Global Maternal and Child Health:
Medical, Anthropological, and Public Health Perspectives
*Series Editor:* David A. Schwartz

Laura Briggs Drew
Bonnie Ruder
David A. Schwartz *Editors*

# A Multidisciplinary Approach to Obstetric Fistula in Africa

## Public Health, Anthropological, and Medical Perspectives

Springer

# Global Maternal and Child Health

## Medical, Anthropological, and Public Health Perspectives

**Series Editor**

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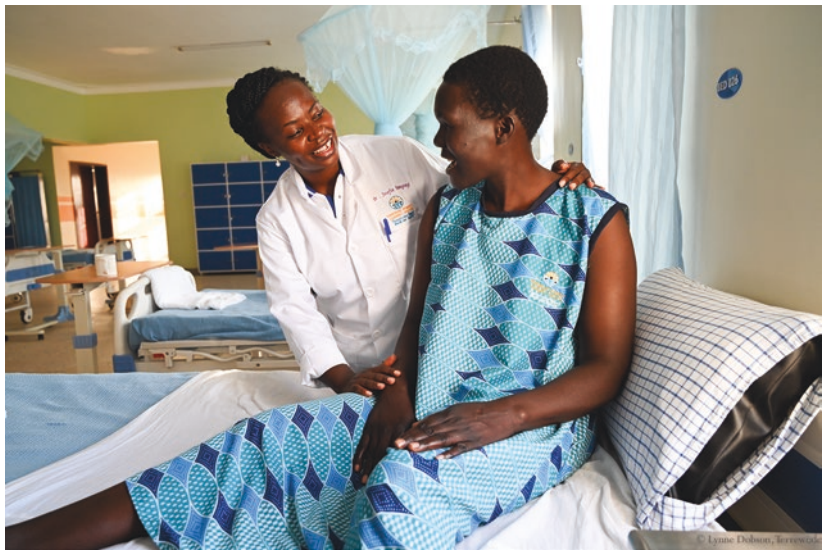

An obstetric fistula patient consulting with her fistula surgeon, Dr. Namugenyi, at the Terrewode Women's Community Hospital in Soroti, Uganda. Photo by: Lynne Dobson, Terrewode Women's Fund

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Editors

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ISSN 2522-8382 ISSN 2522-8390 (electronic)
Global Maternal and Child Health

ISBN 978-3-031-06313-8 ISBN 978-3-031-06314-5 (eBook)
https://doi.org/10.1007/978-3-031-06314-5



This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

*This book is dedicated to the women and girls in Africa who have suffered from the physical, psychological, and social distress caused by obstetric fistula. Obstetric fistulas are both preventable and treatable. Their continued presence among the world's poorest women is a human rights tragedy. The purpose of this book is to bring greater awareness, resources, and collaboration to the collective efforts to finally end fistula and the suffering it causes.*

*The editors and authors of this book also wish to dedicate this collection to the organizations and individuals who are providing fistula treatment and reintegration services to women and girls who have suffered from fistula. International and local nongovernmental organizations (NGOs) have served a tremendous role in providing surgical care for victims of obstetric fistula. NGOs have been at the forefront of making a wide range of services available including rehabilitation, psychological and family counseling, physical therapy, education and vocational training, and assisting women and girls so they successfully reintegrate back into society post-surgical repair.*

*A special dedication of this book is extended to Catherine Hamlin, AC, FRCS, FRANZCOG, FRCOG. Dr. Catherine Hamlin was a pioneer in fistula surgery and an advocate for women and girls who suffered from obstetric fistula. With her husband, Reginald Hamlin, Dr. Hamlin cofounded the Addis Ababa Fistula hospital, which has provided free obstetric fistula repair surgery to thousands of women and girls in Ethiopia. Her lifelong dedication to the prevention and treatment of obstetric fistula brought global awareness to this preventable childbirth injury. Without her work, the eradication of obstetric fistula in our lifetimes would not be as achievable. Dr. Hamlin's dream of eradicating obstetric fistula through over 60 years of service is highlighted in Chapter 2 of this book.*

# Foreword

This book is about obstetric fistula—a preventable and tragic condition that continues to be an important cause of morbidity and mortality throughout Africa as well as in many other parts of the world. It is a terribly debilitating sequelae of childbirth that can be considered to be a disease of poverty and neglect, ruining the lives of countless women and their families. I have spent a good part of my life working to improve conditions for women with diseases such as fistula and pioneered the campaign to abolish female genital mutilation, and I would like to relate a little of my history and how I became involved with the health of women.

