Original Research Article

AMREF Awareness Creation Campaign and Reduction of Obstetrics Fistula Stigma: Evidence from Misungwi District, Tanzania

Abstract

This study aimed to examine the role of AMREF awareness creation campaigns in reducing obstetric fistula stigma in the Misungwi district: a case study of women's empowerment and psychosocial fistula campaigns. The study uses two theories: elaboration likelihood model theory and social cognitive theory. A sample size of 40 respondents was used in the study, including fistula survivors, health workers and fistula ambassadors. The study used both qualitative and quantitative methods for data collection. The study revealed that 54% of the fistula survivors received information about fistula from others who were mentioned as fistula ambassadors, followed by 26% who were health workers, 18% who heard about fistula through media such as radio and 2% from older women, and no one said about personal experience. Regarding how often they look for information on health. The findings revealed that 60% of the survivors said they looked for health information very often, 30% when the need arose and the remaining 10% said they did not so often. Furthermore, the study revealed that 73% of the survivors witnessed that the community around them had enough Amref awareness of fistula, while 27% did not think if the community had enough awareness of fistula. The lack of knowledge about fistula comes with stigma that can be hurtful and invalidating, but it also has more significant repercussions, such as fostering hatred, fear, and intolerance toward other people. Organizations should plan and carry out awareness campaigns in collaboration with respected community members, including local decision-makers, religious leaders, traditional healers, midwives, and other professionals in the health care industry, to have a positive impact on the obstetric fistula program.

Keywords: Awareness, Awareness creation, Stigma, Obstetric fistula, Vesicovaginal fistula

1. Introduction

Obstetric fistula is more common in Africa and other developing regions than in developed nations, according to research by Wall (2001). It is one of the most dangerous birth problems in this region of the world. Over two million women and girls worldwide suffer from obstetric fistula, with Africa having the highest prevalence, according to the World Health Organization (WHO). According to a 2010 estimate by the United Nations Population Fund, at least 20% of women endure some kind of injury, infection, or impairment during childbirth, and over a million children lose their lives as a result. More than two million women and girls in developing nations are affected, and at least 100,000 new cases are reported each year.

Obstetric fistula is a maternal health problem in Tanzania. Each year, some 3,000 Tanzanian women experience obstetric fistula, a condition that leaves them unconfident and causes them to uncontrollably leak urine and/or feces, which is among the serious and distressing maternal

morbidities. Women, especially in some rural areas, suffer from fistula for a long period without treatment. During this period of suffering from obstetric fistula, women experience significant psychological trauma. Obstetric fistula survivors are too often shunned by their communities and abandoned by their husbands. Due to the isolating nature of fistula, many Tanzanian women are unaware that their condition is treatable and either blame them selves for their misfortunes or believe they are cursed. To fight fistula in Tanzania, different measures are taken by government and nongovernmental organizations, including Amref Health Africa in Tanzania. Amref Health Africa offers comprehensive care to women who have fistulas, and the organization also helps women establish income-generating businesses, improving their confidence and assisting them in achieving financial independence. They also offer surgical repair, continuous psychosocial support, entrepreneurial training, and initial finance.

Amref Health Africa (Amref) has taken the lead in promoting, organizing, and putting obstetric fistula prevention and management into practice. The socioeconomic determinants of health are addressed by Amref. Amref works with various stakeholders to address the sociodeterminants of health, such as economic empowerment and education for girls, using a holistic approach to the building of the health system across the continuum of care.

Additionally, Amref works to strengthen communities' ability to handle the first and second delays as well as the survivors' reintegration. Empowering women living with obstetric fistula through treatment, psycho-social support, and livelihood opportunities projects has provided millions of individuals through fistula awareness programs with pertinent information on both the prevention of obstetric fistula and the reintegration of survivors. Amref educates communities about the root causes of fistula to reduce stigma, encourages people to seek prompt maternal health care as a preventive step, and promotes awareness of fistula and treatment for individuals who have it. To achieve successful reintegration, Amref empowers survivors to create income-generating activities and to network with other survivors and community members.

Additionally, Amref collaborates with other stakeholders to promote sexual and reproductive health and the right to give women and girls the power to access high-quality care, including family planning services. In addition to providing facilities with specialized equipment for the repair of fistulae and for high-quality obstetric care, Amref assists governments in the development of policy documents to improve the prevention and management of obstetric fistulas.

Despite all these efforts by Amref Health Africa, obstetric fistula remains a significant issue in the Misungwi district. There are myths concerning obstetric fistula, although prolonged obstructed labor without prompt medical treatment is the primary cause.

According to Fiander and Vanneste (2012), obstetric fistula is a consequence of protracted labor in which a hole develops between the vaginal and bladder walls. It is more common in low-income countries with limited access to emergency obstetric care. Untreated obstetric fistula leads to chronic medical, social and psychological problems and represents one of the most degrading morbidities resulting from childbirth.

Obstetric fistula is a direct communication between the vagina and the bladder (vesicovaginal fistula) and/or between the vagina and the rectum (rectovaginal fistula). It usually occurs after prolonged or obstructed labour, spontaneous abortion or female genital mutilation and leads to

physiological anomalies, including continuous loss of urine or faeces through the vagina, urogenital infections, inflammation of the skin (dermatitis ammonia), and kidney infections, and is usually accompanied by other manifestations from the "obstructed labour injury complex", including damage to the cervix or pelvic bones, foot drop, genital lacerations, and amenorrhea (absence of menstruation) (Bangser,2006).

Hilton (2003) quoted that "Fistula patients face high levels of stigma from their families and communities resulting in social and economic exclusions, which in turn lead to high risks of depression and suicide". In sub-Saharan Africa and South Asia, obstetric fistula is very common, as access to and use of emergency obstetric care is limited (Tebeu et al, 2012). According to the World Health Organization (WHO), each year, between fifty thousand and one hundred thousand women worldwide are affected by obstetric fistula. More than two million adolescent women in Asia and Sub-Saharan Africa are predicted to have an untreated obstetric fistula. (Lopez & Murray,1998).

