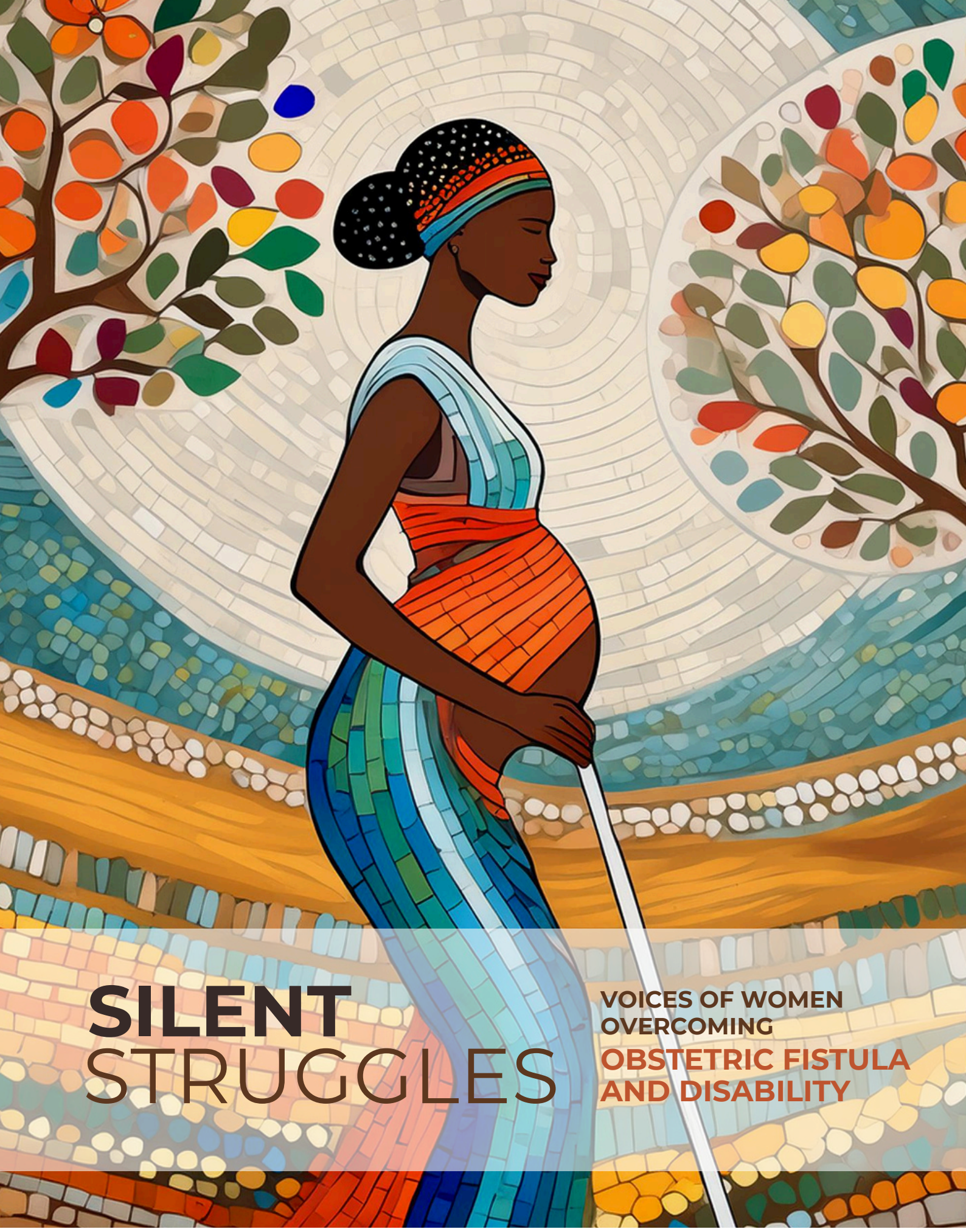

SILENT STRUGGLES

VOICES OF WOMEN OVERCOMING OBSTETRIC FISTULA AND DISABILITY

The impact on quality of life
among obstetric fistula survivors

UNFPA

FOREWORD

CLOSING THE GAP

Obstetric fistula remains one of the most severe and heartbreaking medical conditions impacting women, primarily due to childbirth complications. This condition continues to affect approximately 500,000 women globally, especially in Africa, undermining their health, dignity, and potential.