I was born in 1937 in Hargeisa, British Somaliland, the daughter of a prominent Somali medical doctor. Because girls were not routinely educated in Somaliland, my father arranged for me to be tutored to learn to read and write. In those times, pregnancy and childbirth were dangerous, and in my family, two of my siblings died at delivery. From an early age, I worked alongside my father in his hospital. I'd go in and help him during the school holidays, or whenever he needed an extra pair of hands. There were no bandages, so one of my jobs would be to cut bedsheets into strips, boil them, iron them, and then roll them up. If he had to go away, he'd leave me notes—make sure they feed this child properly or remove those sutures. I would listen to his frustrations too, about the lack of materials and poor facilities. I promised myself that one day I would create the kind of hospital my father would have loved to work in.

After I attended school in Djibouti in French Somaliland, I then traveled to the United Kingdom where I was trained as a nurse and a midwife in the 1950s at the Borough Polytechnic, now London South Bank University, at the West London Hospital, the Hammersmith Hospital, and at the Lewisham Hospital. Midwifery was not my first choice of specialization, as I really wanted to specialize in surgery. It was the one time I remember my father really questioning one of my decisions. He said, "Yes, surgery is great. But what are you going to do for the women back home in Somaliland who need you at the most vulnerable time in their lives?" And I thought, after all the opportunities I've had and the freedom I've enjoyed, I should think about giving something back, so I signed up for midwifery. There was never any question in my mind that I would come back to Somaliland. I was very clear that the knowledge and experience I was gaining in England was for the benefit of the people here. When I came back, there was a definite air of optimism. The British had left, and Somaliland was independent. Still, the infrastructure was virtually nonexistent, and no one knew what to do with a female nurse/midwife, nor how to pay one—I worked

for 22 months without a salary. I also believed that I could use my training as a nurse to return to my homeland and abolish the traumatic practice of genital mutilation and other injuries to young women. Two years after I returned, I was married in 1963 to Mohamed Haji Ibrahim Egal, who became Leader of the Opposition and later became the first Prime Minister of the Somali Republic in 1967, making me the nation's First Lady.


Hon. Edna Adan Ismail

I began to fulfill my dream of building a hospital in Mogadishu for the care of women starting in 1980, but with the start of the Somali civil war in 1981 I had to leave the country—that hospital fell into the hands of the warlords during the civil war. I returned to Somaliland after the civil war in 1991 and found that the entire health infrastructure had, for all intents and purposes, been destroyed by the conflict. At that time, the rates of maternal death and infant mortality were among the highest in the world.

How do you build a hospital in a country with no infrastructure? You just get up and do it. I began to build my maternity hospital in Hargeisa in 1998, on a plot of land donated to us by the government that had once been a killing ground and a garbage dump! Finding that the region lacked trained nurses to staff the hospital, I recruited more than 30 candidates and began training them, while the hospital was still under construction. With the help of financial and material donations from concerned persons, international organizations, businesses, and my own United Nations pension, our hospital opened on March 9th, 2002.

It was when we opened the hospital that we discovered more and more women coming to us with obstetric fistula and I became a bigger advocate for women suffering from maternal morbidities. Obstetrical fistula dehumanizes women—the smell of the feces and urine that leaks out of their bodies stains their clothes but also damages their morale—it totally destroys women affected. The woman becomes rejected. She is put in a hut outside the house because they—her family, relatives, husband, children, the people around her—cannot tolerate the smell of urine which is constant. Many of them commit suicide when they become rejected. And we can all understand how morally destroying it is for a woman—who was once pretty, who was loved, who was a member of that community, a mother to children, a wife to a husband—to suddenly become somebody who is sent out of the house as an outcast simply because she smells bad.