Awareness about obstetric fistula is still low in Tanzania, and some areas, especially rural areas, have misconceptions regarding its causes, clinical presentation, and prevention. Currently, there is an on-going 4-year program, covering the period 2019 - 2022, to eradicate obstetric fistula from Tanzania specifically in the Mwanza region, which is a partnership between Amref Health Africa UK, Amref Health Africa Tanzania, Magu Poverty Focus on Older People Rehabilitation Centre (MAPERECE), and Bugando Medical Centre, funded by The National Lottery Community Fund. However, the task of eradicating this condition remains daunting.

The primary goal of reducing fistula stigma is exposure to various media and community awareness campaigns. As a result, researchers are curious about the patterns of exposure to such messages, which come in a variety of media and formats. One reason for this is that advertisers and program managers use this information in campaign planning and strategies.

This study aimed to assess the role of awareness campaigns in reducing obstetric fistula stigma in rural areas in the Misungwi district. It was guided by the following research objectives:

i. To determine the community level of exposure (understanding) to obstetric fistula messages in Misungwi.
ii. To determine the medium/media used for obstetric fistula intervention among communities in Misungwi.
iii. To explore the effectiveness of the Amref obstetric fistula awareness campaign.

2. Literature Review

When women are unable to receive high-quality emergency obstetric care in a timely manner, an obstetric fistula frequently develops. The most frequent cause of obstetric fistula is prolonged difficult labor during birth, with up to 80% of patients needing two or more days of labor (Boene et al, 2020). It is a significant illness associated with childbirth that affects up to 1 million women globally, with thousands of new instances occurring each year, primarily in Sub-Saharan Africa (Adler et al 2013). Women who are affected experience uncontrollable urine and/or feces leaks. In addition to the persistent vaginal irritations brought on by urine leaks, prolonged obstructed labor can induce cervical sores and nerve damage, which can result in infertility and paralysis (Wilson et al, 2011).

Fistula in women has long-term emotional, financial, and physical repercussions. Many people lament the trauma of having to support their families financially. They face shame and humiliation as a result of their inability to discuss their fistula experience (Krause et al, 2017). The lack of social aid, lack of knowledge about rehabilitation following fistula repair, and inadequate awareness of fistula within communities can all be used to explain this sensation of isolation (Changole et al, 2017).

In 2005, the WHO projected that more than 0.5 million deaths were related to pregnancy and delivery, and since 1990, there has not been any evidence that the situation has improved. Eight percent of these maternal deaths are due to obstructed labor. According to estimates, 1.8 women survive with an obstetric fistula, such as a urethro-, uretero-, vesico-, or recto-vaginal fistula, for every woman who passes away from untreated obstructed childbirth (AbouZahr, 2003)

Furthermore, Wall (2006) quoted that

> "These fistulae indicate embarrassing problems like fecal and urine incontinence, damaged pelvic tissues, social disturbance, and restricted reproduction. They pose significant obstacles to surgical treatment and social restoration. Although the conditions have been well known throughout history in most societies, they are now mostly restricted to low-income nations and are seen as a sign of inadequate access to basic healthcare. For instance, a 2005 epidemiological survey in Ethiopia revealed that 0.22% of women between the ages of 15 and 49 had or had obstetric fistula.

Obstetric fistulas can have a variety of causes, including female genital mutilation and protracted or obstructed spontaneous abortion. However, the outcomes of obstetric fistulas are not merely physiological. Women who experience incontinence frequently experience severe social stigma and associated mental health problems; as a result, these women are either marginalized by their families and communities or marginalized themselves. Such stigma and solitude reduce their likelihood of receiving treatment. These women are less likely to be aware that fistulas can be treated and where to get treatment because they live outside the centers of their cultures.

Approximately 46,000 women in Tanzania are thought to be living with obstetric fistula (National Bureau of Statistics of Tanzania & ICF Macro, 2011). However, Tanzania has made efforts for many years to find women with fistulae and immediately send them to free surgical repair (Fiander & Vanneste, 2012). Using community ambassadors, mobile phone technology, and funding transfers for ambassador incentives and patient transportation, nongovernmental organizations such as Amref Health Africa in Tanzania and Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) are implementing a national initiative to identify and refer patients (Fiander & Vanneste, 2012). Similar approaches, as well as radio commercials and community outreach initiatives, are used by other hospitals in Tanzania that perform fistula repairs to locate and recommend women for treatment. Nearly 1,000 obstetric fistula repairs were performed nationwide in 2011. (Ndahani, 2012). Although surgery might treat a fistula's physical symptoms, it might not be enough to solve all of the problems that fistula-afflicted women must deal with (Nielsen et al., 2009).

Msele et al. (2013) stated that obstetric fistula is an indicator of poor quality of obstetric care. In research conducted among women with fistula in Tanzania (Msele et al, 2013), women who had suffered serious birth injuries such as obstetric fistulas and the health workers who looked after

then found the maternity and emergency obstetric care provided inadequate. Birth accounts of women with obstetric fistula suggest a health system failure in which health units fail to provide essential care to women, the health workers are disempowered, community expectations of the health system are low and rates of home deliveries are high.

Obstetric fistulas are abnormal openings that develop between the birth canal and the urinary tract (ureter, bladder and urethra) or rectum. Most obstetric fistulas follow obstructed labor, one of the major causes of maternal mortality and morbidity in Sub-Saharan Africa. Such fistulas are usually associated with cephalopelvic disproportion, whereby the baby's head presents with diameters whose dimensions are larger than the proportions of the pelvic canal through which it passes (Kelly, 2014). This abnormality is associated with delays in seeking or receiving appropriate emergency obstetric care (Neilson et al,2003).

