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

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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 Knafli’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). McMicheal (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 (Whittemore & Knafelz 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, PsychoInfo 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

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 & Member 2008, Khisa & Nyamongo 2012, Mselle *et al.* 2012, Donnelly *et al.* 2015). Browning and Member (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 p.1761) 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

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 were 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, Alio *et al.* 2011, Mselle *et al.* 2012, Landry *et al.* 2013, Donnelly *et al.* 2015). Conversely others argued that women who underwent successful repair reintegrated 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 Knafli'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

- Abrams P (ed), (2012) *Obstetric fistula in the developing world. An international consultation on vesicovaginal fistula*. China: Societe Internationale d'Urologie.
- Ahmed S & Holtz SA (2007) Social and economic consequences of obstetric fistula: Life changed forever? *International Journal of Gynecology and Obstetrics* 99(1), S10-S15.
- Alio AP, Merrell L, Roxburgh K, Clayton HB, Marty PJ, Bomboka L, Traoré S & Salihu HM (2011) The psychosocial impact of vesico-vaginal fistula in Niger. *Archives of gynecology and obstetrics* 284(2), 371-378.
- Arrowsmith S, Hamlin EC & Wall LL (1996) Obstructed labor injury complex: Obstetric fistula formation and the multifaceted morbidity of maternal birth trauma in the developing world. *Obstetrical and Gynecological Survey* 51(9), 568-574.
- Bangser M (2006) Obstetric fistula and stigma. *The Lancet* 367(9509), 535-536.
- Bangser M (2007) Strengthening public health priority-setting through research on fistula, maternal health, and health inequities. *International Journal of Gynecology and Obstetrics* 99(1), S16-S20.
- Browning A & Menber B. (2008) Women with obstetric fistula in Ethiopia: a 6-month follow up after surgical treatment. *BJOG: An International Journal of Obstetrics & Gynaecology* 115(12), 1564-1569.
- Creanga AA, Ahmed S, Genadry RR & Stanton C (2007) Prevention and treatment of obstetric fistula. *International Journal of Gynecology and Obstetrics* 99, S151-S154.
- Creanga AA & Genadry RR (2007) Obstetric fistulas: A clinical review. *International Journal of Gynecology and Obstetrics* 99(1), S40-S46.
- de Bernis L (2007) Obstetric fistula: Guiding principles for clinical management and programme development, a new WHO guideline. *International Journal of Gynecology and Obstetrics* 99(1), S117-S121.
- Dolan LM, Dixon WE & Hilton P (2008) Urinary symptoms and quality of life in women following urogenital fistula repair: a long-term follow-up study. *BJOG: An International Journal of Obstetrics & Gynaecology* 115(12), 1570-1574.
- Donnelly K, Oliveras E, Tilahun Y, Belachew M & Asnake M (2015) Quality of life of Ethiopian women after fistula repair: implications on rehabilitation and social reintegration policy and programming. *Culture, Health & Sexuality* 17(2), 150-164.
- El-Gazzaz G, Hull TL, Mignanelli E, Hammel J, Gurland B & Zutshi M (2010) Obstetric and Cryptoglandular Rectovaginal Fistulas: Long-term Surgical Outcome; Quality of Life; and Sexual Function. *Journal of Gastrointestinal Surgery* 14(11), 1758-1763.
- EngenderHealth (2012) *Living with obstetric fistula: qualitative research findings from Bangladesh and Democratic Republic of Congo*. New York: EngenderHealth.
- Farid NF, Azhar M, Samnani SS, Allana S, Naz A, Bohar F, Syed S & Syed S (2013) Psychosocial experiences of women with vesicovaginal fistula: a qualitative approach. *Journal of the College of Physicians and Surgeons Pakistan* 23(11), 828-829.
- Gebresilase, Y. T. (2014) A qualitative study of the experience of obstetric fistula survivors in Addis Ababa, Ethiopia. *International journal of women's health*.
- Khisa AM & Nyamongo IK (2012) Still living with fistula: an exploratory study of the experience of women with obstetric fistula following corrective surgery in West Pokot, Kenya. *Reproductive health matters* 20(40), 59-66.
- Landry E, Inoussa M, Kanoma B, Lynch M, Mussell F, Podder DC, Wali A, Mielke E, Barone MA, Frajzyngier V, Ruminjo J, Asimwe F, Barry TH, Bello A, Danladi D, Ganda SO & Idris SA (2013) Profiles and experiences of women undergoing genital fistula repair: findings from five countries. *Global public health* 8(8), 926-942.
- Maulet N, Keita M & Macq J (2013) Medico-social pathways of obstetric fistula patients in Mali and Niger: an 18-month cohort follow-up. *Tropical medicine & international health : TM & IH* 18(5), 524-533.

