Social Reintegration and Rehabilitation of Obstetric Fistula Patients Before and After Repair in Sub-Saharan Africa: A Systematic Review

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DOI: http://dx.doi.org/10.3126/njog.v13i2.21714

ABSTRACT

Aims: Social reintegration and rehabilitation of obstetric fistula patients before and after repair enhance their overall status, which may be unattainable even with a successful repair. Nonetheless, there is little traceable documentation about it even with supportive programs and projects, the thrust of this study.

Methods: This is a systematic review involving a search of relevant literature from PubMed, Google scholar, PsychINFO, African Journals Online, Australian Journals Online, and open access journals of international organizations such as WHO, UNFPA, USAID, Engender Health, Fistula Foundation and Fistula Care Plus published between 1978 to date. Of the 46 articles identified, 25 were suitable for achievement of this study's purpose.

Results: Sub-Saharan African countries have recognized the overall burden of obstetric fistula and have devised strategies for its holistic management. Most countries have National Obstetric Fistula Strategic Frameworks which emphasize multi-sectoral and multidisciplinary approaches other than medical paradigms. Social reintegration and rehabilitation have been done through the identification of individual patient's need/s. Projects and programs aiming to combat obstetric fistula and restore patients' self-worth and dignity are: Lamaneh Suisse, and Delta Survie in Mali, Dimol in Niger, Medecins Sans Frontieres (MSF) in Burundi, FORWARD in Nigeria and Sierra Leone, Handicap International in Benin Republic, Women For Africa in Ghana and Liberia, TERREWODE and CoRSU both in Uganda, Hamlin Fistula Ethiopia in Ethiopia, and others which cut across the region.

Conclusions: Effective social reintegration and rehabilitation strategies are still inadequate in Sub-Saharan Africa due to lack of political commitment and inadequate outreach programs.

Keywords: obstetric fistula, recto-vaginal fistula, social reintegration, vesico-vaginal fistula.

INTRODUCTION

Reintegration refers to the reacceptance of the obstetric fistula patients back into their social environment following their harrowing experiences of either fecal or urinary incontinence and in some instances, both of which have been associated with loss of self-esteem and dignity. It is therefore aimed at enabling them realize their full potential in life and gain emotional and psychosocial stability through culturally accepted counselling, peer and community support.[1] Rehabilitation on the other hand, refers to any experience that strives to improve the quality of lives of women before or after corrective surgery.[2] It is sometimes used interchangeably with reintegration, and includes programs aimed to improve overall status of women, through empowerment and enhancement of their socio-economic status such as vocational training, social rehabilitation and counseling.[1] Several studies have been done on the management of obstetric fistula most especially on its treatment, complication and outcome.[3,4] Little is documented concerning social reintegration and rehabilitation before and after obstetric fistula repair which motivated the need for this study.[5-7]

In the developing countries, it is usually due to prolonged obstructed labour when there is a disproportion between the fetal parts and the mother's pelvis.[8-11] This is associated with a number of factors including income inequality as well as low level of education early marriage, teenage pregnancy, decision making by husband only, malnutrition among adolescents and young mothers, unskilled birth attendance due to poverty and illiteracy, insufficient Vitamin D and Calcium ions and Female Genital Mutilation (FGM).[4,5,9,11-14] According to Ahmed and Hotez, FGM contributes 7.3% to the total prevalence of obstetric fistula globally.[15] Each year, 15 million women suffer chronic disabilities as a result of childbirth. Despite this very high number, maternal

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morbidity has not received the full attention that it deserves in the area of maternal health.[13] The global prevalence of obstetric fistula as estimated by WHO in 2010 was 2 million mothers with an incidence rate of 50,000 to 100,000 women of reproductive age per annum.[1,2,16] The majority of them are from South Asia and Sub-Saharan Africa with Sub-Saharan Africa having an estimated prevalence of 188 per 100,000 mothers of reproductive age .[13,17-19]

Due to the high prevalence of obstetric fistula in Sub-Saharan Africa, part of it has been named the fistula belt. It stretches from Mauritania in West Africa to Eritrea in East Africa with annual incidence rate of 33,000 obstetric fistula patients.[2] However, the above-mentioned incidence rate is an estimation and it is expected to be higher since it is based on self-reporting victims.[20] The situation of obstetric fistula prevalence does not vary significantly in almost all Sub-Saharan African countries.[21-25] The governments in all countries are making tremendous efforts to end obstetric fistula within a generation by intensifying actions geared towards this such as its prioritization within health interventions, and raising awareness on its cause and ensuring availability as well as accessibility to its treatment and management but still community outreach programs are still inadequate.[26-29,31,32.]