Obstetric fistula is a physically and socially disabling obstetric complication that affects many women annually (Mselle et al, 2011). It has a devastating social, economic and psychological effect on the health and well-being of affected women. According to Ahmed and Holtz (2007), the stigma, deep sense of loss and loss of dignity and identity associated with fistula have a negative impact on quality of life. Obstetric fistulas are one of the most distressing maternal morbidities (Bangser, 2006). In addition, they are often associated with various comorbidities, such as obstetric palsy, foot drop, renal failure, osteitis pubis, infertility, vaginal stenosis and pelvic inflammatory disease (WHO, 1989). Furthermore, Yeakey et al. (2009) state that obstetric fistula mostly affects poor women, most of whom have lost their babies, during childbirth. Many affected women have other complications and are subjected to social discrimination and abandonment.

According to Turan et al. (2007), awareness of obstetric fistula is still low in many developing countries where it is prevalent. There are limited data on awareness of obstetric fistula in communities affected by fistula, particularly its presentation, management and prevention. Misconceptions and negative beliefs might hinder seeking care for women with obstetric fistula. Low awareness might deter efforts to integrate women with fistula in their communities before and after surgery for the condition.

Yeakey et al. (2011) state that obstetric fistula repair surgery has been demonstrated to positively impact a woman's life through improvements in her physical condition and her interpersonal relationships. Although some women do not fully recover from the first surgical repair of their fistula and therefore continue to experience symptoms or the need for additional surgery, many women do benefit from surgical repair (Raassen et al, 2008). Lyimo and Mosha, (2019). claim that obstetric fistula is one of Tanzania's most significant and unpleasant maternal morbidities. For example, women can still experience the negative effects of obstetric fistula, such as infertility, spontaneous abortion, and infant death, even two years after having surgery to repair it. Obstetric fistula not only causes urinary and faecal incontinence but also has negative effects on a woman's physical, emotional, and social health. Economically, this permanent impairment affects not only the woman's production but also that of her home and the neighbourhood.

In addition, Lyimo and Mosha (2019) quoted that families and communities around women with obstetric fistula had different understandings about the causes and treatment of obstetric fistula. Most people thought that fistula was caused by being bewitched or cursed by ancestors. Such beliefs affected the behaviour of women seeking obstetric fistula treatment and often meant that they sought traditional medicines (mineral- or plant-based medicines and spiritual therapies). In

communities with a high rate of maternal death and frequent unmanaged obstructed labor, obstetric fistulas continue to be a serious public health issue. In high-income nations, obstetric fistula can be avoided, cured, and eliminated; nonetheless, it still affects many women in low-income nations. Lack of knowledge could hinder efforts to incorporate fistula patients into their communities both before and after surgery. Due to erroneous information regarding fistula, women who have it may become objects of shame, mockery, hostility, and social avoidance. None of these actions will benefit fistula-afflicted women. Since fistula can affect any woman, the community should assist those who have it.

Fistula sufferers smell awful because urine or feces leak out of them. Because of the smell, people frequently avoid them. Many fistula-afflicted women endure stigma, taunting, hostility, and sometimes physical violence. In some situations, the persons concerned can just be unsure about what to do or who to turn to, so they take no action. In Wall and colleagues' research of 899 fistula cases from Jos, Nigeria, 6.5% of patients said they were uninformed of hospital obstetric care availability, and nearly 27% were unable to explain why they delayed seeking help. (Wall et al., 2004)

Sometimes a different course of action will be taken than taking the patient to an obstetric emergency care facility. Obtaining assistance from a local person who is recognized as an authority on issues related to birthing is a typical therapeutic choice. These people serve as "authoritative knowledge" repositories for childbearing issues, serving as "the source" for answers included in the local cosmology. (Davis, 1997). These authorities could be midwives, shamans, or religious leaders (pastors, priests, imams, etc.) who are believed to have specialized knowledge or abilities that could be helpful in treating labor complications. Churches are frequently the first place of shelter for dystocia patients in Christian Africa. Prayer and religious rituals are frequently used as therapy, although they ineffectively address the issue of mechanical obstruction (Adetunji, 1992). Muslims frequently turn to various forms of Islamic folk medicine in an effort to harness the power they believe the Koran to be endowed with. For instance, in northern Nigeria, writing a verse from the Koran that is considered to be "therapeutically potent" on a wooden slate, washing off the ink that was used to write (and thus embody the power of) God's words, and then consuming the inky water as medicine are common treatments for many ills (Wall, 1988). Additionally, if there is suspicion that the pregnant woman has committed adultery or other sins that are preventing her from giving birth, traditional lineage priests or clan elders may be called to the scene to discuss the situation. (Omorodion, 1993 & Chapman, 2010).

In west central Tanzania, among the Sukuma, Denise Allen documented a belief known as usangalija. The Sukuma word for protracted or halted labor is usangalija. It refers to the "mixing" phenomenon, which occurs when a woman accepts "foreign" sperm while carrying a child with a different man as the father. This "mixing of men" poses a risk to both the mother and the child because fatalities are sometimes the result. The fetus is claimed to experience some form of repulsion as a result, going "up in the uterus rather than down the delivery canal" (Allen, 2002).

Allen related a number of instances in which women had a difficult time giving birth and were afterwards accused of adultery. Home treatments for usangalija included doing things such as combining some water with a pinch of sand from the location where a dog, a famously promiscuous animal species, had given birth and giving it to the woman who was in labor to drink. The woman might also be given a drink made from a root that was ground up and mixed with water that was found growing in the middle of the road.

Women frequently have limited independent agency in many communities where obstetric fistulas are prevalent (Okojie, 1994). They might not have much control over whether they engage in sexual activity or whether they choose to utilize contraception when they do. Male attitudes and social variables, such as cowives in polygamous households, which are unknown in the West, have a significant impact on contraceptive agency. (Duze & Mohamed, 2006). When women in fistula-prone communities are pregnant, they might not have much control over whether or not they receive antenatal care or when and under what circumstances they give birth. In many countries, "normal" social connections entail that a woman's ability to procreate must always be plainly under the control of a man, typically her father before marriage and her husband afterward. Bridewealth is the term used in anthropology for money and material possessions (Evans, 1931: Goody and Tambiah 1973), in exchange for the use of her reproductive capability and the adoption of additional obligations on their part, are passed by the husband and his family to the girl's family as part of the marriage contract.