The eradication of obstetric fistula is vital for achieving the Sustainable Development Goals (SDGs) and integral to fulfilling the goals set by the International Conference on Population and Development (ICPD) Program of Action. Ensuring universal healthcare access and upholding sexual and reproductive health and rights are essential to protect women and girls, particularly young women with disabilities, who are at risk of or are suffering from obstetric fistula. These women and girls should not be left behind and overlooked in the sustainable development efforts.

To ensure that there is full inclusion in our global goals, regional aspirations and transformative results, the UNFPA East and Southern Africa Regional Office (ESARO) has released a discussion paper. This document underscores the consequences of obstetric fistula and recounts the experiences of affected women, including those who had disabilities before developing the condition. The brief reviews the current status of obstetric fistula in the region, proposes targeted actions and recommendations for various stakeholders, and aims to deepen understanding of the connection between obstetric fistula and disability by 2030.

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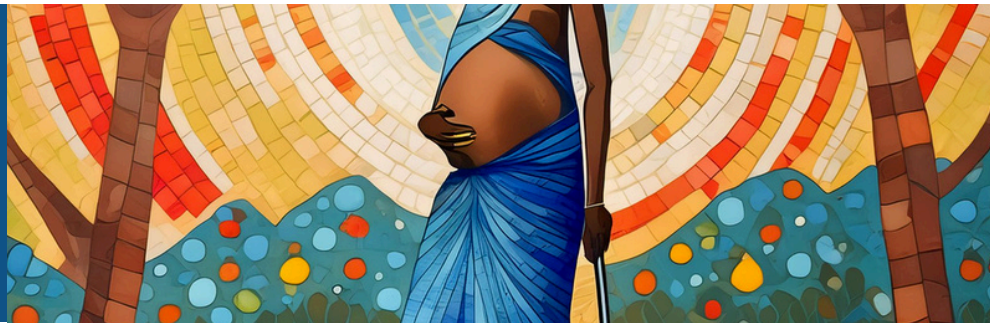

OUR THANKS

The UNFPA East and Southern Africa Regional Office would like to thank the fistula survivors who shared their stories. Their stories highlight their journey with obstetric fistula, the impact on their lives, and the struggle that they go through to get the help they need. Many brave women continue to suffer from this preventable condition that impacts their health, well-being and way of life. This document is dedicated to them and focuses to shine a light on their stories, lives, hopes, and dreams while living with obstetric fistula.

Produced by the Regional Office under the leadership of Deputy Regional Director Chinwe Ogbonna. Conceptualized by Maria Bakaroudis, Comprehensive Sexuality Education Specialist and Disability Focal Point, Jyoti Shankar Tewari, Health Systems Strengthening Advisor. Coordinated by Yousuf Alrawi, Sexual and Reproductive Health Programme Officer and led by Muna Abdullah, Health System Specialist.

We recognize the important role of the UNFPA colleagues from the headquarters in reviewing and providing technical input and UNFPA Country Offices in the region that provided guidance and support. With special thanks to Bridget Asiamah, Obstetric Fistula Coordinator, Campaign to End Fistula, and Daisy Leoncio, UNFPA Regional Communications Adviser.

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BACKGROUND

Obstetric fistula is one of the most devastating medical conditions affecting women as a result of complications arising from a lack of timely and effective interventions for prolonged and obstructed labour.

Obstetric fistula is an abnormal opening between the vagina and bladder and/or rectum through which the urine and foeces continually leak. An estimated 500,000 women around the world are living with the condition. According to a study in the Lancet from 2015, it is estimated that more than 350,000 women are living with obstetric fistula in 19 high-burden countries in sub-Saharan Africa (SSA) with 33,000 new cases occurring every year (an average of 3 per 1,000 births). Most women suffering from the condition can be effectively treated through surgical repairs with a success rate that can reach as high as 95 per cent.

