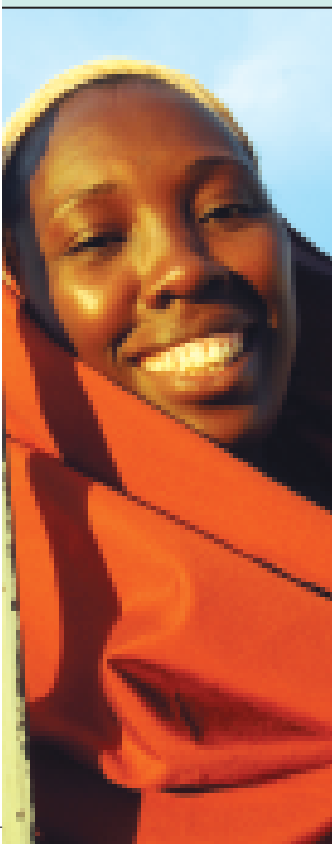


RISK AND RESILIENCE: OBSTETRIC FISTULA IN TANZANIA

An Overview of Findings and Recommendations from the Study



The continuing widespread incidence of obstetric fistula is a signal that health and social systems are failing to meet the basic needs of women. The World Health Organization estimates that approximately two million girls and women live with fistula worldwide, and an additional 50,000-100,000 new cases occur each year [1]. In Tanzania alone, it is estimated that there are approximately 2,500-3,000 new cases of fistula each year [2].

Obstetric fistula is typically seen as a severe and debilitating medical condition sustained during childbirth. However its roots are deeply embedded in social, cultural and economic determinants that underlie poverty and vulnerability. Fistula largely affects girls and women living in rural areas, and those living in poverty. They often lack access to adequate health services and information, cannot pay for medical treatment, and are poorly educated. Moreover, fistula inhibits women's ability to work and to interact with communities, driving them deeper into poverty and further undermining their economic and social position. Despite these

challenges, however, girls and women with fistula are typically strong and resourceful, continuing to support their families and themselves [3].

Risk and Resilience: Obstetric Fistula in Tanzania, examines the many dimensions of obstetric fistula and its related social vulnerability. The study was conducted by Women's Dignity Project and EngenderHealth, in collaboration with Health Action Promotion Association, Kivulini Women's Rights Organization, and Peramiho Mission Hospital. Sixty one Tanzanian women with obstetric fistula participated in the study, together with members of their families and communities, and local health care providers. This policy brief, the introduction to four thematic briefs, begins with an explanation of obstetric fistula followed by an overview of the research study. The brief then presents the key findings from the study together with recommendations on strategies that are urgently required to save women's lives and safeguard their health and well-being.*

WHY THIS RESEARCH STUDY?

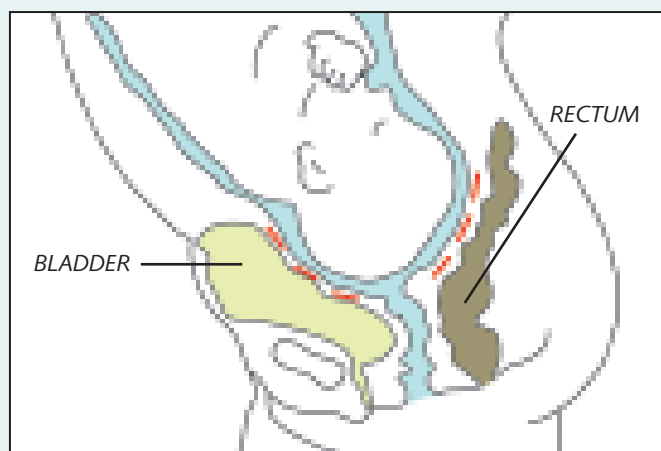
The purpose of the study was to understand the many dimensions of fistula and its related social vulnerability through the experiences and views of girls and women living with fistula, members of their families and communities, and local health care providers. This study presents vital evidence on how health care and social systems often fail to meet women's basic needs, and presents recommendations on how the lives of girls and women can be saved in future.

WHAT IS OBSTETRIC FISTULA?