A broad strategy is needed to remove cultural restrictions on receiving care. The key to minimizing the prevalence of obstetric fistulas is intensive community education regarding obstructed labor, in addition to an effective, welcoming prenatal care system and competent, accessible emergency obstetric services. It is crucial that men recognize the essential stake they themselves have in the health of their mothers, wives, sisters, and daughters, especially in rural areas where fistulas are common. In these circumstances, men can be crucial to the smooth operation of the maternity care system. Raising public awareness of these issues can be especially successful when carefully designed programs that expand the accessibility of professional midwifery care at the local level are paired with an active, continuing social marketing and community education campaign. It may still be possible to lessen the effects of obstructed labor by training, supporting, and using local childbirth monitors who can at least ensure that the sun does not rise twice on a laboring woman without her being sent for competent evaluation and treatment, even in situations where skilled midwives cannot be placed in local communities due to logistical obstacles, a lack of financial resources, or a shortage of trained personnel.

Furthermore, women frequently separate themselves or are isolated by their families and communities because they feel unsuitable to live with the rest of their family. Women with fistulas frequently have their husbands file for divorce. Women who face social marginalization and unrecognition while dealing with a fistula (which can last anywhere from a few months to several years) report a decreased sense of self-worth. Many of these women wind up living separately and without financial support from their husbands due to their physical handicap and the stigma and misinformation surrounding the condition.

Similar results were noted by Kavai et al. (2010), who reported that cultural beliefs and traditional practices reduced the use of medical care by women with obstetric fistula. That study also discovered that most women with obstetric fistula found it difficult to seek modern treatment because of their beliefs and cultural practices.

Internalized stigma describes the patient's own emotions of guilt and low self-esteem (Ahmed & Holtz, 2007; Alio et al., 2011; Gharoro & Agholor, 2009; A. I. Islam & A. Begum, 1992; Landry et al., 2013; Siddle, Mwambingu, Malinga, & Fiander, 2013). Studies undertaken in various African settings have shown that many fistula patients feel ashamed, alone, and depressed and have lower self-esteem (Ahmed & Holtz, 2007; Alio et al., 2011; Gharoro & Agholor, 2009;

Siddle et al., 2013). Additionally, due to their fistula, women with religious affiliations may have challenges practicing their religion and negative cognitions (feelings of conflict, question, and doubt) regarding matters of God and faith (A. I. Islam & A. Begum, 1992; M. H. Watt et al., 2014). The power dynamics of gender, wherein notably in Tanzania a woman's worth is tied to her function as a mother, wife, and farmworker, are paired with these experiences of stigma (being classified as outcasts, associations with bad stereotypes, and discrimination in their daily lives). Clearly, obstetric fistula-affected women fall under the preceding category of stigmatized people (Link & Phelan, 2001).

Understanding stigma is crucial because it not only makes people put off receiving treatment but also because the psychological stress it produces exacerbates the effects of the illness (Corrigan, 2004; Keusch, Wilentz, & Kleinman, 2006; Pachankis, 2007). This stress is exacerbated in particular by conditions and impairments such as obstetric fistula and incontinence that must be actively concealed through behavioral changes. Examining externalized and internalized stigma separately is crucial to comprehending and addressing the stigma related to fistula. Due to the different psychological repercussions of having a potentially stigmatizing feature, studies on other health issues have revealed that internalized stigma may have a significantly larger impact on one's overall well-being (Scambler & Hopkins, 1986). It is crucial to have a complete awareness of the stigma associated with obstetric fistulas since it may have a significant impact on women's decision to seek treatment for one, as well as on their recovery and reintegration after surgery (Corrigan, 2004; Pachankis, 2007). Understanding how stigma is expressed and experienced by people who have obstetric fistulas can assist in guiding efforts to enhance these women's quality of life and wellbeing. Internalized stigmatization among people with fistula does not seem to be correlated with either the proportion of living children or the level of social support given to the mothers. The findings are consistent with the literature and the general population, which is initially surprising because childlessness and infertility are stigmatizing and cause psychological suffering, while social assistance, especially emotional support, should reduce anxiety (McQuillan, Greil, White, & Jacob, 2003).

According to research conducted in northern Tanzania, having children at all was more important than having many; if a woman did not have children, she was labelled "useless," shamed, and treated with disdain (Hollos & Larsen, 2008). This suggests that rather than inquiring about the number of children a woman has, the question should be reframed to inquire whether she has any children or none at all. Unfortunately, the small sample size and sample distribution indicated that this investigation was beyond the purview of this study. Similar considerations apply to social support. Although there were many instances of both tangible and emotional positive social support, given the high rates of internalized stigma in the population and experiences of anticipated stigma, there may be a smaller effect that could become more noticeable in a larger sample size. The quantity of social support itself, however, can be constrained and tainted with underlying familial tensions, negating any beneficial impacts on internalized stigma (Murphy, 1981).

3. Methodology

In this study, the research used a mixed-methods approach with both qualitative and quantitative approaches to understand the role of awareness campaigns in reducing obstetric fistula stigma in rural areas. The researcher used a qualitative approach to collect information through interviews and questionnaires where the quality data were in the form of words according to the objective of