Women with obstetric fistula face many barriers in their lives. They mostly reside in rural areas with bad or no roads, and many live in conflict areas. The majority of women with the injury live in cultural contexts that makes them suffer silently. Obstetric fistula cases are higher in women and girls who experience early marriage and childbearing. Women with fistula tend to be poor, isolated and have little or no education. Other factors significantly contribute to this issue.

Women and girls who have experienced sexual violence, female genital mutilation, and other harmful traditional practices face an elevated risk of developing obstetric fistula during childbirth. Additionally, gender-based violence (GBV) can act as a deterrent for women seeking essential medical care during labour and delivery. Consequently, numerous women and girls encounter difficulties in accessing critical sexual and reproductive health (SRH) information and services, especially high-quality emergency obstetrics care during labour and childbirth. This lack of access places them at an elevated risk of maternal mortality, infant mortality and the development of complications, including obstetric fistula.

Awareness of obstetric fistula remains alarmingly low, as multiple surveys suggest that merely half of women have been informed about this condition. A dearth of information and knowledge persists regarding the causes, its reparable nature and the available facilities for its repair. Additionally, misconceptions surrounding its curability and causative factors abound. Furthermore, economic and social constraints, coupled with feelings of embarrassment, pose substantial barriers to women accessing services, with younger women being particularly affected.

The COVID-19 pandemic has had a detrimental impact on the management of obstetric fistula. Women encountered significant challenges in obtaining timely emergency obstetric care during lockdowns, exacerbated by the reallocation of resources to address other pandemic-related priorities. A study conducted in Zimbabwe highlights the adverse consequences, revealing a stark decrease in the number of women receiving fistula repair surgery in 2020. This decline was attributable to the rescheduling or cancellation of many surgeries, with numerous fistula survivors unable to access hospital care due to pandemic-related restrictions.

Putting an end to obstetric fistula is of importance in the pursuit of Sustainable Development Goals (SDGs) and aligns closely with the core principles outlined in the International Conference on Population and Development (ICPD) Programme of Action. The attainment of universal access to sexual and reproductive health and rights (SRHR) is a critical element in guaranteeing that women and girls facing the threat of obstetric fistula, or already experiencing it, are not marginalized. Extensive research conducted across various African countries underscores the compelling efficacy of fistula repair surgery, comprehensive care, rehabilitation, and reintegration programmes in significantly reducing the enduring burden of disability throughout a woman's lifetime.

OBJECTIVES

The objective of this document is to explore the impact on the quality of life among women living or who have experienced this debilitating condition. In particular, this paper explores the disability aspect of the condition and its effects on physical, mental, social, and economic well-being, and outlines the link between pre-existing disabilities and obstetric fistula.

METHODS

The Regional Office conducted a scoping review of the literature to explore the bi-directional link between obstetric fistula and disability. A variety of terms were used that reflected the topic to search in repositories such as PubMed, Google Scholar, ScienceDirect, and others.

Furthermore, selected UNFPA Country Offices (Kenya, Ethiopia, Mozambique, Uganda, and Malawi) conducted interviews with survivors for human-centred stories to shed light on the impact of the condition on their lives. The timeline of the study is from July to December 2022.

RESULTS

The physical impairment and the social exclusion experienced by women living with obstetric fistula have an impact on their quality of life. The disability-adjusted life years evaluation of the health burden associated with it shows that the years of life lost due to disability is significant considering that the majority of women affected by the condition are still early in their reproductive phase of life.

A study conducted by the International Federation of Gynecology and Obstetrics (FIGO) utilizing the World Health Organization (WHO) Disability Assessment recognized women with the condition are living with a high disability that affects their cognition, mobility, self-care, life activities, and participation.

Obstetric fistula is a major equity issue both in the way it affects vulnerable women and how it reduces their quality of life.

Women enduring obstetric fistula struggle with the ongoing and repercussions of the condition. This medical issue inflicts debilitating physical consequences, encompassing urinary and fecal incontinence, manifesting as a loss of control over bladder and bowel movements. Additionally, it results in genital sores, malodorous wounds, persistent pain, discomfort, and even complications like foot drop, which impairs the ability to lift the front part of the foot, urinary tract infections, nerve damage, kidney stones, and infertility.

