

## Lived Experiences of Obstetric Fistula Survivors in Africa:A Systematic Literature Review

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### Abstract

Obstetric fistula (OF), a hole connecting bladder or rectum to the vagina, is common in Sub-Saharan Africa. Understanding the plight of women living with OF helps policy makers in formulating appropriate intervention programs for affected women. This paper aims to identify, critically evaluate and integrate findings of studies done in Africa. A systematic literature review was conducted. Online literature search for documentation of experiences of women affected by OF was conducted from EBSCOHOST (MEDLINE) and HINARI. Websites for the World Health Organization (WHO), the United Population Fund (UNFPA) and Women and Health Alliance International (WAHA) were also searched. Majority of articles (16 out of 17) for this review showed that women affected by OF suffer physical, social, emotional, economical and psychological negative consequences from the fistula problem. However, there is one study which had totally divergent views from all observations of the other sixteen studies. It noted that women living with OF continue with their lives normally in all aspects and that researchers concluded their preconceived assumptions on the difficulties faced by OF survivors. Of the seventeen studies included in this review, only one was done in Zimbabwe. This review concluded that women affected by OF face emotional, physical, psychological and economic difficulties. Considering divergent views of one of the studies, it is recommended that more researchers from outside Africa conduct similar studies for comparison. This paper also recommends experiences of OF survivors in Zimbabwe to be documented extensively to provide guidance on programming.

**Key words:** literature review, obstetric fistula experiences, Africa

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Date of Submission: 02-12-2019

Date of Acceptance: 18-12-2019

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### I. Introduction

Obstetric fistula is an abnormal hole connecting the vagina to the bladder or the rectum to the bladder mainly as a result of prolonged and obstructed labour. An estimated 50 000 to 100 000 new cases of obstetric fistula occur annually mostly in Southern Africa and Asia<sup>(1)</sup>. Most literature on obstetric fistula focus on quantitative aspects of the problem like prevalence and incidence<sup>(2)</sup>. Documentation of life experiences of women affected by the problem of fistula helps in understanding obstetric fistula from the view point of affected women<sup>(3)</sup>.

This paper seeks to examine research on experiences of obstetric fistula survivors in Africa and specifically in Zimbabwe.

Results from this article will assist health managers, policy makers in health and community leaders in designing programs for survivors of obstetric fistula basing on verbalized experiences of affected women by the affected women instead of basing such programs on theoretical assumptions.

**Broad objective:** To identify, critically evaluate and integrate findings of high quality studies conducted in the past five years on lived experiences of obstetric fistula survivors in Zimbabwe and Africa.

#### Specific objectives

1. To establish to what extend existing literature has progressed towards documenting experiences of women affected by obstetric fistula in Zimbabwe
2. To identify relations, gaps and inconsistency in the literature on lived experiences of women with obstetric fistula
3. To provide implications for practice and policy regarding obstetric fistula programming in Zimbabwe in the future

**Research question:** What are the experiences of obstetric fistula survivors in Africa and specifically Zimbabweans documented by literature?

**Search terms:** Obstetric fistula, lived experiences, fistula, urinary fistula, vesico-vaginal fistula, recto-vaginal fistula

**Inclusion criteria**

Published and unpublished studies on experiences of women affected by obstetric fistula, those studies should have been conducted in Africa in the last five (5) years and they can be either qualitative or quantitative studies.

**Exclusion criteria**

Studies not done in Africa, those more than 5 years old and those which do not relate to the experiences of obstetric fistula affected women.