Returning home gave me an opportunity to be a role model. I started training auxiliaries in the hospital to take better care of the women. From there, I started inviting girls who'd been my pupils back when I was a schoolteacher to come in and help me. Their families didn't want them to get involved with the patients. However, very slowly, they began to get interested and excited by the possibilities. Of that first group, five received scholarships to study in England, and three came back to work here. That's really how nursing in this country got started. Later, I held various roles within the World Health Organization (WHO) and started training midwives for Libya from 1965 to 1967, and from 1986 to 1991, became the WHO Regional Technical Officer for Mother and Child Health, having the responsibility for working to end harmful traditional practices which affect the health of women and children (such as female genital mutilation), and for training midwives and traditional birth attendants in the 22 countries of the Eastern Mediterranean Region. During the last six years of my career with WHO, I became their Representative in the Republic of Djibouti from 1991 to 1997 when I retired and then went home to build my hospital in Hargeisa, Somaliland.

Although I was soon appointed the Minister of Family Welfare and Social Development of Somaliland and became Somaliland's Foreign Minister from 2003 to 2006, I continued to work on improving the quality of healthcare training to prevent maternal mortality and morbidity and increase the quality and coverage of health care throughout the country. We are now proud to have 7 midwifery training schools in Somaliland. The Edna Adan University Hospital now has over 200 staff members, 2 operating rooms, fully equipped laboratory, library, computer facilities, and a complete wing dedicated to the education of nurses and midwives. Our community midwives typically each assist with from 150 to 200 births per year, while some may deliver as many as 400 babies a year if they work in a major regional hospital.

As a result of improved midwifery, the women who suffer from obstetrical fistula are becoming fewer. However, there is still much to do here and elsewhere and in the remote rural locations and beyond. Many girls and women travel for days to come to us. Many have to walk from their towns and villages to arrive here and reach us, weak, anemic, and at times in a state of near collapse. Many have bruises, wounds, and ulcers on the soles of their feet that we have to take care of in addition to their fistula. Their morale is destroyed; their hope in life is lost. And many have doubts that the surgery that we are

offering will really take care and solve their problem. Many cry when they become healed, when they become dry, and when they no longer smell.

Having the surgical skills to repair obstetrical fistula is important, of course. But the prevention of obstetrical fistula is the most important action that we can take because however skilled the surgeon is, sometimes the damage that happens to the pelvic organs of the woman is so bad that they cannot be fixed. Once again, prevention is the best strategy. And to get there we need to improve and expand the training of the midwives who deliver these women. We cannot rest on our accomplishments and need to increase training because there are still locations, especially within Africa, where there are no trained midwives. Poverty exacerbates girl's and women's lack of access to education and quality health care. Furthermore, the lacerations that occur during childbirth can become greatly exacerbated for women who have genital cuts and mutilations. Living in villages without access to running water to clean themselves, women with fistula become social pariahs, shunned and ostracized, facing a lifetime of rejection and shame. I know of one young woman who was almost murdered by her husband because he found her so repulsive to be near.

In a normal delivery—in a hospital with appropriate equipment—under the care of a trained health professional, a baby with a large head would be identified long before the birth and would be delivered instead by cesarean section. Or, if it was delivered vaginally and became stuck in the birth canal, it would be helped out with forceps, vacuum extraction, or other medical interventions that prevent extensive pelvic floor lacerations from happening. A nomadic mother in Africa giving birth out in the bush who has never had prenatal care and is unassisted or being delivered by traditional attendant would have no such help and—if she has been infibulated—then she and her baby are at even a higher risk.