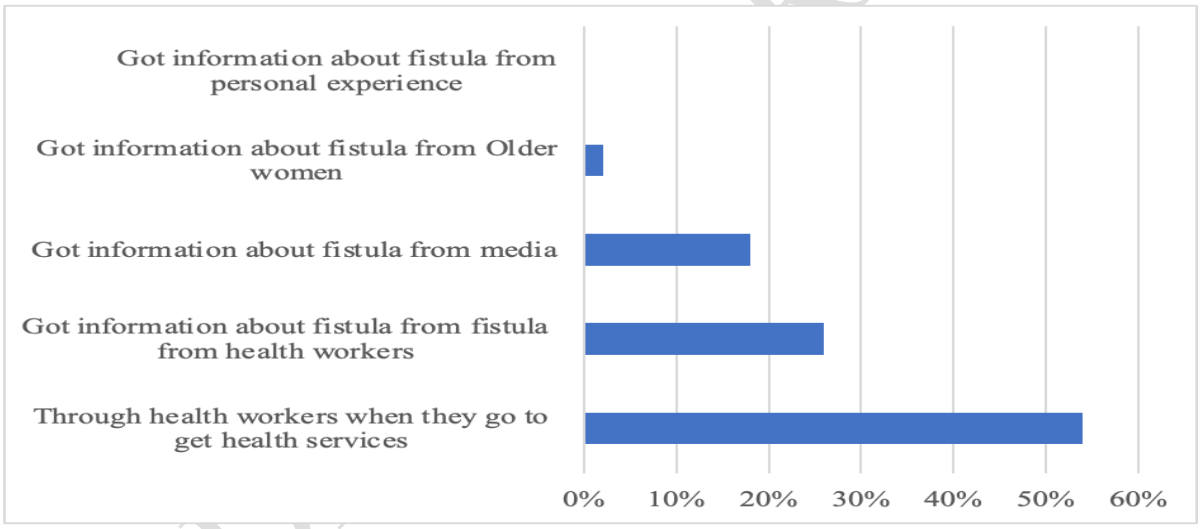
the study. Researchers have decided to use this approach because it provides a deeper understanding of the role of awareness campaigns in reducing obstetric fistula stigma in rural areas.

The study originally planned to have a sample size of 40 respondents. (Includes fistula survivors and fistula ambassadors). For fistula survivors, the respondents were selected from the database of Magu Poverty Focus on Older People Rehabilitation Centre (MAPERECE) who were treated at Bugando Hospital through support from the Fistula project in 2019-2022. The sampling technique used is simple random, where every subject of the population has an equal chance of being selected for the study, and the research decides to choose this technique because it includes the whole population without bias and allows researchers to easily collect data.

4. Findings

The study revealed that more than half (54%) of the survivors received information about fistula from others who were mentioned as fistula ambassadors, followed by 26% who were health workers, 18% who heard about fistula through media such as radio, 2% from older women and no one said about personal experience.

Figure 1: Community source of information about fistula



Through probing during the interview, one of the ex-survivors commented on the awareness of obstetric fistula.

> *"...For the first time I heard about obstetric fistula, I was at a village meeting where a man introduced himself as a fistula ambassador after being given the chance to greet the villagers. He said that fistula can happen to any women who are capable of giving birth",* ***Fistula survivor number 1***

In addition, all the female survivors who participated in the interviews were knowledgeable about fistula, but many reported becoming knowledgeable about fistula after being in contact with a provider at a health facility when attending the ANC or PNC visits.

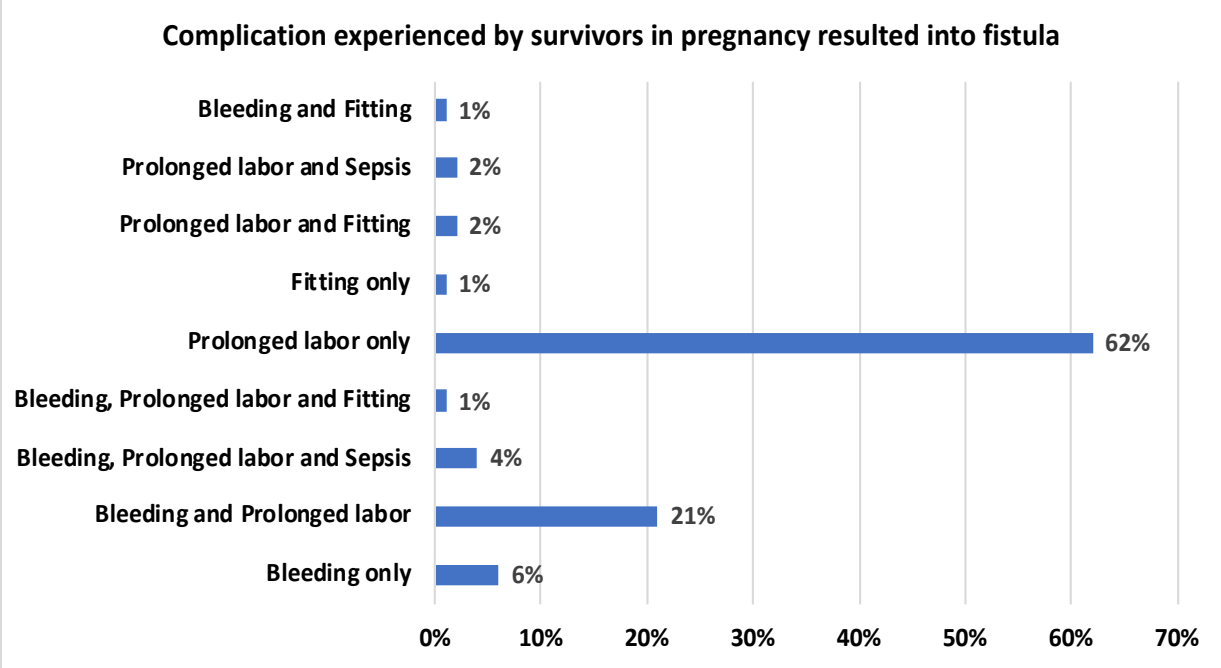
> *"...I went to the clinic I was told by health worker that that treatment is available at Bugando and CCBRT for free of charge"* ***Fistula survival number 2***

Another ex-fistula survivor had the following to comment regarding awareness of fistula and where she got information on fistula.

> *"...The doctor informed me that I have Obstetric fistula for I did not know what I had, I just thought I had tear up like the way my mother told me and she told me to sit on salt water and that will get me better."* ***Fistula survival number 7***

During the delivery period, 62% reported complications of prolonged labor, 21% reported complications of both bleeding and prolonged labor, and the rest reported complications, as shown in figure 2 below. Furthermore, 45% of survivors reported that their pregnancy resulted in a still birth, 44% resulted in an alive baby, and 10% resulted in an alive baby but died a few hours later.

