#### **REVIEW ARTICLE**

## **Current Evidence Supporting Obstetric Fistula Prevention Strategies in Sub Saharan Africa: A Systematic Review of the Literature.**

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#### Abstract

Obstetric fistula has been eliminated in developed countries, but remains highly prevalent in sub-Saharan Africa. The End fistula campaign is the first concerted effort to eradicate the disease. The objective of this review is to retrieve and link available evidence to obstetric fistula prevention strategies in sub-Saharan Africa, since the campaign began. We searched databases for original research on obstetric fistula prevention. Fifteen articles meeting inclusion criteria were assessed for quality, and data extraction was performed. Grey literature provided context. Evidences from the articles were linked to prevention strategies retrieved from grey literature. The strategies were classified using an innovative target-focused method. Gaps in the literature show the need for fistula prevention research to aim at systematically measuring incidence and prevalence of the disease, identify the most effective and cost-effective strategies for fistula prevention and utilise innovative tools to measure impact of strategies in order to ensure eradication of fistula. (*Afr J Reprod Health 2014; 18[3]: 118-127*)

Keywords: Obstetric fistula; Fistula prevention; Prevention strategies; Sub-Saharan Africa

#### Résumé

La fistule obstétricale a été éliminée dans les pays développés, mais reste très répandue en Afrique sub-saharienne. La Campagne pour mettre fin à la fistule est le premier effort concerté pour éradiquer la maladie. L'objectif de ce compte rendu est de récupérer et de lier l'évidence disponible aux stratégies de la prévention de la fistule obstétricale en Afrique sub-saharienne, depuis le commencement de la campagne. Nous avons cherché des bases de données pour la recherche originale sur la prévention de la fistule obstétricale. 15 articles ont satisfait aux critères d'inclusion et ont été évalués pour vérifier leur qualité et l'extraction des données et a été réalisée. La documentation grise a fourni un contexte. Les évidences tirées ont été liés à des stratégies de prévention extraites de la documentation grise. Les stratégies ont été classées à l'aide d'une méthode de cible axé innovante. Les lacunes dans la documentation montrent la nécessité pour la recherche sur la prévention de la fistule pour viser systématique ment la mesure de l'incidence et de la prévalence de la maladie, identifier les stratégies les plus efficaces et rentables pour la prévention de la fistule et d'utiliser des outils innovants pour mesurer l'impact des stratégies afin de garantir l'éradication de la fistule. (*Afr J Reprod Health 2014; 18[3]: 118-127*)

Mots-clés: fistule obstétricale; prévention de la fistule; stratégies de la prévention; Afrique sub-saharienne

## Introduction

Obstetric fistula is a direct communication between vagina and bladder and/or between vagina and rectum, following childbirth. It usually follows obstructed or prolonged labour, which is estimated to cause 76% to 97% of obstetric fistula<sup>1</sup>. Other causes such as spontaneous abortion or more infrequently female genital mutilation have been identified in previous studies. This condition manifests with social, psychological, biological and economic consequences<sup>2</sup>. Obstetric fistula has been eliminated in developed countries, but remains highly prevalent in sub-Saharan Africa<sup>3</sup>. A prospective study conducted in 6 sub-Saharan African countries revealed an overall obstetric fistula incidence rate of 10.3 per 100,000 deliveries<sup>4</sup>. Another study suggested incidence figures of 1-3 per 1000 births in West Africa<sup>5</sup>, with higher rates of 5-10 cases per 1000 births reported

in rural sub-Saharan Africa<sup>4</sup>. These estimates are largely deemed to be under-estimations as most cases go unreported due to the associated stigma<sup>6</sup>.

There have been concerted global efforts geared towards reducing and/or eradicating fistula, but the progress has been slow. UNFPA, in collaboration with other stakeholders, launched the global campaign to end fistula in 2003 with the aim of reducing fistula cases, by focusing on prevention, treatment and social reintegration<sup>7</sup>. Recently, the international fistula day (23<sup>rd</sup> May) was created to draw global attention to obstetric fistula and mobilize support for on-going initiatives<sup>8</sup>. However, donors and researchers involved in the campaign are keener on quick results that come from the treatment component, rather than prevention, which tackles more deeprooted problems<sup>9</sup>.

