TITLE
An integrative review on women living with obstetric fistula and after treatment experiences

Concise title: experiences of women with fistula

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Aim and objectives: To review literature on the experiences of women with obstetric fistula, their lived experiences after treatment; and to provide evidence for future research.

Background: Obstetric fistula is an injury most commonly resulting from a prolonged labour. Long eradicated in developed countries, obstetric fistula remains a public health issue in sub-Saharan Africa and Asia. This is a highly stigmatised health condition, and an understanding of the women’s experience is required to inform holistic approaches for care and prevention.

Design: An integrative review

Data sources: EBSCO host (Academic Search Premier, MEDLINE, PsychINFO, CINAHL), Web of Science; Grey literature and websites of international organizations such as Women’s Dignity Project, EngenderHealth. Keywords, Inclusion and exclusion criteria were defined and 25 articles published between 2004 to January 2015 were identified.

Review method: The review was guided by Whittemore and Knafl’s revised analytical framework. All articles were assessed for methodological quality and critically analysed to elicit emergent themes and subthemes.

Results: Three broad themes were identified: Challenges of living with fistula; treatment and care experiences; and reintegration experiences of women after fistula repair.

Conclusion: Living with a fistula presents multidimensional consequences affecting women, families and communities. Accessing treatment is difficult and there are no standardised treatment packages. Surgical repairs were variable in their success rate. Some authors claim women resume normal lives irrespective of their continence status, whilst others claim they face discrimination despite being continent thereby hindering reintegration. Quality of life is diminished for those remaining incontinent. Post repair psychosocial support services are beneficial for reintegration, but research on programme benefits is limited. Therefore further research is required to support its benefits; and for policy development to meet care provision for women with fistula.

Key words: obstetric fistula, quality of life, post repair care, rehabilitation, reintegration, holistic care, integrative review
SUMMARY BOX

What does this paper contribute to the wider global clinical community?

- Previous research in the area of fistula management has been limited to case report findings, clinical outcomes and risks factors. This review focused on women’s lived experiences to gain an understanding of areas requiring care provision improvements.
- Surgical fistula repairs contribute to improved quality of life, but do not negate all the consequences for women.
- Further research is required on the benefits of post rehabilitation program in enhancing reintegration, and to inform holistic fistula management and policy development.

Introduction

Obstetric fistula is a devastating childbirth condition, commonly resulting from prolonged labour and leading to the development of a hole between the vagina and bladder or rectum which leaks urine or faeces (Wall 2006). Worldwide it is estimated that between 654,000 to 3.5 million women live with fistula, with the majority of these living in sub-Saharan Africa and Asia (Ahmed & Holtz 2007, Abrams 2012). It is a chronic maternal morbidity that affects women, their families and communities (Ahmed & Holtz 2007, Roush et al. 2012, Wall 2012). Obstetric fistula has been eradicated from industrialized countries, yet remains a public health issue in sub-Saharan Africa and Asia; its consequences have a devastating impact on the lives of those affected (Wall 2006, Abrams 2012). The prevalence of obstetric fistula is a reflection of the maternal health of a region; vulnerability to fistula development is linked to social and cultural issues and poor health systems that lead to maternal morbidity and mortality (Roush et al. 2012, Mselle & Kohi 2015). Women with fistula are usually located at the lowest level “socially, sexually, economically, politically and medically” (Wall 2006, p. 1207). Untreated fistulas lead to an uncontrollable flow of urine and or faeces; which has outcomes of unpleasant odour and wetness making women repulsive to their husbands, family, friends and community members (Wall 1998). The psychological impact of an obstetric fistula goes beyond the physical consequences of urine or faecal incontinence, as the stigma leaves some women feeling ostracised from their communities (Bangser 2006, Wall 2006).

The multidimensional consequences of obstetric fistula require an understanding of women’s experiences to guide management beyond surgical procedures (Donnelly et al. 2015). McMichael (2005) argue that systematic reviews of evidence need to be relevant to the needs of developing countries. There is a paucity of systematically reviewed literature on the impact and consequences of obstetric fistula and the quality of life after repair (Ahmed & Holtz 2007, Abrams 2012). The complexity surrounding obstetric fistula requires further investigation to improve understanding of women’s experiences and to assess if holistic approaches may enhance their quality of life (Maulet et al. 2013). Nursing care is a crucial part of multidisciplinary team provision and research findings can enhance nursing practice in holistic care approaches (de Bernis 2006).
Aims

The threefold aims were to: identify literature evidence on the lives and experiences of women with obstetric fistula; to critically review the experiences of women with fistula after treatment and on return to their communities; and to identify gaps in provision, to inform holistic care management.