Figure 2: Complication Experienced by Survivors in Pregnancy that resulted in Fistula



Source: Field Data

In addition, the survivors were asked about their experience in terms of beliefs and practices about pregnancy but mostly about the pregnancy that resulted in fistula. During the probing, one of the survivors shared her experience of losing her child because of prolonged labor as follows:

> *"...I got a fistula in 1991 after giving birth to my second child, I started to feel labor pains around noon, but I was delayed to reach the hospital because there was no transport and there was a heavy rain on that day and therefore I failed to reach the hospital. The next day, my husband managed to get a motorcycle which took me to the hospital where I was able to give birth to a child but unfortunately he had died a few hours later"* **Fistula survival number 3 from Bumeleji village**

Another ex-fistula survivor shared her experience in terms of beliefs and practices about pregnancy as follows:

> *"…When I got my second pregnancy, the midwife told me that, you should come to me on the day of delivery. When my pregnancy was nine months old, I went to that midwife. I stayed for one week, the second week I started to feel pain, the pain started at approximately 88 pm, the pain continued, but I never came close to delivery. Thus, they were forced to pull the baby out manually by using our hands, the exercise that came to conclusion at 8 am. Unfortunately, the infant died. I did not get that disease right away; I took me two weeks afterwards. The midwife told me that I was healthy and ready to go home. I came back home here, after two days at home I started to urinate nonstop"* **Fistula survival number 4**

Additionally, the study revealed that although community fistula ambassadors played a great role in awareness creation, these ambassadors did not have enough knowledge to advise the patients.

> *"…We as obstetric fistula ambassadors we just only give awareness to people, we don't have technical knowledge and equipment to test pregnant women to know the position of the baby in the womb so we just give them advice about fistula and tell them to test other diseases such as malaria and HIV. We advise pregnant women to seek medical examinations from experts who have the capability of testing and knowing the position of the baby in the womb and to know if the baby is too big. This helps to give precautions to the mother as she prepares to give birth through normal ways or through caesarian section."* **Fistula ambassador number 1**

In addition, another fistula survivor shared her experience that she went through during her pregnancy

> *"...In 1982 I got the problem of urinating nonstop shortly after giving birth and the infant never made it alive. I remember to go through pain for two consecutive days. I went to the hospital the third day, and I gave birth on the second day after arriving at the hospital. I was allowed to go back home after a short period of time, but after staying at home for two days, I started to see segments of blood coming out through the urinary system, followed by nonstop uncontrolled urinating. When my husband saw the situation, he decided to take me to Bukunge Hospital. At the hospital, we were told to go to Moshi, but my husband could not afford that, so he decided to take me back home, ever since I have not been able to receive any kind of treatment"* **Fistula survival number 5**

Furthermore, another fistula survivor commented on the accessibility of health services during her pregnancy and delivery.

> *"…When I got my second pregnancy, the midwife told me that, you should come to me on the day of delivery. When my pregnancy was nine months old, I went to*

that midwife. I stayed for one week, the second week I started to feel pain, the pain started at approximately 88 pm, the pain continued, but I never came close to delivery. Thus, they were forced to pull the baby out manually by using our hands, the exercise that came to conclusion at 8 am. Unfortunately, the infant died. I did not get that disease right away; I took me two weeks afterwards. The midwife told me that I was healthy and ready to go home. I came back home here, after two days at home I started to urinate nonstop". **Fistula survival number 6**

4.2 Barriers to Eradicate Fistula

Even if women and girls receive support from a family member or someone in their life, they often isolate themselves from the community due to feelings of shame associated with incontinence. In discussion with survivors during the questionnaire interview, the majority of survivors reported experiencing psychological distress, feelings of shame, humiliation, sadness, unworthiness and hopelessness. Survivors also reported spending most of their time in isolation and avoiding social gatherings and interactions due to discomfort of "being noticed" or "laughed at". Most of the women also reported an inability to carry out daily tasks and responsibilities such as caring for one's own children, going to the market, fetching water and farming.

Accessibility of Treatment

Obstetric fistula survivors reported mixed experiences on how they accessed treatment linked at local referral centers. Survivors reported that they had been identified and linked to service by fistula ambassadors who visited them at their home during the campaign to raise awareness about fistula within the communities.

"...I remember in one of the village meetings, fistula ambassador told us that fistula treatment is provided free of charge at Bugando Hospital and any woman who sees symptoms of urinary linkage without knowing it should come at our Kibigwa Dispensary or communicate with me via my number to determine how we can help each other to get to Bugando for treatment" **Fistula survival number 10**

4.3 Medium/Media Used to Intervention Obstetric Fistula Among Communities in Misungwi.

The study went further to understand where communities obtain information on health, particularly fistula. The findings revealed that the majority (65%) indicated health workers when they went to get health services, 25% said through community health workers, and the rest obtained information through media, which was radio.

The researcher revealed that radio shows and IEC material were used by fistula ambassadors within their local communities. One of the ambassadors from Busongo Misungwi said the following.

"...MAPERECE use of radio to sensitize the community on the causes of fistula, with the aim to dispel myths, and on the availability of fistula repair services. For example, there were talk shows in Sibuka FM, featuring fistula survivors and ambassadors in the lead creating awareness of fistula and the importance of women accessing fistula repair. Additionally, during the seminar which we attended as we were given IEC materials written in simple language and pictures focusing on fistula for the aim of informing communities on fistula" **Fistula Ambassador number 4**

The discussion with one of the fistula survivors revealed that communal public meetings and religious meetings at local mosques and churches were used as a way to intervene in obstetric fistula among communities in Misungwi.