METHODS

A systematic review without meta-analysis was done on the 25 selected articles of studies conducted in various countries in the Sub-Saharan African region, published between the periods 1978 to 2018. These have been identified from online databases: PubMed, Psych-INFO, Google Scholar, and African Journals Online. Time scope for the included articles was based on twenty two years before the 21st century when Primary Health Care (PHC1978), Safe Motherhood (1987) and Health For All by 2000 Strategy were being implemented and now, almost two decades into the 21st century whereby, Millennium Development Goals (MDGs) and the current Sustainable Development Goals (SDGs) have been and are being implemented respectively. From the databases mentioned above, 46 articles were identified about social reintegration post obstetric repair. However, 25 met the inclusion criteria and were analysed for this study as shown in Figure [1.33-35]

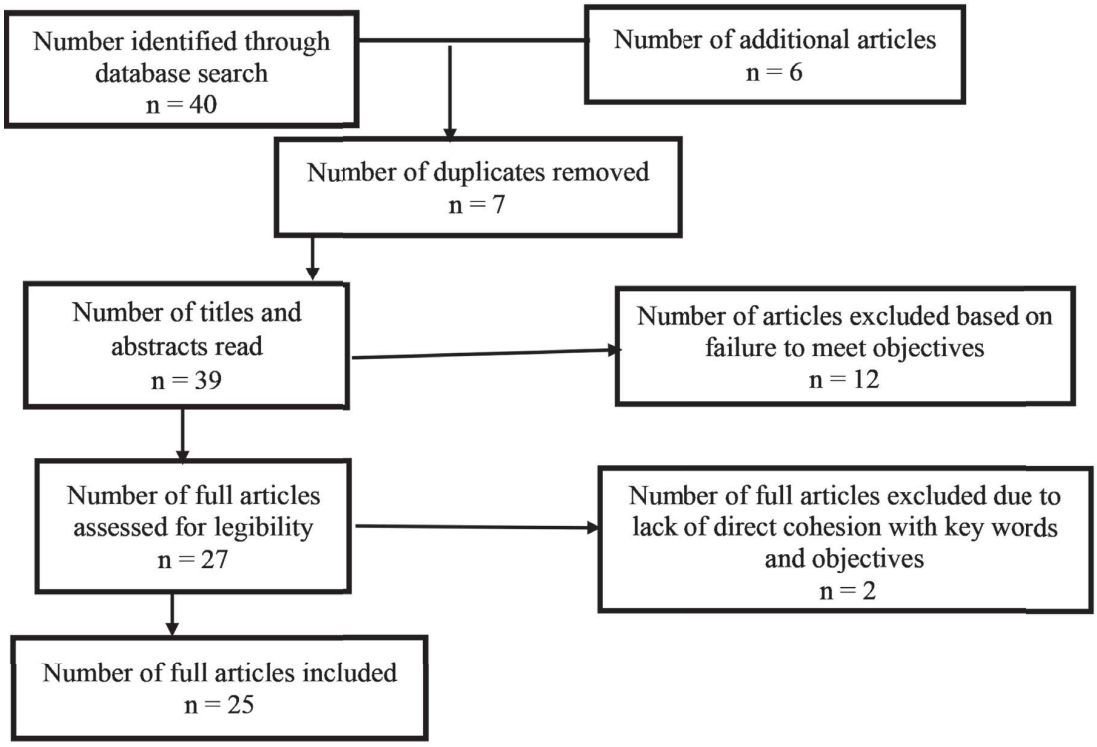

Figure 1: PRISMA flowchart of literature selection and inclusion criteria (Guided by Moher, D. et al. 2009)