In actual fact, fistula prevention appears to be such an understudied area that a recent commentary described it as "neglected"<sup>10</sup>. It is an area that is frequently hidden under the broad rubric of maternal health and is therefore not sufficiently prioritised, even in recent initiatives launched in Africa to improve maternal health. This under-prioritisation is puzzling, especially at a time when 'near-miss' and maternal morbidity is high up on the agenda; as it is well documented that obstetric fistula is entirely preventable<sup>11</sup>. For such an extremely devastating condition, we opined that there is a need to explore this "neglect" and to retrieve and link available evidence towards responding to the "neglect". A review provides a basis for validating this assumption. Our research question was, "What is the recent evidence supporting obstetric fistula prevention strategies?"

This review builds on previous research by synthesizing available evidence from scarce sources to support prevention strategies used in obstetric fistula programming as well as identifying gaps within the literature, with a bid to proposing a research agenda.

## Methods

## Literature search strategy and procedure

We conducted a preliminary search in February 2013 to identify previously published research on fistula prevention, refine objectives, test proposed

search terms and identify potential contribution of our review. We then independently repeated the search, using our agreed search strategy to retrieve articles between 6<sup>th</sup> and 9<sup>th</sup> of March 2013. We searched journal repositories such as PubMed, BioMed Central, Google Scholar, African Journals Online and Directory of Open Access journals for articles on obstetric fistula prevention. The comprehensive search was subsequently repeated using the same strategy on 14<sup>th</sup> July 2013 in order to verify previous outputs. Search strings utilised "obstetric fistula", included the term "vesicovaginal fistula", "rectovaginal fistula", "vaginal fistula", "fistula", "obstructed labour", "prolonged labour" combined with either "prevention" or "prevention & control".

In addition, grey literature was explored. This was important for this area of study, as our preliminary search revealed that there had been several prevention strategies implemented in the field, which had not been published in scientific journals. For our review, findings from these sources were not included in our evidence table, but were utilised for context provision and linked to scientific evidence that supports their implementation.

## Inclusion and Exclusion criteria

Only peer-reviewed articles published after 2003, which was the year where the End fistula campaign was launched, were included. This was a year when global attention shifted to obstetric fistula and deliberate attempts have since been made to eradicate the disease<sup>7</sup>. The search included only quantitative and qualitative primary research that principally discussed obstetric fistula prevention. Thus, commentaries and editorials were excluded. Articles that focused on other comorbidities that could occur concurrently with fistula, such as uterine prolapse and other complex obstetric injury such as vaginal scarring and stenosis were excluded. Articles that looked at obstructed labour through a prevention perspective were included, as there is evidence to support that most obstetric fistulae are caused by obstructed labour<sup>12</sup>. The search included articles in English and French and was limited to research conducted in sub-Saharan Africa. A 3-step inclusion approach (Bibliographic data – abstract – full text)

was used. If the bibliographic data already excluded the paper, based on the set inclusion criteria, the paper was removed. At the abstract stage, research methodology was reviewed to remove studies that did not present original research. We complemented our search by reviewing the reference list to identify other primary research. Subsequently, the remaining studies were critically examined to ascertain that they met the inclusion criteria. Finally, we consulted as a team to agree regarding final eligibility of articles. After identification of duplicates, 15 articles were included in the final summary of evidence [Figure 1]. Following a set data extraction process, pre-specified data were retrieved from these studies [Table 1].

#### Data extraction and synthesis

This involved reading through full text of included studies to extract data about the author(s), country

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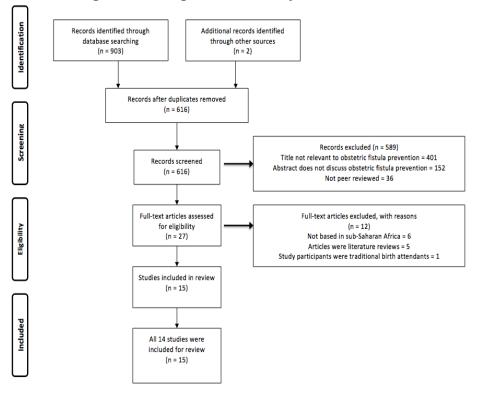
or region of study, year of publication, study design, sample size, population characteristics and key evidence. A post-study discussion was conducted to synergise findings. Based on our reading and in order to systematize our findings, we adopted a new target-focused classification of the prevention strategies, as we opined that this would be more informative and beneficial to our analysis. Using this, we classified prevention strategies into population-based strategies and health-system based strategies.