Obstetric fistula is a severe injury that can develop during prolonged and obstructed labor. Without prompt medical intervention (typically a caesarean section), the constant pressure of the fetal skull in the birth canal cuts off the blood supply to the tissues, causing the tissues to disintegrate (see Figure 1). A hole or 'fistula' then forms between the vagina and bladder and/or between the vagina and rectum. The girl or woman is left with continuous and uncontrollable leaking

from her vagina, resulting in constant and humiliating odor and wetness. In nearly all cases of obstetric fistula, the baby dies. The trauma of labor can result in extreme nerve damage to the woman's lower limbs, leading to paralysis or seriously impeding the ability of the woman to walk normally. Left untreated, fistula can also lead to painful rashes, infections, and ulcerations.

Figure 1: Diagram showing how obstetric fistula can develop during childbirth



* The companion briefs in this series examine, in greater depth, the findings for four focal areas of the current research. A full list of their titles is found on the final page of this brief.

Many women are either unaware that treatment is available to surgically repair fistula, or cannot access or afford the treatment. As a consequence, many girls and women do not receive treatment for their condition. They may become socially ostracized and ridiculed, or become so ashamed of their condition that they isolate themselves from their communities. Others are rejected and abandoned by husbands and families. Moreover, women may be left with few, if any, opportunities to earn a living, forced to rely on others to survive [4].

STUDY LOCATION, PARTNERS AND PARTICIPANTS

The study was conducted in three districts of Tanzania: Singida Rural, Songea Rural and Ukerewe. Additional interviews were conducted at Bugando Medical Centre in Mwanza. Study participants were from several different ethnic groups. Data collection took place between July 2003 and September 2005 and was undertaken by two researchers from Women's Dignity Project and two staff from each of the local partners: Health Action Promotion Association in Singida, Kivulini Women's Rights Organization in Ukerewe and at Bugando Medical Centre, and Peramiho Mission Hospital in Songea. Data analysis and write-up were done by staff of Women's Dignity Project and EngenderHealth. The study was approved by the National Institute of Medical Research in Tanzania.

A total of 61 girls and women with fistula participated in the study. The interviews explored women's pregnancy, labor,

delivery, and post-delivery experiences related to the pregnancy that caused the fistula, including their access to resources, social support, antenatal care (ANC), and other health services. Additionally, the women were asked how fistula had affected their lives and the lives of their families including psychologically, physically, financially, and socially. Participants were also asked about the coping mechanisms used to mitigate the impacts of fistula, and recommendations on locally appropriate solutions to prevent and manage the condition. All girls and women living with fistula who participated in the study were provided with surgical repair of their fistula.

In addition, 42 different family members were interviewed to understand their perspectives on experiences and care-seeking behavior related to the pregnancy that caused the fistula, the impact of fistula on the lives of family members, and coping strategies used. Specifically, interviews focused on the actions that the woman and her family and friends took during labor and delivery, and the woman's access to medical, social and financial resources over this period. Lastly, researchers held discussions with 68 community members and 23 health care providers to explore their perceptions of the socioeconomic, cultural, and familial factors contributing to fistula, root causes and beliefs about fistula, and coping strategies used to mitigate its impact.

Study instruments included in-depth interviews, group discussions, and several participatory research methods.



KEY FINDINGS AND RECOMMENDATIONS¹

Fistula provides a critical lens onto the health and social systems that can promote – or limit – the capacity of girls and women to achieve well-being. Underlying the medical presentation of fistula are its true determinants: poverty that constrains families from accessing basic health services; resource limitations that undermine the capacity of health workers to deliver high quality care; insufficient investment in infrastructure that makes transport to a health facility nearly impossible, particularly during times of emergency; insufficient access to information and knowledge about maternal health and pregnancy related emergencies; inadequate education and decision-making status for girls and women; and a continuing acceptance of women dying in childbirth or surviving with unspeakable consequences.