RESULTS

Social reintegration and rehabilitation provide an individual patient or survivor with an opportunity to live normally and be accepted and valued in the community with a given condition as anyone else.[36-40] They include among other domains; leisure, social networking, reacceptance and recognition in community, employment and economic stability, satisfaction, independence, self-regulated coping mechanisms, and embarking on a family role. Therefore, the fact that obstetric fistula is associated with maternal morbidity, disability and the adjusted quality of life, the need for community reintegration and rehabilitation is inevitable.[16,41-44]

Sub-Saharan countries since the beginning of the 21st century recognized the burden of obstetric fistula and devised strategies for its holistic management. Among other strategies were: developing and implementing National Obstetric Fistula Elimination Strategies, ensuring that 90% of the repaired clients are socially reintegrated and rehabilitated with dignity and self-esteem, health facilities have pre-natal shelter to host high risk mothers, are able to offer post-operative care in the form of physical and psychosocial support.[44-46] In the process, countries like Uganda, Nigeria, Tanzania, and Guinea have been commended for their best practices in implementation of the same strategies.[47] Nigeria and Uganda have been at the fore front in the coalition and networking to ensure stakeholders form sustainable platforms for collaborative planning and programming so as to eliminate obstetric fistula.[26, 44] Ghana and Liberia have in the recent past been supported by Women for Africa project to design an action plan 2017-2019 focused to fine-tune infrastructure and programs whose aim is to combat and eradicate obstetric fistula and address all issues pertaining marginalization and stigmatization of the survivors.[45, 46]

Nonetheless, countries like Mali, Benin Republic, Togo, Chad Republic, Zambia, Mozambique and Malawi are still grappling with reintegration and community outreach programs.[8] Most facilities in these countries have no rehabilitation infrastructures, and there is inadequate support from stakeholders at policy levels.[46]

However, surgeons and care givers have been receiving skill training drawn from a curriculum by EngenderHealth to enable them provide holistic care to obstetric fistula patients. The approaches to social reintegration and rehabilitation cannot be generalized across Sub-Saharan Africa since studies have expressed deviation in political commitment, awareness of obstetric fistula and economic capacity to facilitate treatment, reintegration and rehabilitation processes. Also, across the region, different organizations are involved while using different strategies although some cut across.[47- 49] This calls for a separate presentation of the situation in various Sub-Saharan African countries as below:

Ethiopia

Having sustained obstetric fistula during childbirth, ethiopian women are stigmatized and they end up losing their dignity. However, the Ethiopian government in collaboration with NGOs offer soap, clothes, and transportation fund as part of social reintegration. Communities are in most cases not supportive except the Orthodox Church which has registered a record of providing food, money and accommodation for its members.[47] Having had successful repair, patients are eager to engage in advocacy, and raise awareness about the condition. More so about the importance of antenatal care and giving birth in a health facility.[47, 50]

The main project involved in the holistic management of obstetric fistula including reintegration and rehabilitation of obstetric fistula patients post repair in Ethiopia is Hamlin Fistula Foundation. The organization aims at eradicating obstetric fistula forever through its prevention by providing quality care during child labor and treatment of patients. It has been able to treat over 50,000 obstetric fistula patients registering over 95% success rate, refurbished 6 specialist hospitals, and trained surgeons and nurses just like other organizations supporting the management of obstetric fistula in the sub-Saharan African region.[50]

Sierra Leone

Being able to live the life like before has always been a source of joy to women in Sierra Leone. Survivors have been brought on board to advocate for, mobilize patients for health care services, and sensitize them on myths and misconceptions because their voice is a true representation of the situation at hand and is more heard than any other. They have been actively involved in capacity and life skills development in form of leadership, teamwork, vocational and literacy

training. This has been stirred by FORWARD and Haikal Foundation.[51]