#### Quality assessment and appraisal

Critical appraisal checklist for surveys <sup>25</sup> by the Centre for Evidence-Based Management (CEBMa) was used for quality assessment, as most of the studies included in our review are cross-sectional studies. Each criterion received a "yes" (Y), "no" (N) or "can't tell" (C) response. [Table 1].

## Results

Figure 1: PRISMA flow diagram describing article inclusion process



Adapted from the 2009 PRISMA Flow diagram<sup>13</sup>

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|                     | Year of     | Region/                           |                             |  |  |  |  |  |  |  |
|---------------------|-------------|-----------------------------------|-----------------------------|--|--|--|--|--|--|--|
| Author(s)           | publication | Country of study                  | Study design                | Population characteristics   |  |  |  |  |  |  |
| Bangser             | 2007        | Tanzania                          | Qualitative (Study 3)       | Women who recently delivered babies.   |  |  |  |  |  |  |
| Gerten et al.       | 2009        | Nigeria                           | Cross-sectional             | 50 fistula patients.   |  |  |  |  |  |  |
| Hassan et al.       | 2009        | Sokoto, Nigeria                   | Qualitative + retrospective | 130 fistula patients.  |  |  |  |  |  |  |
| Melah et al.        | 2007        | North Eastern Nigeria             | Prospective                 | 80 fistula patients and 80 inpatients without fistulae.  |  |  |  |  |  |  |
| Meyer et al.        | 2007        | Niamey, Niger                     | Qualitative                 | 58 women treated for vesicovaginal fistulae.   |  |  |  |  |  |  |
| Muleta et al.       | 2007        | Ethiopia                          | Cross-sectional             | Women who have or had fistula  |  |  |  |  |  |  |
| Nathan et al.       | 2009        | Tanguieta, Benin                  | Qualitative                 | 37 fistula patients  |  |  |  |  |  |  |
| Roka et al.         | 2013        | Kenya                             | Unmatched case-control      | Fistula patients delivered during previous 5<br>years. Controls: Women who attended<br>obstetrics and gynaecology clinics. |  |  |  |  |  |  |
| Stekelenburg et al. | 2004        | Zambia                            | Cross-sectional descriptive | 332 women in the catchment areas of five rural health centres.   |  |  |  |  |  |  |
| Tebeu et al.        | 2009        | Far North Province,<br>Cameroon   | Qualitative                 | 42 fistula patients.   |  |  |  |  |  |  |
| Tsui et al.         | 2007        | Niger, Nigeria and<br>Tanzania    | Retrospective               | 4798 deliveries in Niger, 3552 in Nigeria and 6789 in Tanzania   |  |  |  |  |  |  |
| Turan et al.        | 2007        | Northern red sea zone, Eritrea    | Qualitative                 | Women seeking medical care for fistula.  |  |  |  |  |  |  |
| Umoiyoho et<br>al.  | 2013        | Taraba and<br>Adamawa,<br>Nigeria | Qualitative                 | 450 participants (350 women and 100 men).  |  |  |  |  |  |  |
| Wall et al.         | 2004        | Jos, Nigeria                      | Retrospective               | 932 fistula patients   |  |  |  |  |  |  |
| Yisma et al.        | 2013        | Addis-Ababa,<br>Ethiopia          | Cross-sectional             | Obstetric care givers in public health institutions.   |  |  |  |  |  |  |

Table 1: Profile of articles included for review

#### **Obstetric fistula prevention strategies**

Several strategies have been employed for fistula prevention, although with minimal success. However, there have been attempts to classify these strategies in a more systematic way. From our review, we identified two classification systems:

#### WHO classification

World Health Organization classifies fistula prevention strategies into primary prevention strategies (focused on contraception), secondary prevention strategies (ensuring women can access skilled care for delivery) and tertiary prevention strategies (early screening for fistula for most at risk women)<sup>14</sup>.