> *"…Our pastor in his local church in here in Misungwi whose wife had once been a fistula survivor always encourages couples to support each other, and men should not divorce their wives and leave them with children because of fistula which is treatable"* **Fistula survival number 5**

To cement religious meetings as a way to intervene in obstetric fistula, one of the husbands of a fistula survivor commented as follows:

> *"...I am a street preacher and use his platform to talk about fistula. I share my testimony with people: this is not just a thing that you hear about on the radio; it's truly happening to some people. It has happened to my house. I give a positive testimony: at least it can be cured. I advocate for people to get out and reach out for medical services."* **Fistula husband**

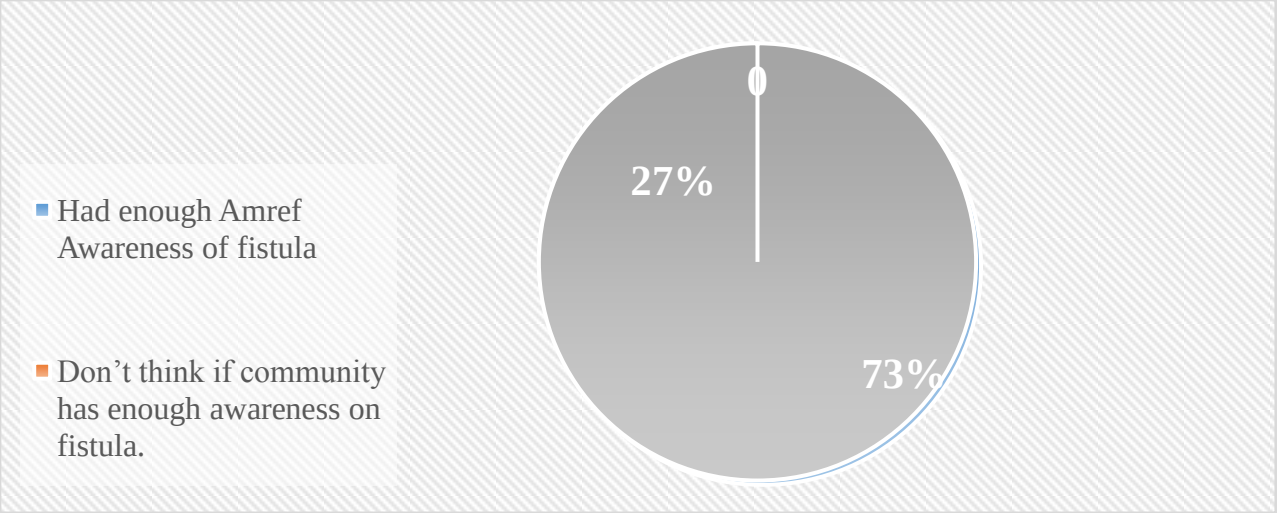
Without being left behind, traditional healers and traditional birth attendants were also used as medium interventions for obstetric fistula among communities through awareness creation on how fistula is caused by lack of access to good healthcare during complications and is not a result of witchcraft. One of the traditional healers from Idetemya who was trained by MAPERECE and Amref on fistula issues had the following to comment:

> *"…Most of the patients we got did not believe that obstetric fistula can happen to them and so we took advantage of that and made it a source of income. For example, when we were dealing with them, we asked for cows while knowing they would not heal, but today people do not give out their cows, we thought this problem is caused by bewitching but after getting educated we now know that it is not"* **Traditional Healers.**

4.4 Effectiveness of the Amref Obstetric Fistula Awareness Campaign

To explore more, the study asked fistula survivors how they think that the community has enough awareness raised by Amref on fistula. The study revealed that 73% of the survivors witnessed that the community around them had enough Amref awareness of fistula, while 27% did not think if the community had enough awareness of fistula. (Figure 3).

Figure 3: How the community thinks that they had enough awareness raised by Amref on fistula.



Through the fistula awareness campaign, household visits for counselling fistula survivors and their families became possible. Through interviews with the ambassador, the following were commented on regarding the effectiveness of Amref's awareness of fistula:

> *"...In general, our work has been to provide education at health centers, we visit families and in the end we bring up those suffering from obstetric fistula. When we discovered the presence of obstetric fistula patients, we gave them a green light to the Bugando referral hospital. Since 2019 up to now I managed to visit more than 100 houses in the Gulumungu ward for counselling women and their families. I also managed to refer 5 fistula survivors who were treated at Bugando Hospital, and now they have recovered and are doing well"* **Fistula Ambassador Number 6.**

Fistula survivors often face social stigma and suffer from low self-esteem. The Amref fistula awareness campaign revealed that the majority of fistula survivors who were hiding before have been open and are now coming out to explain their situation and seek treatment.

> *"I have lived with fistula for 34 years since I was 19 years, and it happened after giving birth to my second child in 1987. I did not know that it was a fistula until 2019 when I attended a village meeting and the fistula ambassador shared stories and testimony about the fistula and that is when I knew that the fistula was cured. He added that if we know any woman who suffers from fistula, let him know. After the meeting I went to the ambassador and told him that I also have a fistula and he assisted and escorted me to Bugando for treatment"* **Fistula survival number 15**

Through the Amref obstetric fistula awareness campaign, fistula repair surgery became possible for women and girls from low-income families.

> *"...My husband was disappointed because we were told at Bunda Mission Hospital that repair expenses are approximately 1,500,00/=TZS, which we couldn't afford to pay. Through the support of Amref, we managed to get free treatment at the Bugando Hospital free of charge, and now I am doing well."* **Fistula survival number 15**

Through the fistula campaign, the study revealed that women who have received fistula treatment also receive seed money/capital, with the aim of regaining/obtaining their financial independence and promoting their overall well-being. To cement this, the following were commented on as follows:

"…my family was very happy. One the day when they came to give me some money at home, my mother-in-law commented, 'you treated her [repaired OF] without any costs on us, an illness we did not even think was possible to cure! You are still following her progress at home and even supporting her to engaged in a business…I have no words…I cannot express my gratitude enough… May God continue to be with you and bless you all that are involved…and may this project continue because I have certainly seen its benefits…" **Fistula survival number 8**

Based on the study, community-based fistula ambassadors who have been visiting survivors at their homes to raise awareness of the condition were crucial in connecting survivors to care.