- McMicheal C, Waters, E & Volmink J 2005. Evidence-based public health: what does it offer developing countries? *Journal of Public Health* 27(2), 215-221.
- Mohammad RH (2007) A community program for women's health and development: Implications for the long-term care of women with fistulas. *International Journal of Gynecology and Obstetrics* 99(1), S137-S142.
- Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *British Medical Journal*. Available at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2714657/> (Accessed 14/11/2014).
- Mselle LT, Evjen-Olsen B, Moland KM, Mvungi A & Kohi TW (2012) "Hoping for a normal life again": reintegration after fistula repair in rural Tanzania. *Journal of obstetrics and gynaecology Canada : JOGC = Journal d'obstétrique et gynécologie du Canada : JOGC* 34(10), 927.
- Mselle L & Kohi TW (2015) Living with constant leaking of urine and odour: Thematic analysis of sociocultural experiences of women affected by obstetric fistula in rural Tanzania. *BioMed Central Women's health* (15) 10. Available at (Accessed 8 December 2015).
- Muleta M, Hamlin EC, Fantahun M, Kennedy RC & Tafesse B (2008) Health and social problems encountered by treated and untreated obstetric fistula patients in rural Ethiopia. *Journal of obstetrics and gynaecology Canada : JOGC = Journal d'obstétrique et gynécologie du Canada : JOGC* 30(1), 44-50.
- Mwini-Nyaledzigbor PP, Agana AA & Pilkington FB (2013) Lived Experiences of Ghanaian Women With Obstetric Fistula. *Health Care for Women International* 34(6), 440-460.
- Nathan LM, Rochat CH, Grigorescu B & Banks E (2009) Obstetric fistulae in West Africa: patient perspectives. *Am J Obstet Gynecol* 200(5), e40-e42.
- Nielsen HS, Duffy S, Lindberg L, Nygaard U, Aytenfisu H, Johnston OL, Sorensen B, Rudnicki M, Crangle M & Lawson R (2009) A community-based long-term follow up of women undergoing obstetric fistula repair in rural Ethiopia. *BJOG: An International Journal of Obstetrics & Gynaecology* 116(9), 1258-1264.
- Pope C & Mays N (eds) (1999) *Qualitative research in health care*, 2nd ed. edition. London :: BMJ Books.
- Pope R, Bangser M & Requejo JH (2011) Restoring dignity: social reintegration after obstetric fistula repair in Ukerewe, Tanzania. *Global public health* 6(8), 859-873.
- Roush K, Kurth A, Hutchinson MK & Van Devanter N (2012) Obstetric fistula: what about gender power? *Health care for women international* 33(9), 787-798.
- Siddle K, Mwambingu S, Malinga T & Fiander A (2013) Psychosocial impact of obstetric fistula in women presenting for surgical care in Tanzania. *International Urogynecology Journal* 24(7), 1215-1220.
- Turan JM, Johnson K & Polan ML (2007) Experiences of women seeking medical care for obstetric fistula in Eritrea: implications for prevention, treatment, and social reintegration. *Global public health* 2(1), 64-77.
- Umoyoho A J, Inyang-Etoh EC, Abah GM, Abasiattai AM & Akaiso OE (2011) Quality of life following successful repair of vesicovaginal fistula in Nigeria. *Rural and Remote Health* 11(3), 1734.
- Velez A, Ramsey K & Tell K (2007) The Campaign to End Fistula: What have we learned? Findings of facility and community needs assessments. *International Journal of Gynecology and Obstetrics* 99(1), S143-S150.
- Wall LL (1998) Dead Mothers and Injured Wives: The Social Context of Maternal Morbidity and Mortality among the Hausa of Northern Nigeria. *Studies in Family Planning* 29(4), 341-359.
- Wall LL. (2006) Obstetric vesicovaginal fistula as an international public-health problem. *The Lancet* 368(9542), 1201-1209.
- Wall LL (2012a) Obstetric fistula is a "neglected tropical disease". *PLoS neglected tropical diseases* 6(8), e1769.