Methods

A literature search employed an integrative methodology wherein studies were identified, analysed and synthesised to determine the existing level of knowledge. This method enabled diverse methodologies to be reviewed and summarized to provide an understanding of the area of interest (Whittermore & Knafl 2005).

The electronic databases searched were: EBSCO (Academic Search Premier, MEDLINE, PsychINFO, and CINAHL), Science direct, POPLINE, SCOPUS, Web of science, Bioline international and African journal online. Website searches were also undertaken consisting of: World Health Organization (WHO), UK Department for International Development (DFID), United Nations Population Fund (UNFPA), Fistula Foundation Worldwide, EngenderHealth, International Federation of Obstetrics and Gynaecology (FIGO), United States Agency for International Development (USAID) and Women’s Dignity Project. In addition, Grey literatures such as conference proceedings, and official publications such as Demographic Health Surveys, and technical or research reports by government agencies were searched.

The search terms included: obstetric fistula, Vesicovaginal fistula, urogenital fistula, lived experiences, experiences, characteristics, psychosocial support, social support system, reintegration, rehabilitation and quality of life. The inclusion criteria consisted of empirical research published in English between 2004 to January 2015 which provided a description of women’s lived experiences of fistula and experiences after treatment. The excluded criteria revolved around clinical management procedures or surgical outcomes or demographic characteristics, or those focused on risk factors for fistula development, clinical classifications of fistula, and descriptions of single medical conditions. The following appraisal tools were used to review the literature: Critical Appraisal Skills check list programme (CASP) for qualitative studies; Evaluation tools for quantitative research and mixed method studies (Long 2005) and quality in qualitative health research (Pope & Mays 1999). These tools provided a template of key questions to assist in the critical appraisal.

Search outcome & audit trail

The procedure used for the selection is presented in figure 1 using a modified PRISMA diagram (Moher et al. 2009). The database searches of EBSCO (Academic search premier, CINAHL, PsycholInfo and Medline) yielded 1194 articles. The removal of duplicates from the EBSCO database reduced the number to 900. These were screened by title and abstract resulting in 851 being excluded, and 49 articles being selected. This process was duplicated in the databases of POPLINE, Web of Science, Science Direct, SCOPUS, Bioline international and African journal online. All articles identified in these databases except one from Web of Science were already selected from the EBSCO database. Two additional articles were identified from EngenderHealth website; altogether making a total of 52 articles. The excluded articles consisted of those covering clinical repair procedures, case reports,
prevalence surveys, classifications of fistulas, clinical symptoms assessments, surgical and management outcomes, sociodemographic characteristics of women with fistula and risk factors that contribute to fistula development. A further 27 articles were excluded as six were systematic reviews; two presented the same data in articles already included; six were on risks factors; 9 were commentaries; and four were on clinical outcomes.

Results

Table 1 summarises the 25 selected articles by author, year, country, research design, sample size and study aim. The themes were identified by grouping common findings and meanings. All identified major themes and subthemes were scrutinised to reflect the review aim and to establish the similarity and differences across the meanings under the identified themes.

Themes

Challenges of living with fistula

In all the studies, women living with fistula and the impact upon them, their families and communities presented as multidimensional negative experiences. These experiences included:

Psychosocial experiences

The most widely reported challenges were the psychosocial consequences of fistula; mainly stigma, physical isolation and loss of status (Women's Dignity Project & EngenderHealth 2006, Turan et al. 2007, Muleta et al. 2008, Alio et al. 2011, Khisa & Nyamongo 2012, Gebresilase 2014). The uncontrollable flow of urine or faeces meant constant wetness and unpleasant odour which repulsed husbands, family members and people in the community (Women's Dignity Project and EngenderHealth 2006, Muleta et al. 2008, Alio et al. 2011, Siddle et al. 2013, Mwini-Nyaledzigbor et al. 2013). The wetness and unpleasant odour, according to Siddle et al. (2013) had the most distressing effect on the women. This distress was due to them being shunned, insulted and excluded from activities (Mwini-Nyaledzigbor et al. 2013). This was particularly evident in women being excluded from religious activities (Farid et al. 2013, Siddle et al. 2013); with Muslims being predominantly affected because of their ritualised activities (EngenderHealth 2012, Farid et al. 2013, Siddle et al. 2013). Additionally women reported feelings of depression, worthlessness and suicidal thoughts (Alio et al. 2011, Siddle et al. 2013). In such instances, according to Gebresilase (2014) the body becomes a barrier leading to the loss of independence; by being unable to undertake daily activities or fulfil their role as a wife, ultimately having a profound effect on their relationships (Gebresilase 2014). Consequently, family members suffered psychological stress over the plight of their daughters or wives (Women's Dignity Project & EngenderHealth 2006, Turan et al. 2007, Yeakey et al. 2011).