5 Discussion.

In this study, the findings revealed that fistula survivors were knowledgeable about fistula, but many reported becoming knowledgeable about fistula after being in contact with a provider at a fistula ambassador through home visits or health facilities when attending ANC or PNC visits and others who learned about fistula through media. Most communities were aware of symptoms related to fistula, and the work of linking identified fistula cases by ambassadors was one of the greatest achievements in this project. Different perceptions emerged from the study regarding the perception of people to fistula survivors. The findings revealed that women with obstetric fistula were laughed at, disrespected and discriminated against by their community and were not allowed to be mixed with other people because of their smell. In some cases, these women were isolated and made to eat alone. It was obvious that stigma is still prevalent in communities and for fistula patients to self-isolate themselves. Community sensitization through fistula ambassadors, mass media and health facilities was a main source of information for the majority of the participants in this study, although the issue of free services is not well documented, and it will continue after phasing out the project.

The study reveals that many individuals had little knowledge of the disorder, its causes, or its prevention and held many false beliefs. The main causes of obstetric fistula include prolonged obstructed labor and the lack of competent obstetric emergency care. Because of this, many members of the community were aware of some of the risk factors for obstetric fistula but were either ignorant of the process by which fistula occurs or had misconceptions about the reason.

The participants, especially in cases where there were obstetric problems, correctly linked obstetric fistula to a woman in labor delaying seeking early medical assistance. Obstetric fistula may not be well known, but even if it is, this may be because many communities do not want to acknowledge the prevalence of the problem there. Many people in rural areas may claim ignorance of the disease because of the stigma attached to it.

The community was also aware of a number of ailments that, while they might not always be causes or predisposing factors for obstetric fistula, are risk factors for the condition. Predisposing factors for obstetric fistula include early marriage, induced abortions, employment of traditional birth attendants, rape, domestic violence, and caesarean sections (operations). A significant contributing factor to fistula is widespread poverty (Pope et al. 2011). Similarly, obstetric fistula victims frequently come from underprivileged backgrounds, are undernourished, lack basic education, and reside in isolated or rural locations (Pope et al. 2011). The fact that the community blamed careless or inexperienced medical professionals for the fistula may have a negative impact on how expecting mothers in labor, especially those who had challenging deliveries, behave when seeking obstetric treatment. Similar findings have been reported in a

study conducted in Tanzania (Mselle et al., 2013). According to the study's findings, (real or imagined) poor birthing experiences could damage the reputation of the healthcare system, lower community expectations of facility births, and ultimately decrease the number of births that take place in such facilities. These mothers may believe that anyone undergoing emergency surgery, such as a caesarean section, has a high likelihood of developing the illness. This would be terrible since, rather than a procedure to ease the problems, the failure or delay in addressing the complications after childbirth is to blame.

Although they were aware of the risk factors for obstetric fistula, many members of the community believed that the condition was caused by curses, cultural spirits (who believed it was a curse from the gods), sexually transmitted diseases, having sex during menstruation, and improper use of family planning methods. These false beliefs concerning the cause of obstetric fistula are widespread in rural areas. According to a study by Kazaura et al. (2011), obstetric fistula was linked to missing family planning pills for a few days. Similarly, obstetric fistula has been linked to cultural spirits and having sex while pregnant.

Spiritual causes were listed as one of the considered risk factors for obstetric fistula in a 2003 study on perceived causes of obstetric fistula in Nigeria by Femi and Ada. Women are typically compelled to use traditional birth attendants because of certain cultural beliefs about childbirth, social stigma associated with having a caesarean section delivery, preference for giving birth with them, and perception of unpleasant and abusive experiences during delivery (perceived to be common in many medical centres) (Femi and Ada, 2003). The choice to avoid health centers or hospitals may be so strong in some women that the mother will merely seek out another traditional birth attendant, even though health workers may direct such women to hospitals if they recognize or foresee issues. The risk of obstetric fistula is increased in this way.

From the results, the study found that awareness of the community regarding fistula was raised through fistula ambassadors who play an active role in raising awareness about fistula, where to access repair surgeries, and dispelling myths and misconceptions about the condition in village meetings and home visits. Health workers during ANC/PNC visits and media such as local radio to reach the community and tackle stigma associated with fistula.

Discrimination and disrespect were raised as attitudes of the community towards fistula survivors. Several barriers that hinder the eradication of fistula have emerged, such as psychological distress, feelings of shame, humiliation, sadness, unworthiness and hopelessness. Survivors also reported spending most of their time in isolation and avoiding social gatherings and interactions due to discomfort of “being noticed” or “laughed at”. Most of the women also reported an inability to carry out daily tasks and responsibilities such as caring for one’s own children, going to the market, fetching water and farming.

6 Conclusion and recommendations

The study noted that fistula ambassadors who have been visiting the survivors at their home have raised awareness about fistula within the communities were the ones who played the big role in linking survivors with treatment. Findings from this study added new knowledge to the body of evidence that could be used as a guide for both government and development partners such as Amref to design intervention programs for the improvement and enhancement of access to

quality obstetric services. Additionally, the results from this research exert a meaningful impact on public health practice in that area, improve access to quality fistula service care, and could be a foundation for future research on obstetric fistula.

Stigma is still a major challenge in society, so education is still very important so that communities can help survivors cope with the challenges of illness and provide psychological support. Stigma can have detrimental and severe effects. The lack of knowledge of others that comes with stigma can be hurtful and invalidating, but it also has more significant repercussions, such as fostering hatred, fear, and intolerance toward other people. Organizations should plan and carry out awareness campaigns in collaboration with respected community members, including local decision-makers, religious leaders, traditional healers, midwives, and other professionals in the health care industry, to have a positive impact on the obstetric fistula program.

Moreover, Amref should identify organizations and groups in the community already engaged in the work they want to do. Learn about the work they already do that may benefit the campaign, and consider their standing in the neighbourhood to determine whether they can make a beneficial contribution. In addition, more campaigns from stakeholders and government regarding that treatment of fistula is only at the hospital and not by traditional healers and pastors. Fistula education should be provided at all levels ranging from family to community to nation as a whole. Traditional healers and religious leaders should be given education on fistula if they are sent to the patients to direct them to the hospital for further investigation and treatment.

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