- Wall LL (2012b) Overcoming phase 1 delays: the critical component of obstetric fistula prevention programs in resource-poor countries. *BMC pregnancy and childbirth* 12(1), 68-68.
- Wall LL & Arrowsmith SD (2007) The "continence gap": a critical concept in obstetric fistula repair. *International Urogynecology Journal* 18(8), 843-844.
- Whittemore R & Knafl K (2005) The integrative review: updated methodology. *Journal of Advanced Nursing* 52(5), 546-553.
- Women's Dignity Project & EngenderHealth (2006): *Risks and resilience: obstetric fistula in Tanzania*.
- Yeakey MP, Chipeta E, Rijken Y, Tauro F & Tsui AO (2011) Experiences with fistula repair surgery among women and families in Malawi. *Global Public Health* 6(2), 153-167.

Table 1. Articles retrieved from systematic search

Author, year and country	Aim	Sample	Research design
1. Alio <i>et al.</i> (2011). Niger	To understand the psychosocial effects of Vesicovaginal fistula	21 women	Qualitative; ethnographic method
2. Bangser (2007). Tanzania & Uganda	To study the determinants of fistula to guide public health interventions	Study 1: 137 women Study 2: over 136 hospitals Study 3: not stated Study 4: secondary data sources	Qualitative and quantitative of four projects
3. Browning and Menber (2008). Ethiopia	To evaluate the outcomes of repair and quality of life, six months post-surgery	240 women	Quantitative
4. Dolan <i>et al.</i> (2008). United Kingdom	1.To examine long term lower urinary tract symptoms incidence 2.To establish onset time of symptoms with regards to repair 3.To study the effects of urinary symptoms on quality of life and linkages between abnormality before repair, fistula site and symptoms after repair	31 women	Quantitative
5. Donnelly <i>et al.</i> (2015). Ethiopia	To study the post repair experiences and views about resuming healthy and valuable life	51 women	Qualitative
6. El-Gazzaz <i>et al.</i>	1.To investigate the	100 women	Quantitative

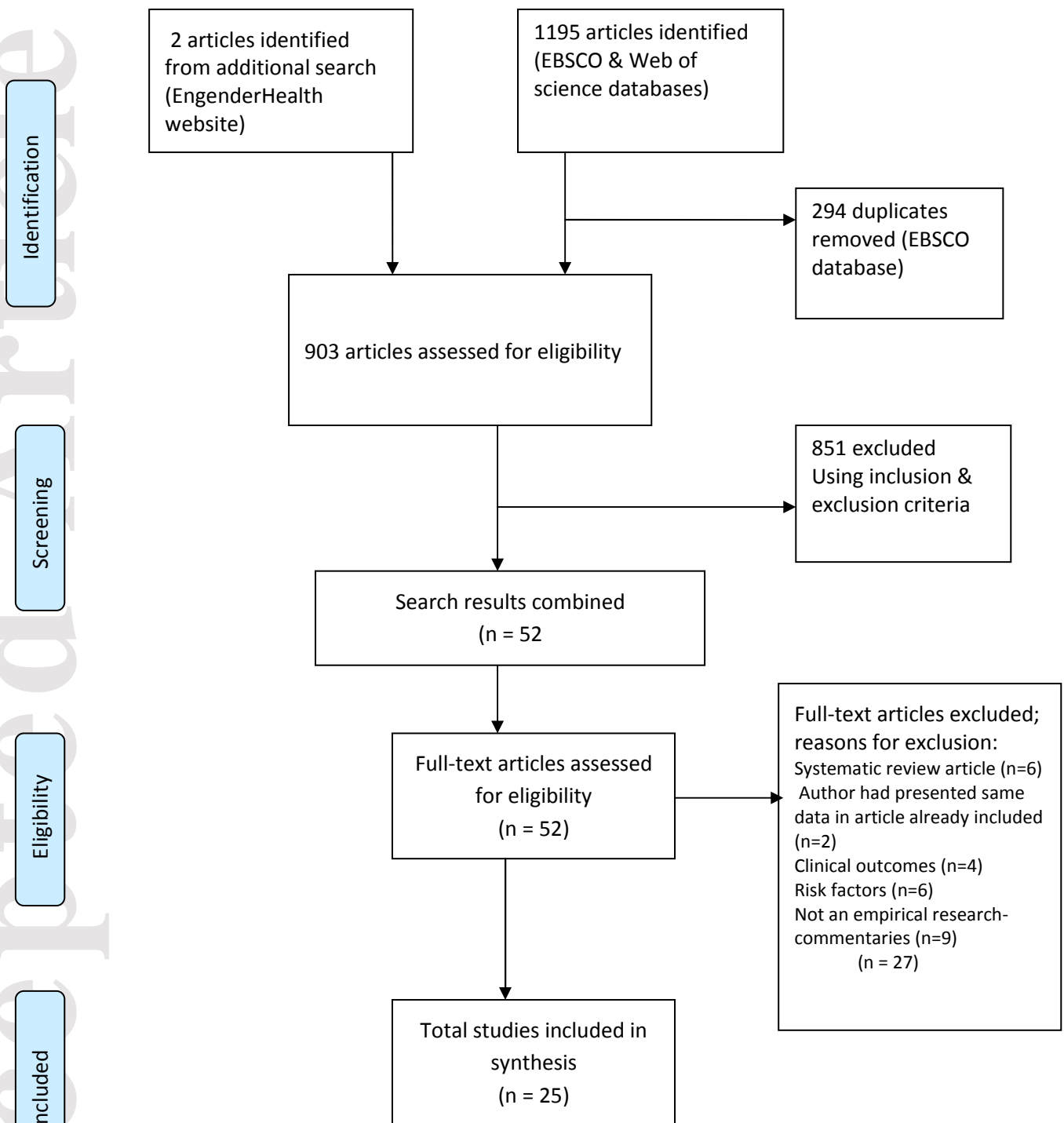
(2010). USA	success rate of repair 2.To assess the long term impact of repair on the on quality of life, sexual capacity and faecal continence		
7. EngenderHealth (2012). Bangladesh and Democratic Republic of Congo	To investigate the social and physical consequences of living with fistula and care seeking attempts	Bangladesh: 4 women DRC: 33 women	Qualitative
8. Farid <i>et al.</i> (2013). Pakistan	To investigate the psychosocial experiences of women after fistula development	8 women	Qualitative
9. Gebresilase (2014). Ethiopia	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
10. Gharoro and Agholor (2009). Nigeria	To assess the psychosocial issues women with fistula and their families experience	20 women and 10 family members	Quantitative and qualitative study
11. Khisa and Nyamongo (2012). Kenya	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 <i>et al.</i> (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
13. Mohammed (2007). Nigeria	To evaluate the impact of rehabilitation program on women after fistula repair	145 women	Quantitative