#### Classification based on the Haddon Matrix

The Haddon matrix was used to categorise factors influencing the formation of obstructed labour induced fistulae into pre-injury (pre-event) factors, factors influencing outcome of obstructed labour (event) and factors influencing aftermath of obstructed labour (post-event). In synthesising information generated from the matrix, this article classified prevention strategies into short and long-term strategies. Though this classification focuses on only obstructed labour induced fistulae, it generally captures strategies used for fistula prevention<sup>2</sup>.

#### **Population-based strategies**

Promoting education of the girl child is crucial to preventing fistula in the long run<sup>29</sup>. A study in North-Eastern Nigeria showed that illiteracy contributed to 96.3% of cases<sup>16</sup>, while another study in Cameroon revealed that 81% of patients received no formal education<sup>15</sup>. Evidence supports that knowledge and awareness on fistula amongst young women who had attained post-primary education is better than women who have no education or only primary education<sup>30</sup>. It is particularly crucial to focus on educating women about risks associated with early marriage and early pregnancy, including fistula, as has been implemented in Ethiopia<sup>9</sup>, because there remain

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study carried out in Nigeria showed that

educational materials can be useful in enlightening

women about fistula<sup>17</sup>.

some misconceptions about the cause of fistula. Some fistula patients actually blame "God", "destiny" or the "fistula repair surgery"<sup>19</sup>. A pilot

 Table 2: Quality assessment of included studies

|        |   | Bangser (2007) | Gerten et al. (2009) | Hassan et al. (2009) | Melah et al.( 2007) | Meyer et al. (2007) | Muleta et al. (2007) | Nathan et al. (2009) | Roka et al. (2013) | Stekelenburg et al.l (2004) | Tebeu et al. (2009) | Tsui et al. (2007) | <b>Turan et al. (2007)</b> | Umoiyoho et al. (2013) | Wall et al. (2011) | Yisma et al. (2013) |
|--------|---|----------------|----------------------|----------------------|---------------------|---------------------|----------------------|----------------------|--------------------|-----------------------------|---------------------|--------------------|----------------------------|------------------------|--------------------|---------------------|
|        |   |                | Ŭ                    | J                    |                     |                     | $\cup$               | 3                    |                    | 1 (2004                     |                     |                    |                            | 013)                   |                    |                     |
|        | Appraisal questions   |                |                      |                      |                     |                     |                      |                      |                    | Ð                           |                     |                    |                            |                        |                    |                     |
| 1      | Did the study address a clearly focused question?   | Y              | Y                    | Y                    | Y                   | Y                   | Y                    | Y                    | Y                  | Y                           | Y                   | Y                  | Y                          | Y                      | Y                  | Y                   |
| 2      | Is the research method (study design) appropriate for answering the research question?          | Y              | Y                    | Y                    | Y                   | Y                   | Y                    | Y                    | Y                  | Y                           | Y                   | Y                  | Y                          | Y                      | Y                  | Y                   |
| 3      | Is the selection method of subjects clearly described?  | Y              | Y                    | Y                    | Y                   | Y                   | Y                    | Ν                    | Y                  | Y                           | Y                   | Y                  | Y                          | Y                      | Y                  | Y                   |
| 4      | Could the way sample was obtained introduce (selection) bias?                                   | Y              | Y                    | N                    | С                   | Y                   | N                    | Y                    | Ν                  | Y                           | С                   | Ν                  | С                          | С                      | N                  | Ν                   |
| 5      | Was the sample representative with regard to the population to which findings will be referred? | Y              | N                    | С                    | C                   | C                   | Y                    | N                    | Y                  | Y                           | С                   | Y                  | C                          | C                      | Y                  | Y                   |
| 6      | Was the sample size based on pre-<br>study statistical power<br>considerations?                 | С              | N                    | N                    | N                   | N                   | Y                    | Ν                    | Y                  | Ν                           | Ν                   | Ν                  | Ν                          | Ν                      | С                  | Y                   |
| 7      | Was a satisfactory response rate achieved?  | Y              | Y                    | С                    | Y                   | Y                   | Y                    | Y                    | Y                  | Y                           | Y                   | Y                  | Y                          | С                      | С                  | Y                   |
| 8      | Are measurements likely to be valid and reliable?   | Y              | С                    | Y                    | C                   | С                   | Y                    | С                    | Y                  | Y                           | С                   | С                  | С                          | С                      | Y                  | Y                   |
| 9      | Was statistical significance assessed?  | N              | Ν                    | N                    | N                   | N                   | Y                    | Ν                    | Y                  | Ν                           | N                   | Y                  | Ν                          | Ν                      | Ν                  | Y                   |
| 1<br>0 | Are confidence intervals given for main results?  | N              | N                    | N                    | N                   | N                   | Y                    | Ν                    | Y                  | Y                           | N                   | Y                  | N                          | Ν                      | Ν                  | Y                   |
| 1<br>1 | Could there be confounding factors that haven't been accounted for?                             | Y              | Y                    | Y                    | N                   | С                   | N                    | Y                    | Ν                  | Ν                           | С                   | Ν                  | С                          | Y                      | Ν                  | Ν                   |
| 1<br>2 | Can the results be applied to your organization ( <i>sub-Saharan Africa</i> )?                  | Y              | Y                    | Y                    | Y                   | Y                   | Y                    | Y                    | Y                  | Y                           | Y                   | Y                  | Y                          | Y                      | Y                  | Y                   |