Marital disruptions, sexual and reproductive life

Three of the studies argued that in the majority of cases, fistula development led to marital disruptions, rejections and total isolation from families (Alio et al. 2011, Khisa & Nyamongo 2012, Mwini-Nyaledzigbor et al. 2013). This is because fistula interferes with sexual relations, hence
contributing to marital disruptions (Landry et al. 2013; Mwini-Nyaledzigbor et al. 2013). In polygamous circumstances as reported by Mwini-Nyaledzigbor et al. (2013) even though the women were still living with their husbands, sexual relationship ceased after fistula development. Sexual interference was a consequence of dyspareunia, alongside problems caused by incontinence odours and soiling (Women’s Dignity Project & EngenderHealth 2006, Browning & Menber 2008, EngenderHealth 2012). Some women who continued their sexual relationships highlighted issues of embarrassment from leakages, whilst others viewed it as torturous to please their partners (EngenderHealth 2012). Furthermore, Turan et al. (2007) and Mwini-Nyaledzigbor et al. (2013) reported women’s other physical symptoms were genital itch, soreness, burning sensation, plus the presence of pus and blood in their urine.

Studies by Women’s Dignity Project and Engenderhealth (2006), Muleta et al. (2007), Yeakey et al. (2011), Landry et al. (2013), and Donnelly et al. (2015) reported some husbands supported their wives in dealing with their fistula problems. But those left unsupported and rejected tended to return to their birth homes (EngenderHealth 2012, Landry et al. 2013). However there were exceptions to this, as a study in South Nigeria highlighted that all the women living with fistula remained in their marital home (Umoiyoho et al. 2011). Another mitigating factor impacting on marital stability was the presence of children (Turan 2007, Pope et al. 2011).

**Socioeconomic experiences**

The inability to work as a result of stigma or ill health, led to economic hardship (Women’s Dignity Project & EngenderHealth 2006, Turan et al. 2007, Landry et al. 2013, Mwini-Nyaledzigbor et al. 2013), and contributed to an overreliance on others for their livelihood (Women's Dignity Project & EngenderHealth 2006, Khisa & Nyamongo 2012). Furthermore, engagement in the community required women’s hygiene to be maintained but this required additional resources contributing to the strain on family income (Women’s Dignity Project & EngenderHealth 2006, Yeakey et al. 2011, Mwini-Nyaledzigbor et al. 2013). However, at the same time, Nielsen et al. (2009) reported some women; mainly farmers (92%) were able to continue their income generating activities while living with fistula, with only 22% not working. Pope et al. (2011) argued financial hardship was more distinct for those who lacked financial independence before fistula development and those no longer living with their husbands. Interestingly socioeconomic comparisons between women in Bangladesh and Democratic Republic of Congo (DRC) demonstrated DRC women had more financial freedom and autonomy; as despite the restrictions of fistula, they could still engage in financial activities (EngenderHealth 2012).

**Coping with fistula**

Four studies focused on women’s coping mechanisms for daily living (Women’s Dignity Project & EngenderHealth 2006, EngenderHealth 2012, Mwini-Nyaledzigbor et al. 2013, Gebresilase 2014). These coping strategies involved dealing with the physical hygiene difficulties and having to launder their clothes more, use of perfumes, lotions, ‘padding’, bathing, all of which could be problematic due to water scarcity (Women’s Dignity Project & EngenderHealth 2006). Other coping strategies to
nullify the effects of leakage included restricting fluid and food intake, the use of plastic bags to protect clothing, putting sawdust in the plastic bag to absorb the flow, plus avoiding public areas (EngenderHealth 2012). However even when using these strategies, women found them ineffective in managing their overall hygiene problems (EngenderHealth 2012).

Gebresilase (2014, p. 1038) described other coping mechanism dimensions as being “problem focused” and “emotion focused”. The “problem focused” involved productive techniques of relying on family support, disposing of possessions and “orientating to reality” (Gebresilase 2014). The “emotion focused” approach involved ways to avoid isolation, suicidal ideas or attempts and a move towards adopting a positive attitude. Gebresilase (2014) alleged using these strategies helped women in dealing with their fistula.