Moreover, obstetric fistula exerts substantial adverse effects on women's social, family and sexual relationships. Survivors of this condition find themselves at an elevated risk of experiencing GBV from partners who may perceive them as unable to fulfil their expected roles within the relationship. This distressing reality is compounded by the stigma, discrimination and rejection, often worsened by the lack of support from both their families and communities. For married women affected by fistula, the anguish deepens as they confront divorce, primarily attributed to their perceived inability to satisfy their husband's sexual needs and, in some cases, to bear children.

Even more, women living with obstetric fistula develop depression, anxiety and post-traumatic stress disorder or make suicide attempts. They experience a loss of hope, fear of future life, low self-esteem and feelings of dependency. On the economic side, women living with obstetric fistula face significant challenges in undertaking economic activities due to ill health, stigma, depression, divorce/separation, and social isolation, which lead to a loss of source of income and increased dependency.

Additionally, women who have pre-existing disabilities, especially those related to mobility, pelvic outlet abnormalities and cognition face more difficulties and stigma in accessing quality and tailored SRHR information and services, including during labour and delivery, which puts them at a higher risk of having poorer health outcomes, including developing obstetric fistula.

TIRUMAED'S STORY *Ethiopia*

Tirumaed is a resident of the Desta Mender (Joy Village) in Ethiopia. She was disabled in one of her legs from a very early age which limited her movement and prevented her from reaching the health facility and led to her being eight days in labour. Her family took her to a small clinic in the district on the fifth day, but they were told that her condition was beyond the clinic's capacity and were told to take her to Bahir Dar, the capital of the Amhara Region, for treatment and care.

The family feared that she might die along the way, so they brought her back home and after eight days of labour, the pregnancy ended up in stillbirth. She developed obstetric fistula at just 17 years old.

After developing the condition, both legs became affected among other physical complications. She had to be helped by her family members as she could hardly make any movement without support, and she went to stay with her parents as she was deserted by her partner. Further, Tirumaed faced stigma and difficulties in engaging in her community and work. She lived with this debilitating condition for 10 months.

She received obstetric fistula repair at Addis Ababa Fistula Hospital and rehabilitation through a centre for fistula survivors set up by Hamlin Fistula Ethiopia and supported by UNFPA on the outskirts of Addis Ababa.

After the obstetric fistula surgery, she was able to get physiotherapy for one year. Today, she is more equipped to take care of herself better.

"Things have changed a lot for the better for me, thank God," says Tirumaed. After she came to Desta Mender, she got the chance to be trained in handicrafts such as knitting, sewing and embroidery. She also started school and reached the 7th grade. Currently, Tirumaed is back to work as a cashier for the café.

An estimated 36,000 to 39,000 women live with this terrible morbidity in Ethiopia, and between 3,300 and 3,750 new obstetric fistula cases occur in the country every year according to the National Strategic Plan for Elimination of Obstetric Fistula (2021-2025). Since 2010, UNFPA has been partnering with the Ministry of Health and other partners to train integrated Emergency Obstetric Officers and midwives through supporting the Integrated Emergency Surgery and Obstetrics and Accelerated Midwifery Training Programmes.

UNFPA has been also supporting the fistula centres at Arsi, Gondar and Jimma and partnering with Hamlin Fistula Ethiopia to repair and treat women. As part of the scale-up of the programme, support has also been provided for the social reintegration of treated fistula patients in Addis Ababa and three regions.

RACHEL'S STORY

Malawi

Rachel Kachepatsonga always knew that she was born different. As she grew up, she started to notice other people looking at her. Because of her small stature, her peers at school would stare at her with inquisitive eyes. Often self-conscious, she didn't go far with her primary school by dropping out of her classes.

She got into a relationship, but her boyfriend was ridiculed for dating her, and he decided to end the relationship. She knew that her disability would be a stumbling block in her love life, and she decided to stay single.

Later, Rachel met a man whom she thought genuinely cared about her. Despite her disabilities, she didn't have problems getting pregnant and had her first baby in 2017. However, she had to go for specialized services because of her disabilities.

"When I was attending the antenatal clinic at our local health centre, the health staff noticed my disabilities, and they advised me that for childbirth, I should go to the main hospital for delivery," she added. "They explained to me that because of my disabilities and my height, I needed special services, which they didn't offer at the health centre."