Key: Yes-Y, No-N Can't tell-C

Fistula prevention also involves educating local communities about the cultural, social and physiological factors that influence and increase risk of fistula formation<sup>29</sup>. It is evident that there is a lot of misconception around aetiology and risk factors of the condition<sup>20</sup>. *Community-based social education programs, such as the Tostan program in West Africa<sup>31</sup>, have been used to prevent fistula, by leveraging this non-formal educational program to put communities, especially rural ones, "in charge of their own futures", thereby improving ownership and sustainability of such* 

*interventions*<sup>11</sup>. In addition, previous patients who have been treated have also acted as community advocates for fistula prevention in Kenya, Bangladesh, Nigeria, Ghana, Côte d'Ivoire and Liberia, sharing their experiences and helping to dispel cultural myths<sup>32</sup>.

A study showed that 28% of women and girls who developed fistula were younger than 20 years, with antecedent obstructed labour in most cases. The study concluded that if the risks associated with early childbirth were eliminated, the predicted proportion of women who experienced

prolonged or obstructed labour would reduce by 11.2% in Niger, 11.4% in Nigeria, and 13.1% in Tanzania<sup>21</sup>. Another study in Jos, Nigeria showed that "typical" women living with fistula report being married early (15.5 years)<sup>12</sup>. Evidence from a study carried out in Burkina Faso showed that the risk of early marriage has an urban-rural variation. The risk of being married by 15 years of age amongst young women living in rural areas is five times higher than urban young women; rural young women are approximately three times more likely to have been pregnant before 18 years<sup>30</sup>; and 95 % of fistula patients reside in rural areas<sup>16</sup>.

Applying defined time limits for home delivery that shows limited progress has also been proposed as a strategy so that women who insist on home delivery do not continue to labour in vain and have a benchmark after which they are to present in hospitals, to be managed by skilled birth attendants<sup>11</sup>. A study conducted in Niamey, Niger revealed that the average labour of women who had fistula lasted 2.61 days, while an average of 1.61 days passed before they sought assistance in health institutions<sup>23</sup>. In another study in Cameroon, 76% of fistula patients were in labour in excess of 12 hours<sup>15</sup>.

Studies have described fistula patients as being usually malnourished (averagely 44kg), small and short, with an average height of 146.2 cm<sup>12,16</sup>. This is significant, as previous studies have shown that women who are  $\leq$ 150cm have a higher risk of obstructed labour<sup>33</sup> and thus fistula<sup>34</sup>. Our review did not identify any programs aimed at improving nutritional status of women as a strategy for reducing fistula incidence.

Some authors have pointed to the possible contribution of gender inequality to fistula prevalence<sup>34</sup>, especially with perpetuation of harmful traditional practices such as female genital cutting. In addition, high levels of unmet need for contraception have also been linked to preponderance of fistula cases<sup>35</sup>.