Ghana

Obstetric fistula patients in Ghana are marginalized and stigmatized. They therefore, require support after repair to reconnect with their families, friends and communities.[46,49] The report of the Africa regional fistula meeting held in Accra, Ghana 2004 highlighted efforts by the Ghanaian government and stakeholders to ensure social reintegration of obstetric fistula patients and survivors. Ghana has registered successful stories on social reintegration and rehabilitation of obstetric fistula patients. This has been ensured through annual training of successfully repaired clients in income generating activities mainly tie and dye, saponification, and pastry making by UNFPA. Counseling about pelvic floor exercises, safe child delivery, resting after repair, and abstinence for at least six months after repair, is offered by nurses who have received special training in obstetric fistula patients' care.[48]

A non-governmental organization known as Women for Africa works with Tamale Teaching Hospital in Tamale, Northern Ghana and in Liberia to see to it that obstetric fistula is eradicated in these countries.[49]

Zambia

Although there is no known documentation of obstetric fistula outreach programs to ensure patients' social reintegration and rehabilitation in Zambia, hospitals receive support from the government, philanthropic organizations and individuals such as Holy Spirit Sisters, one Dr. Kelly known to donate logistics that aid in repair of obstetric fistula.[46] A prominent center for repair of obstetric fistula patients in Zambia is Monze Mission Hospital.

Eritrea

Eritrea like many other countries in the fistula belts follows the curriculum designed by Engender Health to train specialists, nurses and social workers on how to manage obstetric fistula patients.[46] In the curriculum, pre and post-surgery counseling sessions are highlighted and this has made tremendous impact on patients' knowledge of obstetric fistula, behavior intentions, and their self-esteem.[2] Other skills they are trained in are: being able to assess and acknowledge client's needs, listening to the clients' concerns and providing answers to questions raised, provision of adequate information about obstetric fistula, its holistic clinical care, prevention, conditions that can be treated and those that might fail, self-care, length and outcome of treatment.[50]

Nigeria

Nigeria having 40% of the global burden of obstetric fistula has put in place measures to eradicate obstetric fistula and its sequels.[6,23] The federal ministry of health designed a National Strategic Framework for Elimination of Obstetric Fistula in Nigeria which guides activities conducted at Federal, state, local level, civil society, and those of and by development partners. The country has 12 dedicated centers for obstetric fistula surgery which also take care of reintegration and rehabilitation as important components of holistic care. Each year, the centers repair 2000 to 4000 obstetric fistula patients, however, the backlog is enormous and it requires more than 100 years to deal with it while ignoring new cases who are 20,000 per annum.

The Federal Ministry of Health and stakeholders are dedicated to reduce obstetric fistula incidence rate by 50% and increase rehabilitation by the same percentage.

A study done in Nigeria by Capes T [53] on postoperative care pointed out that all fistula centers and some teaching hospitals have rehabilitation centers where patients can be referred to after repair. In addition to government activities, the Foundation for Women's Health Research and Development (FORWARD) and AMREF for Health provide a holistic approach of care through surgery, and supporting women to have positive rehabilitation experiences through skills training, and creating community awareness, health education, offering gifts in form of clothing and soap and home based care.[52-54] A study conducted by Ojengbede AO[6] stated that 67% of women who have had successful repair need family support as a backup for their effective reintegration while 60% consider work resumption as imperative in making them feel normal and accepted. In Tanzania, same factors were mentioned by 68% of the successfully repaired obstetric fistula patients as imperative in their effective reintegration.

Rwanda

In Rwanda, patients have been known to delay to seek care because health facilities have scarce skilled manpower, and logistics to address the prevention, treatment services, and rehabilitation and social reintegration. There is also still inadequate knowledge concerning obstetric fistula repair services mostly at community level. The integration of obstetric fistula patients is being supported by MOH in collaboration with the Fistula Care Project, USAID, UNFPA, and International Organization for Women and Development (IOWD) and various embassies to counteract the increasing demand for obstetric fistula management through campaigns aimed at increasing awareness, and decreasing social stigma.[55] The Fistula Care Project took an initiative to train 1,220 surgeons and 227 nurses, renovate theater space and provide operating equipment and supplies at various obstetric fistula centers. It also provides fistula repair during outreach workshops. USAID also trained 25 surgeons and has been financially supporting various fistula centres.[56]