**II. Materials and Methods**

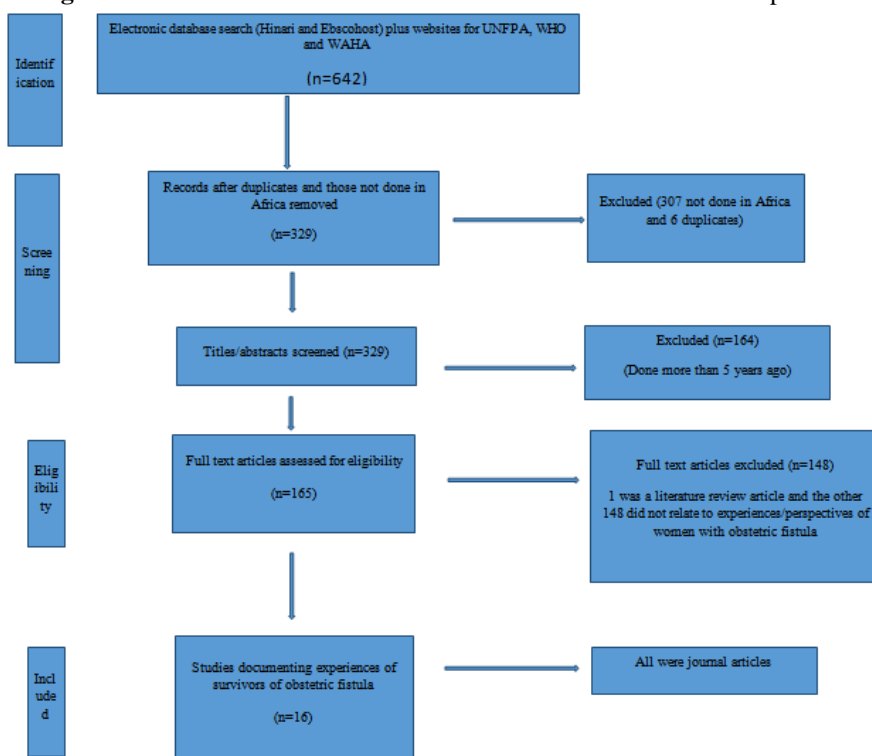
**Study design**

A systematic review of literature on experiences of women affected by obstetric fistula was conducted. Online literature search in ‘Hinari Access to Research for Health’ through the URL <https://www.who.int/hinari/en/> as well as in EBSCOHOST (MEDLINE) was conducted using the key words Obstetric fistula, vesico-vaginal fistula, rectovaginal fistula, lived experiences, experiences and social support. Websites for the World Health Organization (WHO), the United Nations Population Fund (UNFPA) and Women and Health Alliance (WAHA) were also searched. A total of 642 results were obtained. Of these 110 were books, 505 journal articles, 33 book reviews, 26 book chapters and 15 publications. The search was left open to enhance sensitivity so as not to miss relevant study. Of these 642 studies, 313 were excluded on the grounds that they were conducted outside Africa. So 329 were left. The search was refined to include only studies conducted in the last 5 years, i.e. from 2014 to 2019 and 165 studies remained. A preview of the 165 studies conducted in Africa within the last 5 years was done and only 17 were about obstetric fistula survivors’ experiences. One of the 17 was a literature review article so 16 were left. Full articles for these 16 studies were downloaded and read thoroughly especially their methods and results sections.

**The search path way**

The search pathway is presented using the Preferred Reporting Items for Systematic Reviews and Meta- Analyses (PRISMA) flow diagram, as shown in figure 1 below.

**Figure 1: PRISMA Flow chart for the literature search and selection process**



**Studies retrieved from searches and results**

Table 1 below shows the studies included in the review. A total of sixteen articles were included in this review. Of these only one was from Zimbabwe.