#### Health-system based strategies

Previous studies have shown that risk factors for

developing fistula include delay in seeking or receiving care for more than 6 hours of labour onset, taking more than 2 hours to reach a health facility and/or labour duration of more than 24 hours. Measures to improve health-system's response including improved access to emergency obstetric care, incorporating safe and timely intervention for women presenting with obstructed labour have been suggested in the literature<sup>24</sup>.

Recurrent training of skilled birth attendants on emergency obstetric care has been proposed in a previous study. The study revealed that some fistulae still occur from ineptitude of "skilled birth attendants", as 43% of fistula patients thought that their fistulae were a result of trauma they experienced from previous operative deliveries<sup>25</sup>. In addition, training on partograph use in monitoring labour, so as to identify labour at risk of mal-progression is crucial<sup>26</sup>.

In reality though, these professionals are not sufficient or are totally absent in some rural communities. There is substantial evidence that shifting tasks to lower cadre health workers, especially in rural areas could potentially solve the chronic human resource shortage<sup>36</sup>. In Ethiopia, a country where there are about 200 practising obstetrician-gynaecologists for an 84 million population, a midwifery school trained midwives from rural areas on emergency obstetric care for a 3-year period<sup>9</sup>.

Ensuring that the care provided by health workers is affordable, safe and timely for women in need of care is important<sup>17,25</sup>, especially for women in the most deprived settings<sup>27</sup>. Previous studies showed that while 83% of women in urban areas delivered their babies in health facilities, 80% of rural women gave birth at home<sup>37</sup>. Nongovernmental organisations have worked with Niger Republic - offering free caesareans - thereby preventing consequences of obstructed labour induced fistula<sup>29</sup>, but coverage of facilities that provide such emergency obstetric care is limited and well below the recommended minimum coverage levels of 1 comprehensive emergency obstetric care and 4 basic emergency obstetric care facilities per 500,000 population<sup>38</sup>.

#### Proposed classification for obstetric fistula prevention strategies [Table 3]

Table 3: Evidence to support prevention strategies for obstetric fistula in sub-Saharan Africa

| Prevention of obstetric fistula  |  |  |  |  |  |  |  |
|--|--|--|--|--|--|--|--|
| Population based strategies  | Health system based strategies   |  |  |  |  |  |  |
| <ul> <li>Promoting minimum of post-primary education for girls<sup>15,16</sup>.</li> <li>Providing sexual education that includes information about fistula<sup>17-19</sup>.</li> <li>Educating communities about cultural, social and physiological factors that influence and contribute to fistula<sup>20,21</sup>.</li> <li>Delaying early marriage and early childbirth<sup>16,22</sup>.</li> <li>Eradicating malnutrition<sup>12,16</sup>.</li> <li>Defining time limits for labour at home without progress<sup>15,23</sup>.</li> </ul> | <ul> <li>Scaling-up accessibility to, availability of and provision of emergency obstetric care<sup>24</sup>.</li> <li>Training and re-training of skilled birth attendants on operative delivery<sup>25,26</sup> and use of partograph<sup>27</sup>.</li> <li>Provision of affordable, safe and timely interventions for women in need of care,<sup>17,25</sup> especially for women in deprived settings<sup>26</sup>.</li> <li>Reducing distance to access care and provide affordable transportation to convey women to health facilities<sup>16,20,28</sup>.</li> </ul> |  |  |  |  |  |  |

Affordable care is an essential consideration in planning services, as 49% of fistula patients interviewed in Tanguieta, Benin Republic, reported lack of financial resources as reason for not seeking care when pregnant<sup>25</sup>.

## Discussion

Our classification system [Table 3] closely aligns with both the WHO and Haddon matrix-based classification. Population based strategies essentially correspond to long-term strategies, while health system based strategies are largely short-term strategies<sup>2</sup>. We argue though that a target-focused classification system could possibly be more informative and can potentially draw the attention of potential funders and program managers to the direct beneficiaries of proposed interventions.