Quality of life

In the review, different tools were used by the studies to investigate the quality of life. But generally the quality of life was lower while living with fistula. In the study by Nielsen et al. (2009) the King’s Health Questionnaire validated tool that measures quality of life in women with urinary incontinence was used. The quality of life was statistically significantly lower while living with fistula (p=0.001); the lowest scores were for areas that measured the level of social interactions. Umioyoho et al. (2011) used the World Health Organization Quality of Life (WHOQOL BREF) questionnaire to measure physical, mental, social and environmental health. The lowest score was in the social health domain followed by mental health. The Pope et al. (2011) study used the Perceived Quality of life tool (Patrick, 2000), modified for the rural Tanzanian context it calculated quality of life based on a 10 point scale. They investigated physical, mental, level of social support and financial wellbeing among three groups, women with repaired fistula, women without fistula (control group) and women in hospital for repair. Women in hospital for fistula repairs had the lowest score. These women had a decrease in score from the period before fistula to the period after fistula development. In the studies by Pope et al. (2011) and Nielsen et al. (2009) the score for quality of life was considerably lower while living with fistula.

Treatment and care experiences of women

Care seeking experiences

Studies by Women’s Dignity Project & EngenderHealth (2006), Yeakey et al. (2011), and EngenderHealth (2012) described women’s experiences of the difficulty in accessing treatment. Alio et al. (2011) concurred and added how women expressed incidences of numerous failed attempts to get the right care. Additionally, Women’s Dignity Project & EngenderHealth (2006), and Yeakey et al. (2011) highlighted the lengths women went to, in trying to access help such as seeking traditional remedies and religious healers, as well as making numerous visits to hospitals. Furthermore EngenderHealth (2012), and Mwini-Nyaledzigbor et al. (2013) cited concerns around financial constraints, the lack of access to professional care at hospitals, the lack of knowledge of repair

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services and spousal assistance, all of which contributed to women resorting to traditional remedies or over the counter remedies to try to obtain a cure.

Women’s attempts to seek a cure were not done in isolation, as family and community members provided support through financial assistance, helping with chores and giving emotional support (Women's Dignity Project & EngenderHealth 2006, Bangser 2007, Yeakey et al. 2011, Pope et al. 2011). The women without family support experienced greater challenges in seeking treatment (Women's Dignity Project & EngenderHealth 2006, Yeakey et al. 2011).

Treatment management experience

Treatment is usually by surgical repair of the fistula (Alio et al. 2011, Yeakey et al. 2011). However, surgical repairs held varying degrees of success of continence and successful closure without leakage varied from 13% to 82% (Women's Dignity Project & EngenderHealth 2006, Turan et al. 2007, Donnelly et al. 2015). Four of the studies cited women could have up to three repairs before becoming continent, and even then some remained incontinent and bereft of hope (Yeakey et al. 2011, Alio et al. 2011, Khisa & Nyamongo 2012, Donnelly et al. 2015). Nevertheless, after discharge, some women had continence restored over time (Browning & Menber 2008, Muleta et al. 2008, Yeakey et al. 2011). It was also noted that surgical repair contributed to women’s improved psychological health; expressed as joy, along with a deep sense of relief and appreciation (Donnelly et al. 2015). Yeakey et al. (2011) alleged that surgical repair experience was defined by the social change in status rather than the physical change in status. Two of the studies reported that despite the level of continence women were generally satisfied with the fistula repair (Turan et al. 2007, Yeakey et al. 2011). Conversely a Kenyan study by Khisa & Nyamongo (2012) alleged women felt worse off after unsuccessful repairs.

Post repair rehabilitative/ reintegration services

Post repair rehabilitative counselling was another form of psychosocial support in the treatment care plan, but this was not provided in all fistula repair facilities (Yeakey et al. 2011). A total of eight articles emphasised reintegration services. Mohammed (2007), Alio et al. (2011), Landry et al. (2013), and Gebresilase (2014) discussed psychological counselling and rehabilitative services. These services included literacy classes, skills empowerment, provision of seed grants, follow up to the community and education on fistula in the community. These services are viewed as beneficial for reintegration; an essential part of the holistic care approach for fistula treatment (Mohammad 2007, Alio et al. 2011, Mselle et al. 2012, Landry et al. 2013, Donnelly et al. 2015). Mohammed (2007) asserted that rehabilitation post repair, empowered women socioeconomically especially if they owned businesses in their communities. However, Nathan (2009) disagreed stating there was no need for reintegration assistance and emphasized that successful surgical intervention was sufficient for reintegration. Similarly in the Malawi study, even though women did not undergo a post repair rehabilitation counselling, the women experienced limited hindrances in reintegration (Yeakey et al. 2012). Even though a facility based approach appears useful in providing reintegration support, Velez (2007) noted that reintegration and rehabilitation services provision across 20 countries was
grossly inadequate. Additionally, Donnelly et al. (2015) affirmed uncertainty about whether a standardised structure for post repair support services for fistula care existed.

