 21 – Mar 6, 2005)</td>
<td>Women living with untreated fistula in Kano, Katsina, Kebbi, and Sokoto states, Nigeria</td>
<td>Over 100 providers trained in fistula surgery, post-op care and counseling; 10 doctors, 40 nurses, and 60 social workers and volunteers trained in fistula management; infrastructure and facilities upgraded</td>
<td>Over 1000 women with fistulas arrived at the facilities for treatment; 564 received care with an 87% success rate</td>
<td>None</td>
<td>High</td>
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<td>8.</td>
<td>Marcus et al. 2009</td>
<td>Ethiopia (Jul 2006 – Sep 2009)</td>
<td>Women with fistula in the Amhara region, Ethiopia</td>
<td>Pre-repair centres provide medical care, food, baths, and clothes; counseling regarding fistula, hygiene, FP, HIV, and sexual relations after surgery; Community outreach program with educated volunteers who disseminate fistula information to people in churches, mosques, markets, schools, and homes</td>
<td>Fistula pre-repair centers established to identify fistula repair patients, screen women for repair, and provide pre-surgery care; Transportation to hospital also provided</td>
<td>Facility shortages; Awareness</td>
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<td>9.</td>
<td>Raassen 2006</td>
<td>Tanzania, Somalia, Uganda, &amp; Kenya (1 year)</td>
<td>Women needing fistula repair</td>
<td>Flying Doctors Service providing VVF-repair at remote government &amp; mission hospitals in EA; includes training local Drs.</td>
<td>In 2004 over 1300 VVF/RVF repairs performed in Eastern Africa by AMREF; increase in number of hospitals offering fistula repairs</td>
<td>Facility Shortages</td>
<td>None</td>
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<tr>
<td>Study</td>
<td>Location</td>
<td>Type of Women</td>
<td>Description of Interventions</td>
<td>Outcomes</td>
<td>Success Rate</td>
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<td>Ramsey et al. 2007</td>
<td>Nigeria (Feb 21 – Mar 6, 2005)</td>
<td>Women arriving for fistula repair at 4 repair centers during fistula fortnight</td>
<td>Fistula Fortnight: Included patient recruitment, mobilization of traditional and political leaders, and awareness-raising among the general population</td>
<td>Renovations to established repair centers in northern Nigeria; provision of equipment and supplies; training of providers; flying in international surgeons</td>
<td>High</td>
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<td>Sunday-Adeoye &amp; Landry 2012</td>
<td>Nigeria (Jun – Jul 2008)</td>
<td>Women potentially living with fistula Ebonyi State, Nigeria</td>
<td>Radio and television messages, and community gatherings to spread the word about screenings</td>
<td>Fistula screening services and free surgery offered</td>
<td>Medium</td>
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<td>USAID 2010</td>
<td>Nigeria (Oct 2006 – Jul 2010)</td>
<td>Women in northern Nigeria waiting for treatment at facilities offering fistula repair</td>
<td>Formation of a clinical peer-support network and 28 pooled effort events (5-7 days), in which host repair facilities invite 3-5 surgeons from other facilities to work together for a time period</td>
<td>Facility shortages</td>
<td>Medium</td>
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<td>USAID/ACQUIRE 2007</td>
<td>Ethiopia (Jan 2006 – Mar 2007)</td>
<td>Women living with fistula in Ethiopia and health care providers</td>
<td>Community sensitization activities to increase awareness of fistula</td>
<td>Improving capacity to deliver fistula screening and care, at 18 facilities; preparing health workers and TBAs to refer women with fistula; improving referral system; providing supplies/equipment</td>
<td>Medium</td>
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