The best way to overcome obstetric fistula is through the education of girls and women, through improved training of health professionals, and through better equipment and coordination of health facilities. This book, *A Multidisciplinary Approach to Obstetric Fistula in Africa: Public Health, Anthropological, and Medical Perspectives*, highlights such strategies as solutions to prevent and treat obstetric fistula. Within this text are the opinions and experiences from a wide range of experts with differing educational backgrounds—anthropologists, nurses, physicians, midwives, epidemiologists, public health specialists, maternal and child health specialists, and others. The authors come from not only Africa but around the world, writing on the physical, psychological, medical, and societal effects of obstetric fistula throughout the continent of Africa.

I am honored to have been asked to write this Foreword. I am thrilled that a multidisciplinary approach is being explored by the editors—Laura, Bonnie, and David—who themselves represent a variety of specialties. These perspectives will help find solutions and help ensure that one day obstetric fistula surgeries in hospitals like mine will become unnecessary and obsolete.

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# Acknowledgments

We, the editors, would like to acknowledge each of the dedicated individuals who contributed to this book's content. We appreciate the time the authors took to develop their respective chapters and their ongoing efforts to provide treatment to women and girls who have suffered from obstetric fistula as well as their work towards obstetric fistula prevention. We also extend our appreciation to the women and girls who have endured obstetric fistula. Their stories and experiences highlight the urgent need to address this preventable childbirth injury. Without their advocacy in communities and their participation in obstetric fistula research studies, we would not know how to best prioritize efforts so we can achieve the goal of obstetric fistula eradication. We also thank our families, friends, and colleagues, who throughout the years have continuously supported our work on this collaborative effort.

# Contents

# Editors and Contributors

## About the Editors

**Laura Briggs Drew, PhD, MPH** received her PhD in Maternal and Child Health from the University of Maryland (UMD) School of Public Health in College Park. She was appointed as a Maternal and Child Health Student Fellow with the American Public Health Association in 2016–2017. Laura completed her Master of Public Health in Epidemiology and Interdisciplinary Specialization in Global Health at the Ohio State University. Prior to UMD, she worked with University of North Carolina Project-Malawi on various research studies that aimed to improve the quality of life for women with obstetric fistula at the Freedom from Fistula Foundation's Fistula Repair Centre at Bwaila Hospital in Lilongwe, Malawi. Laura's primary research interests focus on the intersection of human rights and reproductive, maternal, and child health outcomes. Her research focuses on birth outcomes, intimate partner violence, female genital cutting, sexual health, infertility, infectious diseases, and gender inequality. Laura's research has been published in numerous public health journals, including *Women's Reproductive Health*, *BMC Pregnancy and Childbirth*, *American Journal of Preventive Medicine*, *PLOS Neglected Tropical Diseases,* and *Journal of Women's Health*. Laura's work has received support and recognition from multiple institutions, including the Maryland Population Research Center and the Delta Omega Honorary Society in Public Health.

**Bonnie Ruder, PhD, MPH, CPM** holds a PhD in Applied Medical Anthropology and a Master's in Public Health in International Health from Oregon State University. She is the cofounder and Executive Director of Terrewode Women's Fund, a US-based nonprofit organization; a senior research consultant with the International Fistula Alliance; and sits on the Board of Governors for Terrewode Women's Community Hospital. She conducts research on maternal health and obstetric fistula and has worked on projects in Uganda, Somalia, The Gambia, Zimbabwe, and the USA. Her research focuses on obstetric fistula, residual incontinence post-fistula repair, maternal and infant health, reproductive justice, traditional birth attendants, social justice and systems of oppression, and community-engaged research. Bonnie is a licensed midwife with over 20 years' experience, working primarily in the USA. She has also attended births in Haiti after the 2010 earthquake and at a referral hospital in Soroti, Uganda. Her current research examines the COVID-19 pandemic's impact on gender and maternal health in Uganda.