**Table 1: Studies included in the review**

Author, year and country	Aim of the study	Sample size	Research design
Khisa et al (2017) Kenya	To explore health seeking behaviors of women with obstetric fistula	121	Qualitative
Changole et al (2017) Malawi	To understand lived experiences of women with obstetric fistula in Malawi	25	Qualitative
Baragein et al (2015) Uganda	To explore experiences of Ugandan women living with genital fistulas	8	Qualitative
Animut et al (2019) Ethiopia	To explore lived experiences of women living with obstetric fistula at three hospitals in Ethiopia	10	Qualitative
Gebresilase (2014) Ethiopia	To explore evolution of obstetric fistula survivors' perceptions of their social relationships and health since developing fistula	8	Qualitative
Dennis et al (2016) Tanzania	To explore the experiences of social support of Tanzanian women after fistula repair and reintegration	79	Mixed methodology
Javis, Richter and Vallianatos (2017) Ghana	To explore the cultural, social and economic needs and challenges of women in Ghana as they resumed their day-to-day living after obstetric fistula repair	99	Qualitative
Khisa, Wakasiaka, McGowan, Campbell and Lavender (2016) Kenya	To gain understanding of first-hand experiences of women prior to and following repair of vaginal fistula to determine the most effective support mechanism	16	Qualitative
Khisa, Nyamongo, Omoni and Spitzer (2019) Kenya	To explore the experiences getting back into communities and their return to normalcy after surgery in 3 VVF repair centers in Kenya	60	Qualitative
Msele and Kohi (2015) Tanzania	To explore socio-cultural experiences of women living with obstetric fistula in rural Tanzania	16	Qualitative
Mawunganidze, Sodi, Mutambara and Nkiwane (2015) Zimbabwe	To determine how obstetric fistula affects women's intimate partner relationships or other social ties	11	Qualitative
Ruder, Cheyne and Emasu (2018) Uganda	To examine the experiences of Ugandan women of obstetric fistula with the aim of adding narrative depth to existing literature	17	Qualitative
Heller and Hannig (2017)	To challenge the common violence of culture against the biomedical salvation of women living by fistula	Not stated	Qualitative
Khisa, Nyamongo, Omoni and Spitzer (2017) Kenya	To establish Obstetric fistula affected women's health seeking behaviors	121	Qualitative
Kay et al (2015) Rwanda	To reveal illness narratives of Rwandan women with urogenital fistulas to appreciate their unique experiences	11	Qualitative
Mohamed, Ilesanmi and Dairo (2018)	To describe and explore the experiences of women living with obstetric fistula following corrective surgery	21	Qualitative

**III. Results**

Table 2 shows results from individual studies, areas of divergence and convergence.

**Table 2: Findings from individual studies**

Article	Documented experiences of OF survivors	Relations with other literature	Inconsistencies with other literature
I stayed with my illness <sup>(4)</sup>	Reasons for not seeking treatment early: individual – shame, suffering, hygiene, stigma, isolation, divorce and separation. Health system – missed diagnoses, no screening, no referral to surgeons, no surgery facilities, no surgeons. Economics – lack of information, lack of transport, cost of surgery. Social factors – supportive family, husband, peer, community	Purposive sampling Participants suffer isolation, physical and emotional problems	No significant divergence from other studies
I am a person but I am not a person <sup>(5)</sup>	Women stayed alone for fear of “anticipated” stigma not really enacted stigma.	Isolation. Lowered self-esteem.	Anticipated vs actual stigma
I am alone and isolated <sup>(6)</sup>	Self and social isolation. Coping mechanisms use of cloths to trap urine and self-isolation.	Isolation. Stigma. Smell	Self-imposed stigma of affected women
The sun keeps rising but darkness	Smells. Stigma and isolation. Self-	Almost the same as the other	First to mention