Reintegration experiences of women after fistula repair

Impact of post repair rehabilitation program

There were differing opinions on the value of how reintegration experiences were undertaken. For example, in a study by Alio et al. (2011) women described their future plans rather than their reintegration experiences. Landry et al. (2013) highlighted reintegration experiences were investigated through a large multicentre study in five countries, using a structured questionnaire, but in each of the study sites reintegration services varied. Such services included one or some of the following; support group programs, sexual and reproductive health counselling, psychological counselling, skill empowerment and literacy classes. But service differences across the countries were not investigated and no qualitative insights of women’s reintegration experiences were included. In Gebresilase’s (2014) qualitative study, none of the rehabilitated women returned to their community after treatment. Hence this reaffirmed the assertion by Donnelly et al. (2015) around the uncertainty of whether a standardised structure exists for post fistula repair support services.

Marital, sexual and reproductive life experiences after repair

In four of the studies women’s reproductive and sexual lives after reintegration remained in jeopardy in the short-term (Browning & Menber 2008, Khisa & Nyamongo 2012, Mselle et al. 2012, Donnelly et al. 2015). Browning and Menber (2008) reported that at six month post repair, one third of women had resumed sexual activity and 90% of these had no pain. However Dolan et al. (2008) cited the continuance of sexual dysfunction, such as vaginal dryness, dyspareunia and disturbance due to urinary symptoms. There were also timescale differences between studies for the resumption of sexual activity after repair. As Nielsen et al. (2009) noted 71% had resumed sexual activity after 21 months, whilst El-Gazzaz et al. (2010) cited 47% at 39 and 45 months. In the El-Gazzaz et al. (2010) study, they used the “Female sexual function index” to determine the sexual function and reported no significant differences between the women who were healed and those who did not in the domains of desire, arousal, lubrication, orgasm, satisfaction and pain. Generally the fear of fistula recurring was reported to hinder sexual activity after repair (Muleta et al. 2008, Pope et al. 2011, Khisa & Nyamongo 2012, Donnelly et al. 2015). Additionally fertility concerns were attributed to an inability to engage in sexual activity alongside cultural expectations in childbearing and these were identified as reproductive health needs (Pope et al. 2011, Mselle et al. 2012, Donnelly et al. 2015).

The post-surgical abstinence from sex and loss of uterus contributed to marital instability (Khisa & Nyamongo 2012). This period of sexual abstinence varied from three months to one year post repair (Yeakey et al. 2011, Khisa & Nyamongo 2012, Donnelly et al. 2015). Three studies reported, women lacked the desire or interest in sex due to their fistula experience (Turan et al. 2007, Pope et al. 2011, Khisa & Nyamongo 2012). Conversely Mselle (2012) asserted some women wanted to regain

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their reproductive childbearing ability even though they did not wish to remarry. This desire was based on societal expectation of women’s worth being linked to motherhood (Alio et al. 2011, Pope et al. 2011, Khisa & Nyamongo 2012, Mselle et al. 2012). Hence childbearing remained a major reason for women accessing fistula repair alongside that of continence (Khisa et al. 2012).

**Socioeconomic and work experiences after repair**

Across the studies, women demonstrated a desire to resume work and be self-sustaining after returning to their communities (Alio et al. 2011, Pope et al. 2011, Mselle et al. 2012, Donnelly et al. 2015). Mselle et al. (2012) asserted economic self-sufficiency was closely linked to regaining dignity. However, the ability to resume normal work was not always possible due to women being physically unfit to carry out strenuous duties (Pope et al. 2011, Donnelly et al. 2015). Consequently, these women became economically dependent on family income for sustenance, and their quality of life and reintegration became compromised (Mselle et al. 2012).

One study by Pope et al. (2011) contradicted this as they asserted even though women experienced physical challenges the majority resumed their farming and household chores one year post repair. For these women their health challenge was not connected to their financial hardship but was a general phenomenon (Pope et al. 2011). The fear of fistula recurring due to physical exertion prevented some women resuming normal activities, but support from their family and community with household chores and establishing business opportunities helped ease their reintegration (Pope et al. 2011). The Women’s Dignity Project and EngenderHealth (2006) believed that positive family, neighbours and community support could be harnessed in community education and advocacy to help prevent stigma.