The population-based strategies are less expensive and more sustainable, but much emphasis is placed on health-system strategies in day to day practice, which are actually more expensive and usually require continuous technical and financial support from international donors. Estimates made before the turn of the century revealed that Africa would need to construct 75,000 new emergency obstetric centres to satisfy the burgeoning need of reproductive age group women<sup>40</sup>. This is a cost-intensive venture for most fistula-prevalent countries, which are mostly lowincome countries.

It is therefore worth keeping in mind that the most beneficial strategies would need to save lives and save cost. In actual sense, health-system based strategies only manage the problem conservatively and do not deal with the root causes of the problem. In developed countries, where there has not been a recorded case of fistula in more than 100 years, population-based strategies were very effective in eradication of fistula<sup>41</sup>. In addition, women in most fistula-prevalent countries may still not be able to access the healthcare system, because they do not own the decision power for their own reproductive and maternal health choices<sup>1</sup>. However, it requires sustained dedication to achieve population-based strategies. Evolution of these structures may take generations to happen, the "quick fix" health-system based but interventions that yield measurable results, do not necessarily create sustainable impact.

A strategic combination of both health-system based and population-based strategies with more attention on the latter may be more effective in eradicating fistula. This would ensure that meagre resources are being used in the most cost-effective manner and that fistula programs are focusing on long-lasting solutions to a persistent problem. Political commitment from governments, financial mobilization and international support for fistulaprevalent countries focused on empowering governments to manage their own problems should be greatly intensified. While the "quick programs" are time bound; local institutions are there to stay in-country and with ample technical support, could successfully follow through with implementation of the population-based strategies. There is also a need for good practice such as involving young girls (especially those who have had fistula) decision-making in and

## So is obstetric fistula really a "neglected disease"?

Without a doubt "Yes, it is". Like most other neglected tropical diseases (NTDs), obstetric fistula principally affects the world's poorest people<sup>42</sup> and is often highly stigmatizing for patients<sup>43</sup>. Unlike other NTDs, there are no proven strategies to control it<sup>42</sup>. This neglect is underscored by the failure of governments of fistula-prevalent countries to prioritise fistula eradication, while other areas of maternal health get attention.

#### Future research agenda

Reliable baseline data need to be generated to show fistula incidence and prevalence. Adaptation of the sibling-based method suggested by Stanton et al<sup>6</sup> could be considered, standardised and rolled out. Ecological studies could be explored to trends in fistula numbers. monitor Also, operational research focusing on identifying best approaches should be encouraged. Evaluations of fistula prevention programs need to utilise standardised indicators to account for outcomes and to measure impact of intervention on behaviour change<sup>14</sup>, and incidence and/or prevalence reduction. Effectiveness studies should be supported by cost-effectiveness studies, to provide a wider base for evidence-based decisionmaking. Finally, there is need for a more systematic approach in accounting for impact of existing strategies. Innovative tools such as the social return on investment method should be considered, as this would give measurable values based on proxies for social value of an intervention compared to the cost of the intervention<sup>44</sup>.

#### Study limitations

First, the review included only articles published in 2003 or later. While there are other articles that discussed fistula prevention before 2003, we do not think that their inclusion would change conclusions of this review. Secondly, most of the studies included had small sample sizes; larger sample sizes would have increased the validity of results, but these are few. Thirdly, the articles hardly present outcome data to assess effectiveness and the review did not include comorbidities that could occur with/after fistulas such as uterine prolapse and other complex obstetric injury such as vaginal scarring and stenosis.

## Conclusion

This review has presented essential information to aid policy formulation and program design to prevent fistula. Findings from needs assessments, such as those conducted in the End fistula campaign need to be utilised in developing country-specific, and in some cases communityspecific strategies for fistula prevention in sub-Saharan Africa<sup>45</sup>. There is a need to galvanise support to include fistula eradication in the post-2015 development agenda. Eradication of obstetric fistula is not only a human rights issue, but also a question of equity, in which the poorest and uneducated women living in rural communities are most disadvantaged. It is our responsibility to provide an environment for girls to develop and express their full potentials.

## **Contribution of Authors**

AB and JM were responsible for the conceptualization of this research. AB, OW, SK and JM contributed to the review, analysis, drafting and revising. All authors have approved the final version of the manuscript.

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