14. Mselle <i>et al.</i> (2012). Tanzania	To understand women's expectations and reintegration experiences after repair	151 women quantitative 8 women qualitative	Quantitative and qualitative
15. Muleta <i>et al.</i> (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
16. Mwini- Nyaledzigbor <i>et al.</i> (2013). Ghana	To explore and describe experience of living with fistula from perspective of fistula survivors	10 women	Qualitative
17. Nathan <i>et al.</i> (2009). Benin	To understand obstetric fistula through the views of patients	37 women	Quantitative
18. Nielsen <i>et al.</i> (2009). Ethiopia	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	Quantitative
19. Pope <i>et al.</i> (2011). Tanzania	To explore the meaning of successful repair to women with obstetric fistula and factors affecting their capacity to return to normal life	71 women	Quantitative and qualitative
20. Siddle <i>et al.</i> (2012). Tanzania	To assess the psychosocial impact of fistula	100 women	Quantitative
21. Turan <i>et al.</i> (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	Qualitative

strategies
-to improve clinical and
social services
provided for women
with obstetric fistula

22. Umoiyoho <i>et al.</i> (2011). Nigeria	To assess and compare the quality of life of women after successful repair of fistula	150 women	Quantitative
23. Velez <i>et al.</i> (2007). Bangladesh, Burkina Faso, Cameroon, CAR, DRC, Equatorial Guinea, Eritrea, Kenya, Malawi, Mali, Mauritania, Nigeria, Somalia, Tanzania, Uganda, Zambia	1.To provide a summary of needs assessment by UNFPA 2.To raise awareness and obtain programming information and advocacy for obstetric fistula	Sample: detail not provided	Quantitative and qualitative
24. Women's Dignity project and EngenderHealth (2006). Tanzania	To understand the complexity surrounding fistula and its social consequences through the lives of the girls & women affected, their family, community and care givers in health facilities	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	Qualitative
25. Yeakey <i>et al.</i> (2011). Malawi	To provide an understanding of the perspectives and experiences of women, spouses, female relatives while living with, and post fistula repair	First round - 47 women with fistula Post repair-5 women & 30 family members At follow up - 18 women post repair and 11 family members	Qualitative

TABLES AND FIGURES



Adapted Prisma flow diagram, Moher et al (2009)

Figure 1. Flow diagram of search selection process