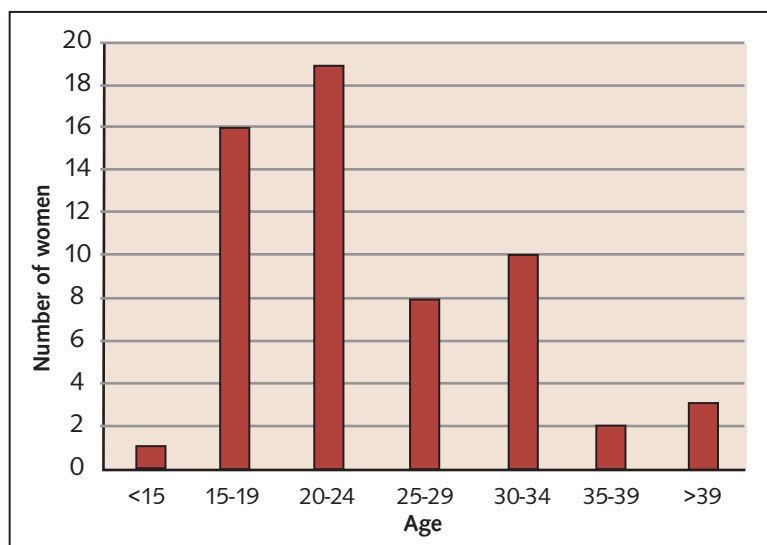
The six major findings detailed below dispel some long-held views on fistula, provide evidence for building locally appropriate solutions to address fistula and its related social vulnerability, and identify entry-points to reduce maternal mortality and morbidity overall.

Finding 1: Fistula affects girls and women of all ages, in first and later pregnancies

Fistula is commonly viewed as a condition that primarily affects adolescent girls during their first pregnancies.

However, data from this study indicates that the median age at which girls and women sustained fistula was 23 years. Fewer than half of the participants were younger than 19 years. Moreover, about half of the women sustained fistula during second or later pregnancies.

Figure 2: Age of Women at Fistula



Recommendation: Public education, policies, and interventions to reduce the risks of fistula must address the full reproductive life-cycle of girls and women.

Women of all ages are at risk of obstetric fistula, including those who have had 'normal' deliveries previously. Therefore, education efforts must inform communities and health workers that all women are at risk of pregnancy and delivery complications that can result in disability or death.

Finding 2: Antenatal care services are widely available and used, but are inconsistent and inadequate.

Nearly all of the women in the study attended antenatal care (ANC) services at least twice, but the services received were inconsistent, inadequate, and differed greatly from the Ministry of Health guidelines. About half of the women were weighed, but fewer than half had their height measured or were given some type of medicine. Only two women reported that they were given medication for malaria. No hemoglobin tests, urine analysis, or blood grouping were reported. For the women who did not go for ANC, it was mostly because services were too far away.

None of the women in the study had any discussion about pregnancy, labor and delivery during their ANC visits, except that in a few cases women were simply told to deliver in a health facility. This reflects a serious 'missed opportunity' to provide women with critical health services and information regarding pregnancy and delivery.

Recommendation: Providers need adequate training, supplies and equipment, as well as supportive supervision, to implement high quality and consistent ANC services.

Clear, evidence-based information on antenatal care, labor, delivery, and post-partum care is fundamental for the adequate training of health care providers. In addition, health workers require specific training in effective and non-discriminatory communication with clients, including vulnerable populations such as poor, disabled, and other marginalized girls and women.

If providers are able to conduct effective ANC sessions to educate clients, then their clients will emerge with information that will be useful to them if an emergency arises during delivery. If critical supplies and equipment are available, and supervision given to health workers, then ANC care can be a more promising means to avert maternal deaths and disability.

¹ The following descriptive indicators with associated percentages of respondents (in brackets) are used to report findings: Nearly All (80-90% of respondents); The Majority (more than 50%); About Half (around 50%); Fewer than Half (25-45%); A Minority (10-25%); and A Few (less than 10%) **3**

Finding 3: The lack of birth preparedness, including basic information on childbirth and taking action around 'delays', increases risk.

The majority of women in the study had planned to deliver at a health facility of some type, although in the end nearly all started labor at home. A majority of the women interviewed faced multiple delays in reaching a facility with the necessary service to enable them to deliver safely. The reason most often cited for delays was that the woman or her family or friends did not identify a problem that needed to be addressed by a skilled health provider.

Fewer than half of the women had set aside some funds for costs related to labor, delivery, post-delivery and/or transport. Thus, when problems emerged, the necessary preparation was lacking.

Recommendation: Concrete information on birth preparedness, that is understood and acted upon, is critical to avoid delays in time of emergency.