**Living with incontinence after repair**

The consequences of being incontinent after repair made reintegration more challenging. The studies by the Women’s Dignity Project & EngenderHealth (2006), and by Bangser (2007), and Donnelly et al. (2015) claimed that women with continuing incontinence experienced ongoing physical and psychological challenges more some women also suffered a fistula repair breakdown after being discharged as continent (Browning & Menber 2008). Fistula recurrence often happened after manual activity, straining, during sexual intercourse, whilst travelling or following another obstructed labour (Browning & Menber 2008).

Unsuccessful repair cases could lead to escalation of negative treatment in the community and feelings of frustration in the family (Women’s Dignity Project & EngenderHealth 2006, Khisa & Nyamongo 2012). According to Khisa and Nyamongo (2012) women experiencing unsuccessful repairs were considered ‘cursed’ by the community. As a consequence these women were unlikely to report improvement in their daily activities (Landry et al. 2013, Donnelly et al. 2015).
Quality of life after repair

Generally the literature demonstrated that after successful fistula repair women who attained continence experience an improved quality of life. The study by Nielsen et al. (2009), showed a statistically significant improvement (p= 0.001) in quality of life after repair. Whilst the study by Umioyoho et al. (2011) using the WHOQOL BREF tool, demonstrated a 90% increase in quality of life after repair in all the domains, with the highest being in the social domain, followed by the physical domain. Additionally, the comparative study by Pope et al. (2011) purported that perceived improved quality of life was attributable to a successful repair and reintegration over time.

Interestingly, Nielsen et al. (2009) and Yeakey et al. (2011) argued that women with persisting incontinence achieved some improvement in quality of life. The improved control for women with persisting incontinence translated into “improved quality of life at home” (Yeakey et al. 2011 p.159). Hence post repair some women do not experience isolation and rejections from the community as the majority were able to socialize and resume normal lives (Bangser, 2007, Women’s Dignity Project & EngenderHealth 2006). However Khisa & Nyamongo (2012) and Muleta et al. (2008) contradicted this evidence stating women continued to face discriminations despite their continence status, which in turn led to lower self-esteem that hindered reintegration. According to Mselle et al. (2012) this discrimination aspect led to women having a lack of desire and unwillingness to return home or marry after treatment. Similarly, Gebresilase (2014) alleged that, in avoiding stigma, rejections and discrimination, some women did not reintegrate back into their family or communities after treatment. These women sought refuge in urban environments and found new freedom in their decision making and self autonomy (Gebresilase, 2014).

Discussion

The review of empirical evidence demonstrated that obstetric fistula has multidimensional consequences on the lives and experiences of women, families and communities. The challenges of living with fistula led to the adoption of various coping strategies. These consisted of physical coping strategies to curb leakage and return to a normal daily lifestyle, but many of these appeared ineffective and affected women’s psychological wellbeing, as they continued living with the unpleasant dehumanising conditions of the leakage. Seven of the studies argued that fistula could affect any woman, but not all lost family or community support after fistula development (Women’s Dignity Project & EngenderHealth 2006, Bangser 2007, Muleta et al. 2008, Pope et al. 2011, Umioyoho et al. 2011, Yeakey et al. 2011, Landry et al. 2013). Evidence also demonstrated that marital stability was linked to women with children as these tended to remain in their marital home.

Another area highlighted was treatment and care experiences. Successful surgical treatment was shown to contribute to improved quality of life. However, in the reviewed articles different validated tools where used to measure quality of life this made comparisons difficult. Hence adopting a standardised tool for measuring quality of life for women with obstetric fistula would enable a standardized assessment for care provision. Standardisation could also address arguments around whether women with persisting incontinence experienced improved quality of life after repair or not. Problems in accessing treatment were also evident and demonstrated that women with family support were more likely to receive treatment. This reinforces the notion that women who access
care are those with support; hence further research is required to evaluate the different factors that aid access to fistula treatment between women with and women without family support.

The review also highlighted the dilemma in sexual and reproductive health issues despite successful repair and highlights the need for more research on improving sexual function and future fertility after treatment. Equally, incontinence after successful repair remains an issue of huge concern. Support in educating the community is needed to redress the stigmatization reported by women with persisting incontinence after repair. But most importantly, obstetric treatment centres need to be able to manage complications before and after fistula closure (Abrams, 2012). Furthermore additional research on irreparable cases is needed to investigate remedies to support women’s coping mechanisms and to enhance their quality of life.