After having given birth to her firstborn, she noticed how difficult it was for her to give birth as she needed special services and decided to use family planning. However, the nearest hospital that offers those services is about 60 kilometres and the roads are heavily eroded, with ravines and ditches along the way.

A year after giving birth, she got pregnant again. But this time, she didn't receive enough support from her husband and family and couldn't go to the health facility for antenatal care.

During delivery, she arrived at Dowa District Hospital and the health staff told her that she was late as the child was already on its way. Worse still, the child was coming out with legs first (breech). Since this wasn't going to be a normal delivery and she was referred to Kamuzu Central Hospital in Lilongwe. After a difficult delivery, she was discharged. Back home, she started having pain in her stomach and she couldn't even go to the toilet for a week.

RACHEL'S STORY

Malawi

"One day, I had this urge to urinate. I went to the toilet and urine just poured from my private parts and I knew that something was wrong," she said. "The next day, I went to the hospital and they told me that I had fistula."

The news was devastating and she started seeking advice. Fortunately, her friend calmed her down, assuring her that the obstetric fistula can be repaired. This was the time the COVID-19 pandemic was at its peak, and she had to live for a year and six months with the condition while waiting for help. "It was a painful period for me, I couldn't associate with my neighbours. Sometimes I would try to visit friends, but they would run away saying I was smelling."

In September 2021, she was referred to Bwaila Fistula Centre in Lilongwe and she got repaired for the fistula. UNFPA supports Rachel and other fistula survivors with a solar kit that consists of a phone charging system and a barbershop kit for income generation.

Obstetric fistula remains a major health problem in the country with the latest national Demographic and Health Survey (DHS) showing that obstetric fistula is estimated to be six for every 1,000 deliveries.

Over the years, UNFPA has worked with the government and local non-government organizations to strengthen the obstetric fistula programme with the main focus of providing surgical interventions by treating women and providing capacity building of medical personnel to perform repairs. UNFPA has supported the development of a national strategy to end obstetric fistula under the leadership of the Ministry of Health. To date, UNFPA has supported the repair of over 2,500 women who presented with obstetric fistula.

VOICE OF KENTE

Uganda

Kente got pregnant at 17 years and had a complicated delivery that resulted in vesicovaginal fistula, rectovaginal fistula and bilateral foot drop.

This was Kente's first pregnancy experience. She felt labour pains while at home. After two days of being in labour, she was taken to a nearby government health facility to seek medical care. The midwife notified her and the relatives that there was no labour progress and she needed to go to a higher-level facility for better management. The health facility team organized transport to Mbarara Regional Referral Hospital, which was about 50 kilometres away, for further management.

When she got to the referral hospital, the doctor could not hear the baby's heart and the birth canal was obstructed - a devastating news for Kente. She was in physical and emotional pain because of the loss of her baby.

The next day she couldn't walk because of the pain she felt in her legs. Kente stayed to recover in the hospital and the bed was always wet, even with the tube or catheter in place. She also realized that feces were coming out uncontrollably. She developed weakness in both her legs, which caused her to lose her self-esteem and she had to go back to her parents for better care and couldn't stay with her husband.

A few months later, Kente had two operations to repair the two fistulae and received psychosocial support. However, the leakage of urine has persisted.

An estimated 100,000 women live with obstetric fistula in Uganda with about 1,900 new cases per year. Only 1,500 fistula repairs are done per year as per the Uganda Department of Health Services in 2016. UNFPA has supported the Government of Uganda through the Ministry of Health in fistula programming in prevention, treatment and rehabilitation.

In the country, UNFPA supports the Fistula Technical Working Group as the main coordination platform for all stakeholders on fistula prevention, treatment and reintegration. UNFPA also co-chairs the committee of national safe motherhood experts that ensures safe birth and prevents obstructed labour in Uganda.

UNFPA works closely with the Ministry of Health in implementing the national strategy to end obstetric fistula. In addition, UNFPA supports fistula repair camps across the country with about 1,500 operations annually. This is done through support to camp-based and routine repair centres, and the supply of equipment, commodities and supplies for fistula.