surrounds us <sup>(2)</sup>	isolation.	studies above	the need for men's participation in survivors' care and support
A qualitative study on experiences of obstetric fistula survivors in Addis Ababa <sup>(7)</sup>	The importance of assessing the fistula survivors s part of the larger community, not in isolation.	Findings correspond with the other studies	Used 2 models. Positive interpretation of situation, having been taught sympathy and understanding of individual behaviors
Experiences of social support among women presenting for obstetric fistula repair surgery in Tanzania <sup>(8)</sup>	Half of the women experienced high levels of social support however those who lack social support, their problem exacerbated existing relationship problems resulting in divorce or separation	This study weakly supports findings of the other studies above since 50% of their study participants suffer challenges as observed in the other studies and the other 50% did not	Women being very assertive and resilient in standing up for their rights to care and relationships
Exploring the needs and challenges of women reintegrating after obstetric fistula repair in northern Ghana <sup>(9)</sup>	Women had to prove themselves worth of acceptance back into the community resulting in those who had unsuccessful repair hiding any signs of incontinence	Extra needs for hygiene and inability to work drove women further into poverty	Survivors initiated fistula campaigns as a way of overcoming challenges
Understanding the lived experiences of women before and after fistula repair: A qualitative study in Kenya <sup>(10)</sup>	Following repair, women experience an instant and euphoric phase of wellbeing but after some time, psychological effects persist	Need for intensive psychological intervention	No significant divergence from other studies
A grounded theory of regaining normalcy and reintegration of women with obstetric fistula in Kenya <sup>(11)</sup>	There are four possible reintegration statuses: full reintegration, partial reintegration, newly reintegrating and not reintegrated. These statuses are linked to the success of repair	Need to tailor-make interventions to suit the level of integration of the individual woman	No significant divergence from other studies
Living with constant leaking of urine and odour: thematic analysis of socio-cultural experiences of women affected by obstetric fistula in rural Tanzania <sup>(12)</sup>	Four thematic areas obtained relating to hygiene, earning an income, maintaining relationships and keeping association	Isolation, poverty, and discrimination	No significant divergence from other studies
Relationship complexities among women with obstetric fistula in Zimbabwe: an exploratory study <sup>(13)</sup>	Two themes obtained: languishing and flourishing. Languishing related to strained relationships with intimate partners and family while flourishing related to spiritual growth and other church activities as a way of coping	Two different experiences by women with fistula observed, women who get overwhelming support from partners and family while others do not receive any support and as diversional therapy they turn to God or some supernatural being. These women receive their fate and turn to increase worship activities to assist them accept their problem and live positively with it	Self-prescribed diversional therapy as a way of coping. Affected women being assertive and stand up for their rights
Too long to wait: Obstetric fistula and sociopolitical dynamics of the fourth delay in Soroti, Uganda <sup>(14)</sup>	Examined experiences of obstetric fistula survivors in relation to the 3 delays and added a fourth delay: delay in diagnosis of obstetric fistula and receiving treatment	The role weaknesses in health delivery systems play in the occurrence of obstetric fistula	This study pointed to the existence of a 4 <sup>th</sup> delay in obstetric care. The delay to get help for obstetric complications
Unsettling the fistula narrative: cultural pathology, biomedical redemption and inequities of health access in Niger and Ethiopia <sup>(15)</sup>	Interrogation of the common sayings about fistula survivors that they are isolated and stigmatized by communities and family. The authors argue that women affected by obstetric fistula in most instances lead normal lives and are able to maintain normal relations with their families and communities	Nothing in common with findings of the other studies except the need for health care systems to prevent and manage obstetric fistula	Obstetric fistula survivors are not social outcasts as commonly said, most maintain social relationships and are welcome by kin and friends, the ostracization of women is mainly by researchers and donors. Women

			with fistula often lead normal lives and comfortably
I stayed with my illness: A grounded theory study of health seeking behavior and treatment pathways of patients with obstetric fistula in Kenya <sup>(16)</sup>	Hospital care-seeking was the first step for most fistula survivors. However after encounter with unresponsive health care systems, patients often turn to other sources of care or opt to stay at home with their problem	Lack of medical management and surgical intervention. Long periods of staying with fistula	No significant divergence from other studies
Giving voice to the experiences of Rwandan women with urogenital fistulas <sup>(17)</sup>	In post genocide Rwanda, sexual abuse was the commonest cause to fistula occurrence and added on the burden of psychological stress	Social stigma and poverty	Sexual abuse as the major cause of fistula in women as opposed to delayed and obstructed labour
The experience of women with obstetric fistula following corrective surgery: A qualitative study in Benadir and Mudung regions of Somalia <sup>(18)</sup>	Socio-economic and physical problems noted with most of the women	Findings correspond with the majority of the studies	No significant divergence from other studies

#### **IV. Summary of Findings**

##### **Physical implications of obstetric fistula**

From the seventeen studies reviewed, sixteen observed that women affected by obstetric fistula experienced physical consequences such as excoriation of the vulva due to continuous wetness, recurrent bad smells and usual malnutrition due to bid to manage urine and fecal output to minimize incontinence.

##### **Social implications**

Again sixteen of the seventeen studies reviewed observed that affected women lived isolated lives. This was noted to be caused by either self-stigma, societal stigma or both. Women were noted to be shunning public places and mostly confined to their homes. These studies observed that the majority of affected women were divorced or left by their husbands.