Uganda

The Republic of Uganda has got a National Obstetric Fistula Strategy 2011/2012-2015/2016 aimed to eliminate obstetric fistula, rehabilitate and socially reintegrate the patients into their communities. The strategy noted that previously very few organizations had been involved in rehabilitation and reintegration of obstetric fistula patients and even then, the process lacked guidance and was only done through transport refund and general counseling to the patients. Currently, the UNFPA campaign to end fistula, technical working groups formulated by the MOH to coordinate fistula activities in the country, and community based health structure such as Village Health Teams (VHTs), are working hard to ensure referral of the patients and their social reintegration after repair. In line with the Health Sector Strategic and Investment Plan (2010/2011-2014/2015), goals have been formulated and implemented to ensure quality and standard health by all the people in the country.[27, 32, 37, 40, 57] Among other areas of its focus is to eliminate stigma, ostracism, poverty and psychosocial challenges of obstetric fistula through accelerating efforts towards effective social reintegration. These strategies are also incorporated in the national reproductive health policy.[37, 40]

Uganda's approach to the management of obstetric fistula in collaboration with stakeholders has been mass repairs or group rehabilitation. Fistula Care Plus has been working in the country since 2004, to create awareness, about the condition and also support its holistic management. The project also created a "learn from my story" program which is used to create and raise awareness both locally and globally. The Association for Rehabilitation and Re-Orientation of Women for Development (TERREWODE), Uganda Village project in Iganga district, Safe Motherhood Uganda, and Comprehensive Rehabilitation Services in Uganda (CoRSU) in Kisubi, Wakiso district have been offering rehabilitation by training of obstetric fistula survivors and community members as fistula "ambassadors", identification of patients, raising awareness, screening, surgeries, community mobilization, rehabilitation, follow-up and others.[37, 40, 58- 60]

Niger Republic

Niger republic being among countries contributing highest to the global burden of obstetric fistula has an obstetric fistula network aimed to eradicate obstetric fistula. Women led non-governmental organizations are vibrant in carrying out community sensitization by word of mouth about prevention, treatment services, social reintegration and rehabilitation of obstetric fistula patients.[45] Dimol which is one of the vibrant organizations has been actively involved in training of obstetric fistula survivors in income generating activities, counseling, moral support and community health education to ensure patients are fully reintegrated.[18]

However, the country still suffers a challenge of inadequate skilled personnel to provide obstetric fistula repair.[45]

Mali

"Although there is inadequate support at policy levels"[45], Mali is making necessary progress in the reintegration and rehabilitation of obstetric fistula patients through locally based three prominent organizations in collaboration with obstetric fistula centers such as Point G Hospital. The first is Lamaneh Suisse which mobilizes obstetric fistula patients for repair, and follows them up through the next pregnancy to ensure that obstetric fistula does not reoccur. The second is Delta Survie, which strives to improve

economic status of women through textile production and training them in other various income generating activities.[18] The third is Foundation Partage which mobilizes and transports obstetric fistula patients to referral hospitals for repair.[45]

Guinea Conakry

In Guinea, the process of social reintegration and rehabilitation starts in a special home known as "a waiting home". It is a residential area near the health facility where patients reside for two weeks as they await repair. In the process, they are physically and socially supported by their peers and staff members of the organization. After repair, they usually stay for two weeks in the hospital and then return to the waiting home where they stay until they are rehabilitated and feel confident enough to socially reintegrate in the wider community. While at the waiting home, patients are equipped with various skills to enable them have sustainable livelihoods. The Fistula Care Project is very active in ensuring effective community reintegration and rehabilitation of obstetric fistula patients. It initiated a social immersion strategy that mobilizes local volunteer families to host obstetric fistula patients that have been ostracized and abandoned by their loved ones. The social immersion strategy has been commended for improving patients' self-esteem, confidence, and general emotional health.[18, 61]

Kenya

According to Khisa MA1, the obstetric fistula prevalence of Kenya had not been documented, however, that of West Pokot district was 1 per 1000 women of reproductive age. Khisa's study noted a number of social issues around obstetric fistula patients including stigmatization, marginalization, isolation and abandonment by partners, families and friends. However, the government had no comprehensive reintegration program but efforts were made by AMREF to facilitate repairs and socially reintegrate and rehabilitate patients through outreach program and raising awareness. AMREF works closely with hospitals mainly; Ortum Mission Hospital, Jamaa Hospital, Kenyatta National Hospital and Moi Teaching and Referral Hospital.