MAURIDIA

Mozambique

At the age of 22, Mauridia embodies resilience in the face of adversity. Born with a disability that hindered her mobility, she lived her life as best as she can.

Mauridia grew up in Landinho community of Mozambique, an environment where early pregnancy is customary. At the age of 15, she found herself expecting, which made her worried as access to essential healthcare services was difficult. The distance to the nearest health unit was an issue, depriving Mauridia of vital antenatal care and skilled birth attendance.

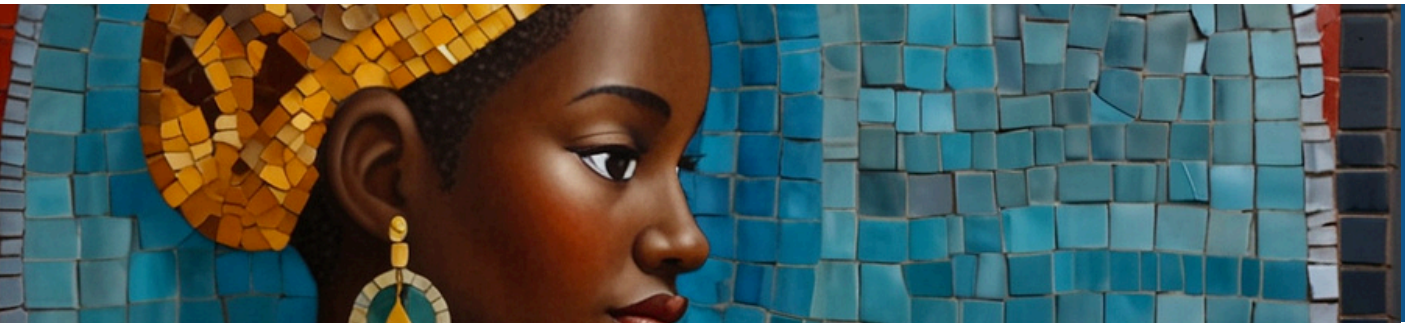
Her pre-existing disability complicated her pregnancy, and she developed obstetric fistula, a condition compounded by discrimination and rejection from the community and family. The community activists provided solace and guidance, directing her towards a nearby obstetric fistula centre for treatment and support.

Following successful medical intervention, Mauridia began her new life. Empowered by her newfound health, she seized opportunities to rebuild her life starting with entrepreneurship, and established her own business. Additionally, she restarted going to school .

In the serendipity of life's twists and turns, Mauridia found love and companionship. Welcoming a new chapter with her partner, Mauridia approached her second pregnancy with cautious optimism. Supported by regular medical care and access to healthcare facilities, she experienced a safe delivery, a contrast to her previous ordeal.

Mauridia's story transcends mere survival and through resilience, determination, and community support, including UNFPA, Mauridia is living out her potential.

RECOMMENDATIONS



WAY FORWARD

Every year, 33,000 obstetric fistula cases occur in Africa. Currently, many women are living with the condition in East and Southern Africa, and some countries in the region are using the DHS to estimate the prevalence. According to the DHS, obstetric fistula prevalence ranges from 0.2 per cent in Kenya to 1.5 per cent in Comoros.

In 2003, UNFPA and its partners launched the global Campaign to End Fistula, now active in more than 55 countries. This campaign works to prevent and treat fistula and to rehabilitate fistula survivors. Access to obstetric fistula surgery has improved in SSA,; however, numerous women continue to face physical and psychological challenges post-fistula repair in resuming prior roles or adjusting to new circumstances. Fistula programmes should be holistic, addressing prevention (effective obstetric care) while ensuring a continuum of care for obstetric fistula survivors, including repair, psychological support and social rehabilitation and reintegration. They must also take into account changing trends in incidence and prevalence
and other factors, such as social determinants to help uncover the underlying inequalities that drive obstetric fistula.

Studies across countries in Africa show that obstetric fistula repair surgery, care and rehabilitation, and reintegration are cost-effective and yield significant results in reducing the lifetime disability burden.

By the end of 2023, UNFPA, as the leader of the global campaign, has directly supported more than 140,000 surgical repairs for women and girls, and partner agencies have supported thousands more. These treatments help to restore survivors' health and hope, empowering them to reclaim their lives and dignity.