Health care providers, women, and their families need comprehensive information on birth preparedness to help in times of emergencies. It must include the 'danger signs' that indicate obstetric complications, the imperative to take quick action when signs and symptoms of obstetric complications first present, and the importance of adequate planning to avoid delays in times of emergency (e.g., saving funds for delivery-related expenses and arranging emergency transport plans). Traditional birth attendants and health workers in peripheral facilities (including lower level cadres) must also

have this basic knowledge so that quick and proper referrals can be made to facilities with qualified medical personnel, supplies, and equipment to manage complications. By understanding and swiftly acting upon complications arising during pregnancy and delivery, the risks of maternal and infant death and injury, including obstetric fistula, can be significantly reduced.

Finding 4: Lack of access to emergency caesarean section poses a great threat to women's lives.

The most commonly cited barriers to facility-based delivery were lack of money, and excessive distance to the nearest hospital. Yet, nearly all the women who did make a move during childbirth eventually got adequate care at the hospital level. The majority of the women incurred costs for transport, and a minority reported having to pay some type of fee for the delivery.

The 2004/5 Tanzania Demographic and Health Survey notes that women do not have sufficient access to essential maternal health services including caesarean section. The 2004/5 DHS also notes that "getting money for treatment" was the single biggest obstacle facing women seeking health care, followed by distance to the health facility and the need to take transportation. Striking differences were reported between rich and poor women, and between urban and rural women. Over half of the poorest quintile cited distance to facility and the need to take transport as big problems. In contrast, less than 20% of urban women and those from the highest quintile encountered these problems [5].





Other data also suggest that fistula can be caused in hospital settings themselves, through improper caesarean section and negligence [6]. This raises serious questions about the provision of quality health care within facilities and the need for rigorous attention to improve the skills, working conditions, and attitudes of healthcare providers.

Recommendations: Girls and women, particularly in rural areas, urgently need access to emergency obstetric care (EmOC) provided by trained health workers. The financial and logistical barriers to EmOC services must be eliminated.

Urgent efforts are needed to expand effective access to emergency caesarean section down to the health centre level. Priority should be given to instituting EmOC in the most underserved regions of the country, and building upon that foundation in the long-run.

Effective action is required to address key barriers that women face in accessing care for labor and delivery. This includes:

- Instituting transportation schemes to help women reach an appropriate facility promptly;
- Monitoring compliance with the Government's statement that services for pregnant women are free and that 'delivery kits' are available in health facilities for all expectant mothers [7];
- Hiring, training, and equitably deploying health workers throughout the country, including those who can perform caesarean section; and,
- Consistently providing supplies and equipment for EmOC services.

By ensuring effective access to high quality and affordable EmOC services, particularly in underserved areas, the incidence of maternal mortality and morbidity in Tanzania, including fistula, can be greatly reduced.

Finding 5: The cost and inaccessibility of high quality fistula repair services are barriers to care for many girls and women.

The majority of the women in the study had lived with fistula for two or more years. At the time of the interview, the majority had already sought fistula repair or were then seeking treatment. Of the women who specified reasons for not getting a repair, the primary reason was that they did not have the money to seek treatment.

The women and families who succeeded in accessing care prior to the interview had sacrificed a significant amount of time and money to get them this treatment, including selling assets to pay for transport and treatment. Nevertheless, fewer than half had a successful repair. In addition, fewer than half of the women who had sought repairs previously went to only one facility. A similar number went either to multiple places (including traditional healers) or to the same facility multiple times seeking repair.

Recommendation: High quality fistula repair services must be made available and accessible to women, and at highly-subsidized or no cost.

Information on where and when fistula repair services are available needs to be widely disseminated. Information

channels that reach rural areas need to be prioritized, for example radio broadcast and informational outreach through faith-based institutions such as churches and mosques.

Beyond information, women must be supported actively to access fistula treatment. Given the severe economic impact of fistula on women and their families, it is imperative that fistula repairs be provided at minimal or no cost. Ideally, support should cover the costs of both transport and treatment. Fistula programs have an ethical obligation to develop mechanisms of such support, so that advocacy on fistula does not raise women's expectations for treatment when treatment is beyond reach.

Finding 6: Even though most women with fistula had support from others, the emotional and economic impacts of fistula are substantial for the woman herself, and for her family.

Although all of the women in the study mentioned being supported by at least one person when they sustained their fistula, the majority of the women reported that they isolated themselves from their community. The women felt a strong sense of shame about their condition and did not want to soil themselves in public or to smell badly. A majority of the women suffered stress and worry, including about the impact of the fistula on their families.