However, one study concluded that women living with obstetric fistula lived normal lives, were loved by their families and community and lived normal vibrant lives like anyone in that community<sup>(15)</sup>. The authors alluded to the observation that the popular “social isolation” is only in the perspectives of researchers and obstetric fistula activists who will be looking for donor empathy to solicit funding. On the issue of marital relationships, this study said that obstetric fistula occurrence did not affected marital status. Affected women still continued in their marital relationships and even engaged in normal sexual activities. Those who left married life, did so on their accord, not related to obstetric fistula presence. On this issue, Heller and Hannig were supported by Dennis et al who found out that half the women they interviewed in Tanzania experienced high levels of support from their families<sup>(19)</sup>

##### **Economic implications**

The majority of the studies noted that poor physical health coupled with social stigma and isolation drive affected women deeper into poverty. However as noted above, one study had a divergent view and concluded that the women are able to perform normal economic activities like anyone. In fact, the authors said obstetric fistula has no effect on the economic status of the affected woman.

##### **Emotional implications**

The study by Heller and Hannig concluded that women affected by obstetric fistula experience emotional stress briefly but overcome that stress and accept their injury like any other injury and continue living their lives normally<sup>(15)</sup>. However, 94% (16 of the 17 studies) of the studies noted that obstetric fistula leave injuries which are deeper than that can be healed by surgery alone. These injuries refer to social, emotional and relational injuries.

##### **Medical implications**

All the studies reviewed confirm the inadequate medical services needed for the prevention and treatment of obstetric fistula. This review noted with enthusiasm the highlighting of a 4<sup>th</sup> delay on top of the tree traditional delays in obstetric car. The fourth delay was pointed out as the delay by health systems to identify and treat labour and delivery complications<sup>(14)</sup>

## V. Discussion

Almost all the reviewed studies concur that harmful practices such as child marriages and early pregnancies contribute to the occurrence of obstetric fistula but there are divergent views that this view is just a dress-down of culture (mostly African and partly Asian culture) and should be treated with care. The authors of this research criticize most of the findings of other researches alluding to the view point that researchers conduct their studies with predetermined conclusions; that all what they are after is gaining financial support for the fistula repair programs across the globe, especially in Africa and Asia. The authors also argue that researchers often tend to glorify and exaggerate the benefit of repair surgeries for obstetric fistula while they noted that the success rate of repairs was not as high as highlighted in other documentations. They also observed that women who would have successfully repaired appreciated the healing but not like it was a miracle.

There is a significant methodological difference between the researchers though. This difference may be contributing to the different opinion between the two view-points. The authors of the divergent study do not reside in Africa. They only went to Africa for the purposes of their study (which took two years). This is unlike the authors of most of the studies, who reside in either Africa or Asia and have a deep understanding of the cultural practices concerned. This difference may be the cause of the divergent opinions and findings between the two researcher groups. The challenge regarding comparing the two ideological theories is the few number of studies (just one against sixteen), on the one side as compared to the other.

All these studies converged to the observation that health care systems are inadequate to effect prevention of obstetric fistula and the treatment and management of survivors in Africa.

## VI. Conclusion and Recommendations

Studies documenting the lived experiences in Zimbabwe are limited. This review revealed two divergent opinions on the experiences of survivors of obstetric fistula. There are women who were noted to be living with obstetric fistula normally then other researchers noted that affected women were negatively affected physically, socially, emotionally and economically by obstetric fistula. These researchers concluded that obstetric fistula survivors need assistance in getting repair surgeries, rehabilitation and re-integration into society.

These divergent observations and conclusions need to be interrogated more in order to make informed and authentic decisions regarding programing for obstetric fistula interventions.

From this review, it is recommended for researchers from outside Africa to document and analyze the experiences of women living with obstetric fistula and those repaired of obstetric fistula so as to allow comparison of findings for findings of studies done by researchers from within and those from outside Africa and Asia.

It is also recommended that researchers document the lived experiences of Zimbabwean women affected by obstetric fistula to see if the usual pattern observed in other African countries prevails in Zimbabwe since there are significant differences in maternal and reproductive health indicators across the countries. For example, antenatal coverage; 93%, institutional deliveries 78% and skilled birth attendance; 73%, are very high in Zimbabwe as compared to other African countries which have high prevalence of obstetric fistula.

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Chipo Chimamise. " Lived Experiences of Obstetric Fistula Survivors in Africa:A Systematic Literature Review" .IOSR Journal of Nursing and Health Science (IOSR-JNHS), vol. 8, no.06 , 2019, pp. 04-10.