Thousands of women and girls have also received reintegration services, including psychological support, skills training and small grants to start businesses. UNFPA has also supported the training of thousands of health workers, including surgeons, midwives, nurses and community health workers. These health professionals all play a role in treating obstetric fistula, preventing its occurrence, identifying survivors and referring them to care.

Achieving universal access to SRHR is key to ensuring that women and girls who are at risk of or suffer from fistula are not left behind in the drive to achieve the SDGs. This includes access to emergency and obstetrics care and obstetric fistula care as part of the essential package of health services without increasing their financial burden. Fistula survivors will need specialized follow-up during subsequent pregnancies.

In East and Southern Africa, the Regional Programme Action Plan 2022-2025 focuses on reaching the most vulnerable populations first in SRHR initiatives. Obstetric fistula has a particularly severe impact on women living in poverty, often leaving their voices unheard. To address this challenge, UNFPA, through its regional and country offices, has been working on to ensure access to obstetric fistula services, encompassing treatment, rehabilitation, and income-generating initiatives. This multifaceted approach includes providing programmatic and policy support, technical expertise, capacity-building for health-care professionals, and financial support. Furthermore, within the region, UNFPA is actively engaged in obstetric fistula prevention by bolstering the field of midwifery and ensuring wider access to emergency obstetric care. These efforts are integral components of a broader initiative aimed at advancing sexual and reproductive health services and rights.

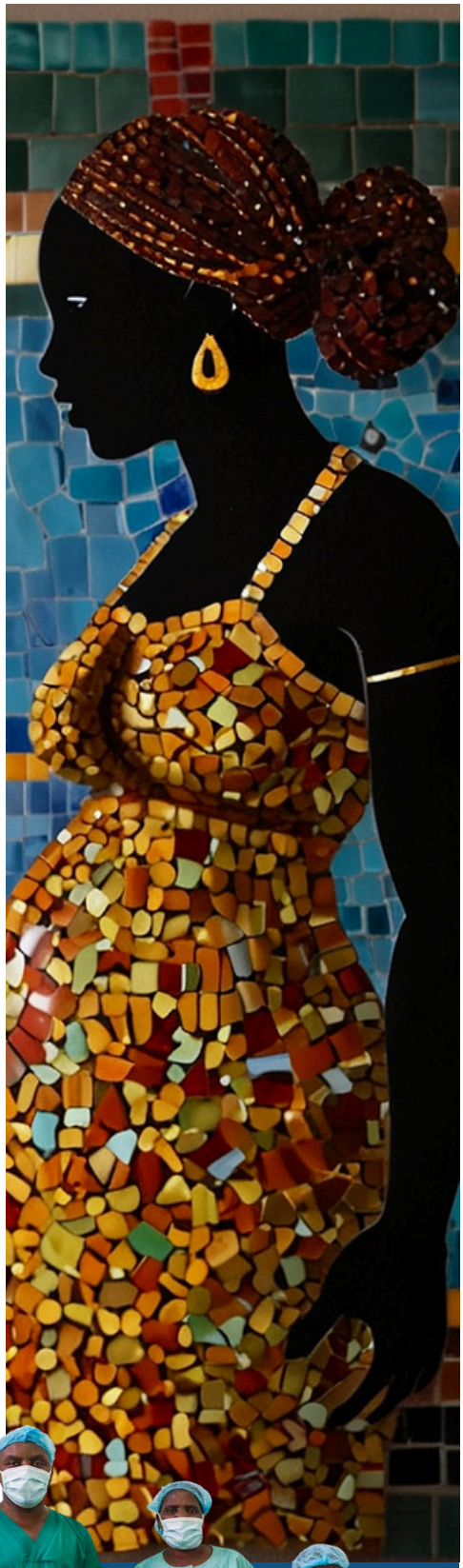
Women living with disabilities are at a higher risk of obstetric fistula. It is important to ensure that women living with pre-existing disabilities have access to quality SRHR information and services, including emergency obstetric care tailored to their needs to prevent the occurrence of obstetric fistula and other complications during pregnancy and delivery. This can be achieved through improving the readiness and functionality of the health systems and empowering health workers to provide accessible, acceptable and quality services to women living with disability and OF.