The WHO guidelines emphasise the aim of undertaking obstetric fistula repair is to ensure women regain their role and place within the community (de Bernis 2007). In this review the majority emphasised that rehabilitation programmes contributed to successful reintegration (Mohammad 2007, Ailio et al. 2011, Mselle et al. 2012, Landry et al. 2013, Donnelly et al. 2015). Conversely others argued that women who underwent successful repair re-integrated well even without assistance (Nathan et al. 2009, Yeakey et al. 2011). However it was noted that social reintegration interventions helped to address the physical, psychological and economic challenges identified by the women to resume life normally within their communities (Abrams 2012). In terms of the benefits of programmes to support women with obstetric fistula conclusions were drawn from a structured questionnaire rather than from women’s personal views. Hence, further insights could be gained by undertaking a qualitative research approach to capture the nuances of women’s reintegration experiences. This in turn would help inform health and social care provision to ensure effective and efficient post repair rehabilitation services are offered. It would also aid in exploring how such programmes could contribute to the reintegration of the women into their communities as suggested by the WHO guidelines for management of obstetric fistula (de Bernis 2007).

The lack of a standardised treatment package for post repair rehabilitative services is evident, as varied services were offered between different centres providing care. Therefore, further research is suggested in developing a standardised model that could serve post rehabilitation services, but which could be adapted dependent upon the context. Yeakey et al. (2011) and Gebresilase (2014) suggested that, accompanying repairs with psychological and social rehabilitation was only useful, if the social conditions that predispose the women to fistula in society were addressed. Gebresilase (2014) speculated that fear of continuing stigma, rejections and discrimination, hindered reintegration back into their family and community life. Landry et al. (2013) believed community based organizations were better equipped to provide post repair services. Hence, further research to identify community based interventions that would boost reintegration is suggested.

The review established that treatment and care contribute positively to the lives of the women, families and communities, with a major theme outlined as that of surgical closure of fistula being the beginning of the road to recovery (Wall & Arrowsmith 2007). Alongside this, as earlier discussed, in ensuring successful fistula surgery there should be efforts to restore normal sexual functions; enhance fertility; heal psychological wounds; and ensure a return to normal lives in the community (Wall & Arrowsmith 2007). Therefore fistula care needs to go beyond surgical fistula repair to
embrace holistic care approaches to comprehensively deal with all the psycho-social issues to promote women’s full recovery and reintegration in society (Donnelly et al. 2015).

Strengths and limitations of the review

Based on the research question, the review was guided by the Whittermore and Knafl’s (2005) integrative review framework. This allowed evaluation of studies of varied methodologies, ensured methodological rigor, reduction of biases and inaccuracies: and hence provided an overview of current studies on the experiences of women with obstetric fistula and highlighted areas where further research was needed. One of the limitations is the period of review which included a timeframe for published articles from 2004. The factor was purposeful as the review is a part of a PhD study and it is a common practice to limit searches to most recent studies, however earlier publications might have yielded useful insights to add to the body of evidence. Secondly this review was limited to articles published in English, which possibly has excluded useful data from non English studies. Thirdly, based on the inclusion criteria, the review was limited to empirical research, hence unpublished articles were not included and these might also have provided useful data. Finally due to the limited number of studies on the subject matter, no paper that fitted the inclusion and exclusion criteria was rejected even though the rigor of a few of the articles could not be ascertained.

Conclusion

Obstetric fistula has been eradicated in the developed world, yet it remains a public health issue in developing countries. This review has demonstrated that the psycho-social consequences of living with fistula, supports a holistic management care approach to address the physical, social and mental wellbeing of survivors. It has also highlighted the dilemma in accessing care, the predicament of women after repairs with persisting incontinence and sexual and reproductive difficulties that negatively affects marital relationships. Additionally, it highlighted a dearth of research on the benefits of post repair rehabilitation programmes on reintegration based on women’s perspectives. Furthermore, there is a need to develop a standardised post repair care plan and a need to develop an evaluation tool for quality of life purposes. Therefore, further research on post repair women’s lived experiences within the community maybe beneficial in providing insights into addressing sexual and fertility issues, improving access to care and addressing the challenges faced by women with persisting incontinence. The research would also provide insights into the benefits of post repair rehabilitation programmes. These findings provide evidence of the need to improve and provide quality care in this area of care provision, and to help guide policy development.

Relevance to clinical practice

An understanding of the lives and experiences of women with obstetric fistula can provide insights into avenues of improving care provision and delivery by health professionals and policy makers. It also exposes areas that need further research for quality care provision.
References


Wall LL (2012a) Obstetric fistula is a "neglected tropical disease". *PLoS neglected tropical diseases* 6(8), e1769.