Tanzania

The reintegration process depends on how long the patient has stayed with obstetric fistula and the previous social experience before repair. A study conducted in 2012 by Mselle TL36 identified some of the social experiences that patients endure. The study noted that only 55% of the participants expressed the desire to ever have children in future and these were mainly those who had had still born. The themes for social reintegration and rehabilitation of obstetric fistula patients, how it has been done and programs involved are summarized in Table 1.

Themes under social reintegration and rehabilitation	How social reintegration and rehabilitation have been done	Programmes and projects
Mental health, Health education, stigmatization, self-esteem, trauma, quality of life, social support, mobility, social interaction, work resumption, being able to meet their needs and those of dependents, negotiating life situations, isolation, psychosocial issues, vocational skills, income generating activities, based groups, access treatment, hope, depression, isolation, shame, dignity and self-identity, symptoms of incontinence, poverty eradication, Primary Health Care, Maternal and Child Health services, literacy, interpersonal communication skills, divorce and separation, fertility, family planning, myths and misconceptions around obstetric fistula, harmful traditional practices	- Use of assessment tool in follow-up - Community mobilization - Case identification - Identification of patient's needs - Social engagement - Counselling and guidance - Physiotherapy - Nutrition - Encouraging family support - Group based model - Behavior change and advocacy - Bonding among peers (Patients), - Peer support - Holistic approach - Multilateral and bilateral partnership, - Social networking - Multidisciplinary approach - Community engagement - Involving Northern Emirs - Adult literacy	- Fistula Foundation - Fistula Care Plus Project - EngenderHealth - TERREWODE - Community Based Organization (CBOs), - Ward Development Communities - NURTW women groups. - Foundation for Women's Health, Research and Development (FORWARD) - Lamaneh Suisse, and Delta Survie in Mali - Dimol in Niger - Comprehensive Rehabilitation Services in Uganda (CoRSU) - Handicap International - Medecins Sans Frontieres (MSF) in Burundi - Hamlin Fistula Ethiopia

Themes under social reintegration and rehabilitation	How social reintegration and rehabilitation have been done	Programmes and projects
	- IEC for behavior change - Social functions, seminars - Social immersion strategy - Elementary education - Skills development (catering, tailoring, craft making, knitting), income generating activities - Involving legislative bodies, and human rights activities - Male partner involvement -Waiting homes -Voluntary host homes	- Community and National projects supported by UNFPA, WHO, USAID, Pathfinder, Family Health International, and AMREF - International Organization for Women and Development (IOWD) - Women For Africa - Embassies

DISCUSSION

Findings indicate that the process of social reintegration and rehabilitation of obstetric fistula patients in Sub-Saharan Africa has not been given the attention it deserves just like its treatment.[6, 30-32, 43, 45] Most studies done about the topic have majorly focused on reintegration and rehabilitation post obstetric fistula repair and yet both are necessary to hasten the healing process and eventually assure a satisfying life to the patient following both physical and physiological disorders they endure including the fact that most of them have had still born babies.[32, 62, 63] The social ramifications following obstetric fistula are deep and yet easily forgettable by communities. The obstetric fistula patients are predisposed to high level depression which requires holistic approach, family and peer support [36, 37, 39] and rehabilitation in order to mend the psycho-social wound.[18, 63, 64]

For survivors to be absorbed in an environment that had been hostile, social reintegration is as important as the physical repair so as to gain normal life index.[32] It can be enhanced through providing opportunities and promoting social networking among the patients with their communities.[6] The engagement of obstetric fistula patients and survivors in advocacy for its prevention, treatment and rehabilitation and social reintegration has been observed to cause positive effect in Ghana, Niger, Uganda, Tanzania, Ethiopia, Nigeria and Mali.[8, 43, 45-47]

The reintegration process begins with case identification, counseling, support to access treatment.[37, 39] This is slightly different from study by Kasamba [10] which states that reintegration should start with creation of awareness of the cause of obstetric fistula, its risk factors, prevention and improving the status of the mother after repair. Whichever approach, it is meant to alter social perceptions of obstetric fistula patients because these may be totally different from reality.[61,63] Without awareness, the community is likely to continuously neglect these mothers when they are practically going through a critical moment that requires societal and individual support.