Obstetric fistula can largely be avoided by delaying the age of the first pregnancy, by the cessation of harmful traditional practices such as child marriage and female genital mutilation, and by timely access to quality obstetric care, especially cesarean section. Issues such as child marriage, female genital mutilation, early unintended pregnancies (including those resulting from gender-based violence) and unmet needs for sexual and reproductive health services including contraception need to be addressed with a disability inclusion lens.

Furthermore, social and cultural practices hinder access to SRHR, including comprehensive sexuality education. Additionally, positioning reintegration and rehabilitation of fistula survivors as part of the holistic approach of fistula programming will include addressing the social and psychological needs of fistula survivors, while also incorporating skills-building, financial support and income generation activities. This will help fistula survivors to resume mobility, increase their social participation, improve self-esteem, reduce stigma, resume work, meet their own needs and the needs of dependents, as well as fulfill their social and economic role in the community.

URGENT EFFORTS

- **Governance and leadership** to develop disability-inclusive obstetric fistula elimination plans, allocating resources for proven intervention, treatment and rehabilitation including the provision of financial risk protection by engaging different stakeholders, including civil society, and community-based organizations, organizations for persons with disability and the private sector in planning and implementation.
- **Readiness and functionality of health systems** to provide emergency obstetric services and tailored sexual reproductive health services for women with disabilities and investing in prevention by strengthening quality pre- and in-service midwifery education, context-specific task-shifting, respectful care and users' experience of care.
- **Fistula programmes and skills of the providers** to recognize the impact of obstetric fistula on the quality of life and the needs beyond surgical repairs and the health system. This includes psychosocial support, social rehabilitation and economic empowerment.
- **Health professionals' skills and attitudes** to provide people-centred, human rights-based, holistic care and recognize the needs of women living with obstetric fistula and/or disabilities.
- **Advocacy and awareness of obstetric fistula** by highlighting the devastating impact of the condition on women and families by ensuring engagement with governments, decision-makers, influencers and communities to raise awareness and intensify actions towards ending it with the Universal Health Coverage momentum.
- **Research, data and innovation** on the bi-directional link between obstetric fistula and disability and harness and leverage innovations, digital technologies, and predictive tools that can transform the way health systems work better for all.



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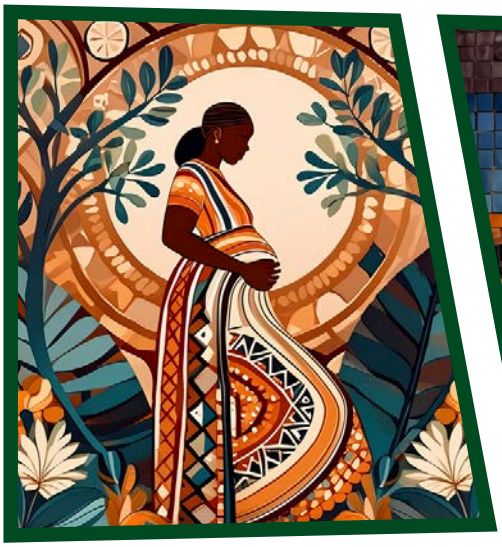




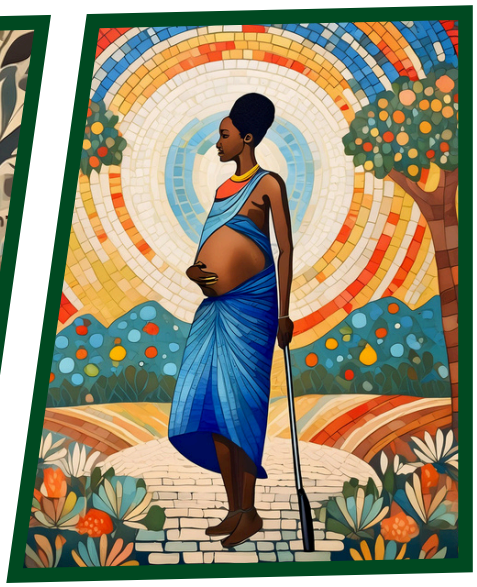

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