Women and their families also suffered economically as a result of the fistula. Nearly all of the women said that fistula affected their ability to work. Of these women, the majority could not work at all. As a result, their families were affected by the loss of the woman's contribution to work in the home, on the farm, or in earning income from other employment. In

addition, families faced higher expenses in the daily management of the woman's condition, such as costs for extra clothes and soap, and in efforts to seek treatment to repair the fistula. Many families made great sacrifices to help girls and women get fistula repairs, including family members forgoing work and income to accompany the women to seek treatment.

Recommendation: Advocacy, support, and reintegration efforts should be instituted to reduce the emotional and economic impacts of fistula.

After successful repair, most women in the study resumed their normal lives, able to interact freely with their families, friends and communities, attend meetings and church services, and take active roles in economic activities. Many called their return to health "a miracle." The findings also show that families - including husbands - can, and do, support women with fistula. These and other positive illustrations of support from family, friends, and communities can be used in public education and advocacy efforts to break the stigma around fistula.

Reintegration programs can strengthen opportunities for successful re-entry after repair. However, to date, only limited information is available on women's experiences with reintegration. Further research is needed in this area so interventions are based on a thorough understanding of what women with fistula themselves need to help them begin life anew after repair. Reintegration efforts should also be mindful of the potentially differing needs of women who have had fistula for different periods of time, as it is possible that stigma and isolation deepen the longer that a woman lives with fistula.



CONCLUSION

The findings of this study point to the urgent need for a robust policy and set of interventions, backed by high level commitment, to reduce maternal death and disability in Tanzania.

Like many countries, Tanzania has had a safe motherhood program in place for decades. However, little progress has been made in saving women's lives. The maternal mortality ratio has not declined in the past decade [5]; emergency obstetric care (including caesarean section) is virtually unavailable to women at the health center level; qualified health workers who could prevent and manage obstetric complications are severely lacking; training and supportive supervision of health personnel is highly inadequate; and drugs, supplies and equipment are severely lacking. The 2004/05 Tanzania Demographic and Health Survey confirm that girls and women have insufficient access to essential maternal health services including caesarean section – services that are critically needed to save lives..

Tanzania needs to care about the fact that women are dying and disabled in childbirth – and act decisively to save women's lives. Highly promising projects in Kigoma, Rukwa, and other regions of Tanzania, together with those in other developing countries, can point the way forward. Tested and successful interventions include, but are not limited to: basic infrastructure improvements for labor and delivery; staff training and supportive supervision; sustained use of standards and protocols; quality improvement measures such as criterion-based audits and case reviews; consistent provision of obstetric supplies and equipment; and functioning referral mechanisms including transport to a facility where emergency obstetric care is available [8] [9] [10].

We know what to do. What is lacking is the political commitment, effective allocation of resources, and deployment of skilled personnel to make a fundamental difference in women's lives.





Bibliography

- [1] Murray C and Lopez A. Health Dimensions of Sex and Reproduction. World Health Organization. Geneva, Switzerland: 1998
- [2] Raassen, T. Personal communication 2005, based on international estimates and local conditions.
- [3] Women's Dignity Project. Faces of Dignity. Dar es Salaam: 2003
- [4] UNFPA and EngenderHealth. Obstetric Fistula Needs Assessment Report: Findings from Nine African Countries. New York: 2003.
- [5] United Republic of Tanzania. National Bureau of Statistics and Macro International. Tanzania Demographic and Health Survey 2004/5. Dar es Salaam: 2005
- [6] Nicol, M. "Hospital Fistula, VVF Patients, Experiences of Health Services". Presentation at the Conference of East, Central and Southern Africa Obstetricians and Gynecologists, October, 2005. Dar es Salaam: 2005.
- [7] Kigoda, A., Deputy Minister of Health and Social Welfare, from her speech to Parliament on 3 July 2006. Dodoma, Tanzania.
- [8] Mbaruku G. and Bergstrom S. Reducing Maternal Mortality in Kigoma, Tanzania. Health Policy and Planning (1995) 10(1): 71-78
- [9] Kayongo M., et. al., Strengthening Emergency Obstetric Care in Ayacucho, Peru. International Journal of Gynecology and Obstetrics (2006) 92: 299-307
- [10] Santos C., et. al., Improving Emergency Obstetric Care in Mozambique: The Story of Sofala. International Journal of Gynecology and Obstetrics (2006) 94: 190-201

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