**David A. Schwartz, MD, MS Hyg, FCAP** has an educational background in Anthropology, Medicine, Emerging Infections, Maternal Health, and Medical Epidemiology and Public Health. He has professional and research interests in reproductive health, diseases of pregnancy, and maternal and infant morbidity and mortality in both resource-rich and resource-poor countries. In the field of Medicine, his subspecialties include Obstetric, Placental and Perinatal Pathology as well as Emerging Infections. An experienced author, editor, investigator, and consultant, Dr. Schwartz has long experience investigating the anthropological, biomedical, and epidemiologic aspects of pregnancy and its complications as they affect society, in particular among indigenous populations and when they involve emerging infections. Dr. Schwartz has been a recipient of many grants, was a Pediatric AIDS Foundation Scholar, and has organized and directed national and international projects involving maternal health, perinatal infectious diseases, and placental pathology for such agencies as the US Centers for Disease Control and Prevention, National Institutes of Health, and

the United States Agency for International Development, as well as for the governments of other nations. He has published 3 previous books on pregnancy-related morbidity and mortality, the first in 2015 entitled *Maternal Mortality: Risk Factors, Anthropological Perspectives, Prevalence in Developing Countries and Preventive Strategies for Pregnancy-Related Deaths*; a book published in 2018 entitled *Maternal Death and Pregnancy-Related Morbidity Among Indigenous Women of Mexico and Central America: An Anthropological, Epidemiological and Biomedical Approach*; and in 2019 a book entitled *Pregnant in the Time of Ebola. Women and Their Children in the 2013-2015 West African Epidemic.* Dr. Schwartz is the editor of the Springer book series *Global Maternal and Child Health: Medical, Anthropological and Public Health Perspectives,* of which this book is a volume. He has been involved with maternal, fetal, and neonatal aspects of such epidemic infections as HIV, Zika, and Ebola viruses, and is currently researching these issues with the COVID-19 pandemic. Dr. Schwartz serves on the Editorial Boards of several international journals and was formerly Clinical Professor of Pathology at the Medical College of Georgia of Augusta University in Augusta, Georgia.

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# Part I

# Obstetric Fistula

# 1 Introduction to Obstetric Fistula: A Multidisciplinary Approach to a Preventable Childbirth Tragedy

Bonnie Ruder, Laura Briggs Drew, and David A. Schwartz

This book discusses an ancient and catastrophic complication of childbirth which remains a modern-day public health tragedy—obstetric fistula. Tragically, this debilitating condition, which is entirely preventable, has continued to occur among hundreds of thousands of the world's poorest women even into the third decade of the twenty-first century. Its continued existence is the result of the low status of women and the unjust and unethical allocation of healthcare resources in the parts of the world where obstetric fistula remains endemic, and an inexcusable failure of political will. This book utilizes a team of expert authors from countries where fistula continues to occur, as well as experts from other parts of the world, to address factors that contribute to obstetric fistula development, including pathophysiological aspects and social determinants of health. Additionally, we bring attention to how an obstetric fistula can negatively impact the quality of life for a woman and her family, as well as efforts to improve fistula prevention, diagnosis, medical treatment, and continuing support for women when they reintegrate into their communities after fistula repair.

An obstetric fistula is caused by unrelieved obstructed labor, which damages tissues in the birth canal and leads to unremitting urinary and/or fecal incontinence. Considered the most severe and debilitating of all maternal morbidities, women with obstetric fistula experience severe physical, psychological, social, and economic consequences. Although individual experiences are unique to each woman, in the worst cases women are ostracized and abandoned by their husbands, families, and communities.

Obstetric fistula rarely occurs in wealthy countries in the Global North where pregnant women have access to high-quality maternal health care. Their prevalence in low-resource countries is a clear indication that healthcare systems are failing to meet the needs of childbearing women. Women and girls in countries across sub-Saharan Africa, referred to as the "fistula belt," experience unacceptably high rates of fistula, a result of the intersection of chronically underfunded and poor-quality healthcare systems, gender discrimination, systems of inequity, and poverty—and its accompanying conse-

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L. B. Drew et al. (eds.), *A Multidisciplinary Approach to Obstetric Fistula in Africa*, Global Maternal and Child Health, https://doi.org/10.1007/978-3-031-06314-5_1

quences for women and girls, including child marriage and low education attainment. The occurrence of obstetric fistula is internationally recognized as a gross violation of women's human rights.