**Table 1. Articles retrieved from systematic search**

<table>
<thead>
<tr>
<th>Author, year and country</th>
<th>Aim</th>
<th>Sample</th>
<th>Research design</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Alio et al. (2011). Niger</td>
<td>To understand the psychosocial effects of Vesicovaginal fistula</td>
<td>21 women</td>
<td>Qualitative; ethnographic method</td>
</tr>
<tr>
<td>2. Bangser (2007). Tanzania &amp; Uganda</td>
<td>To study the determinants of fistula to guide public health interventions</td>
<td>Study 1: 137 women Study 2: over 136 hospitals Study 3: not stated Study 4: secondary data sources</td>
<td>Qualitative and quantitative of four projects</td>
</tr>
<tr>
<td>5. Donnelly et al. (2015). Ethiopia</td>
<td>To study the post repair experiences and views about resuming healthy and valuable life</td>
<td>51 women</td>
<td>Qualitative</td>
</tr>
<tr>
<td>6. El-Gazzaz et al.</td>
<td>1. To investigate the</td>
<td>100 women</td>
<td>Quantitative</td>
</tr>
</tbody>
</table>

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2. To assess the long term impact of repair on the quality of life, sexual capacity and faecal continence

To investigate the social and physical consequences of living with fistula and care seeking attempts
Bangladesh: 4 women DRC: 33 women Qualitative

8. Farid et al. (2013). Pakistan
To investigate the psychosocial experiences of women after fistula development
8 women Qualitative

To investigate the development of survivor’s views of their health and social relationship with fistula
8 women Qualitative; ecological and transactional model of stress and coping framework

To assess the psychosocial issues women with fistula and their families experience
20 women and 10 family members Quantitative and qualitative study

1. To provide information on challenges women with fistula face after repair
2. To understand the community’s views and support given women with fistula
8 women with fistula 12 men and women, participants in FGM awareness workshop Qualitative; exploratory study

12. Landry et al. (2013). Bangladesh, Guinea, Niger, Nigeria, Uganda
To study the lives of women before fistula development and quality of life with and after fistula
Pre-repair - 1354 women Post-repair - 1278 women Quantitative

To evaluate the impact of rehabilitation program on women after fistula repair
145 women Quantitative
14. Mselle et al. (2012). Tanzania
To understand women’s expectations and reintegration experiences after repair
151 women quantitative
8 women qualitative

15. Muleta et al. (2008). Ethiopia
To assess health, social and psychological challenges faced by women post repair and with obstetric fistula in rural Ethiopia
Quantitative- 52 women
Qualitative-27 women with fistula and 7 treated women
Cross sectional survey; quantitative and qualitative

To explore and describe experience of living with fistula from perspective of fistula survivors
10 women

17. Nathan et al. (2009). Benin
To understand obstetric fistula through the views of patients
37 women

1. To assess reproductive and urinary health women after fistula repair
2. To assess the quality of life of women after fistula repair
38 women

To explore the meaning of successful repair to women with obstetric fistula and factors affecting their capacity to return to normal life
71 women

20. Siddle et al. (2012). Tanzania
To assess the psychosocial impact of fistula
100 women

21. Turan et al. (2007). Eritrea
To present the experiences of women in providing directions: - on community mobilization and safe motherhood education
11 new repair patients
15 follow up women
5 family members

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<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Purpose</th>
<th>Sample Size</th>
<th>Study Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>Umoiyoho et al. (2011)</td>
<td>Nigeria</td>
<td>To assess and compare the quality of life of women after successful repair of fistula</td>
<td>150 women</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Velez et al. (2007)</td>
<td>Bangladesh, Burkina Faso, Cameroon, CAR, DRC, Equatorial Guinea, Eritrea, Kenya, Malawi, Mali, Mauritania, Nigeria, Somalia, Tanzania, Uganda, Zambia</td>
<td>1. To provide a summary of needs assessment by UNFPA 2. To raise awareness and obtain programming information and advocacy for obstetric fistula</td>
<td>Sample: detail not provided</td>
<td>Quantitative and qualitative</td>
</tr>
<tr>
<td>Women's Dignity project and EngenderHealth (2006)</td>
<td>Tanzania</td>
<td>To understand the complexity surrounding fistula and its social consequences through the lives of the girls &amp; women affected, their family, community and care givers in health facilities</td>
<td>61 Women and girls, 42 family members of the women and girls, 68 community members living close to women and girls and 23 service providers in facilities close to women and girls</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Yeakey et al. (2011)</td>
<td>Malawi</td>
<td>To provide an understanding of the perspectives and experiences of women, spouses, female relatives while living with, and post fistula repair</td>
<td>First round - 47 women with fistula Post repair - 5 women &amp; 30 family members At follow up - 18 women post repair and 11 family members</td>
<td>Qualitative</td>
</tr>
</tbody>
</table>
Adapted Prisma flow diagram, Moher et al (2009)

**Figure 1. Flow diagram of search selection process**

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