In Eritrea, social reintegration post obstetric fistula repair has largely been conducted through counselling and creation of awareness.[64] This is similar to what is done in Northern Ghana in the same regard.[64] Awareness is made to enlighten, guide and counsel patients about their bodies (self-awareness), how to prevent likely complications post-surgery, and future fistulas. In the process of counselling, their self-esteem is enriched and they are emotionally prepared for community reintegration. Eritrea like many other countries in the fistula belts follows the curriculum designed by Engender Health to train specialists, nurses and social workers on how to manage obstetric fistula patients. In the curriculum, pre and post-surgery counseling sessions are highlighted. The clients should be individually counseled in relation to the complexity of their fistula while emphasizing self-care and the significance of follow up. These strategies have proven to be effective in enhancing patients' level of knowledge, correcting mysteries about cause and cure of fistula, their esteem, and total behaviour change.[64- 66] World over, countries have developed national or sub-national strategies for prevention, treatment, rehabilitation, and reintegration of obstetric fistula patients. Nigeria in collaboration with Tanzania, Sudan, Democratic republic of Congo and Pakistan formulated the Integrated Maternal, Newborn, and Child Health Strategy and also adopted and formulated policies to provide free maternal

health services.[54]

In order to address obstetric fistula and issues around it, a number of specialized centers have been constructed while others have integrated fistula care into their routine. Governments, activists and NGOs involved in its holistic management including the reintegration and rehabilitation processes either internationally, nationally or community level in various sub-Saharan African countries. Remarkable among others are: Fistula Care Project, Women for Africa, Fistula Foundation, and Fistula Care Plus, USAID, IOWD, and various embassies in different Sub-Saharan countries. Other NGOs operating in one or more Sub-Saharan African countries are: Lamaneh Suisse, and Delta Survie in Mali, Dimol in Niger, Women's Health and development Project (FORWARD) in East and West Africa specifically in Sierra Leone, and Nigeria. The Association for Rehabilitation and Re-Orientation of Women for Development (TERREWODE), Uganda Village Project in Iganga district, Safe Motherhood Uganda, and Comprehensive Rehabilitation Services in Uganda (CoRSU) are all in Uganda, and Hamlin Fistula Ethiopia in Ethiopia.[23, 45, 47, 60, 61, 67] The IOWD has been collaborating with individual obstetric fistula consultants to repair patients in West Africa and Rwanda in East Africa and have so far repaired over 1000 obstetric fistula patients.

Women for Africa designed an action plan 2017-2019 which is already implementing to support Ghana and Liberia among other Sub-Saharan African countries and some other countries across the globe to restore obstetric fistula patients' dignity and self-esteem.[45, 47] However, program designers ought to understand that obstetric fistula patients are different as well as their needs, hence their strategies should be contextual and individual patient centered.[3, 6] These countries operate along the guidelines stipulated in their National Obstetric Fistula Strategic Frameworks. They are aided by both their governments in collaboration with international organizations stakeholders; notable are: UNFPA, Engender Health, USAID, WHO, and AMREF for Health.

CONCLUSIONS

Social reintegration and rehabilitation before obstetric fistula repair has not received much attention in most Sub-Saharan African countries, yet it hastens physical and psychosocial healing as one awaits surgical repair. There is still need to support and promote outreach projects and home based care and also to create awareness about misconceptions concerning obstetric fistula so as to encourage and intensify community and family support.

ACKNOWLEDGEMENTS

Immense gratitude goes to online databases such as PubMed-NCBI, Google scholar, Psych-INFO, African Journals Online, all open access journal articles for international bodies and individuals. Special gratitude to Dr. Odugwo Martina Nkechi for supporting the authors through advanced search strategy to get relevant articles for review.

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