The exact prevalence of obstetric fistula is difficult to determine for several reasons. First, obstetric fistula occurs in a small proportion of obstructed labors, and a clinical diagnosis is needed to confirm the presence of obstetric fistula. Public health surveillance systems in the endemic countries are often underfunded and ineffective; as a result, affected women may be difficult to identify. Many women affected by fistula live in rural and remote areas and are outside of the reach of poorly provisioned local healthcare systems. Furthermore, because of the shame and stigma connected to this condition, women with fistula often self-isolate and may be unaware of the cause of their problem or treatment options. Thus, prevalence estimates often rely on hospital data based on the number of patients receiving treatment for fistula or physician's estimates; others are based on countries' rapid needs assessments rather than robust epidemiological studies (Adler et al., 2013; Stanton et al., 2007).

As interest and services for obstetric fistula have intensified in recent years, many countries that participate in the Demographic and Health Surveys (DHS) program have added fistula symptom-related questions to their surveys as a proxy for fistula prevalence. While this is an encouraging development and will assist in estimations of prevalence when combined with diagnostic algorithms (Tunçalp et al., 2014), prevalence rates based primarily on self-reported data are likely to vastly overestimate prevalence, as incontinence secondary to childbirth may be caused by factors such as pelvic organ prolapse and not solely obstetric fistula. To accurately estimate fistula prevalence, reports of symptoms must be followed up with a clinical examination to confirm causation of incontinence, which adds significant complexity and cost.

Results from two recent large-scale, community-based studies that confirmed self-reported fistula symptoms with clinical diagnosis provide insight here. Both studies, one conducted in rural Ethiopia (Ballard et al., 2016) and another in Bangladesh (MEASURE Evaluation, 2018), found that only one-third of women reporting fistula symptoms received a positive diagnosis following clinical examination. The authors of both studies conclude that fistula prevalence based on self-reported symptoms is likely to vastly overestimate the magnitude of the problem (Ballard et al., 2016; MEASURE Evaluation, 2018). Furthermore, both studies found actual prevalence was significantly lower than previous estimates from these countries where clinical diagnosis was not confirmed, 0.06% in Ethiopia versus the previously reported 1% and 0.037% in Bangladesh versus the previously reported 1.21%. Ballard and colleagues point to improvements in the provision of maternal health services as a contributing factor to the overall decline in obstetric fistula.

The United Nations' recent report, "*Intensifying Efforts to End Fistula Within a Decade,*" recently released a new estimate of global fistula prevalence, stating that 500,000 women currently live with fistula, with additional cases occurring annually (2020). This is a significant reduction from previous estimates (which are reflected throughout this book as this latest figure was released as the book was going to press) and is based on modeled data from 55 countries, developed by Johns Hopkins Bloomberg School of Public Health in collaboration with UNFPA and WHO (UN, 2020). This reduction from previous prevalence estimates reflects a more nuanced understanding of the magnitude of fistula burden along with the significant achievements made in the collective efforts to identify and treat women with fistula and prevent the injury from occurring in the first place. Years of dedicated work by practitioners across disciplines to identify and treat women with fistula have had a positive impact, as have efforts to improve the access and provision of maternal healthcare services.

However, the fact that a half-million women continue to endure lives of suffering due to obstetric fistula, a completely preventable and treatable injury, is a stark reminder of the work that remains. In 2018, the UN General Assembly made the call to end fistula by 2030. This is an ambitious and exciting goal, one that requires an all hands on deck approach. In order to truly end fistula within a decade, increased and sustained funding is critical and should be directed to both proven and well-targeted

programs and creative, community-appropriate innovations desperately needed for progress. Collaboration, sharing of best practices, and coordinated efforts will help ensure resources are put to their greatest use to increase awareness and provide comprehensive, high-quality fistula services. Additionally, if we truly hope to end fistula, we must prevent new cases from occurring. Access to family planning information and services; improved sexual, reproductive, and maternal healthcare services with a focus on quality; and training of thousands of additional healthcare workers is essential.

This book provides a unique and timely contribution in our efforts to meet this goal and end fistula by 2030. The detailed chapters encompass a historical and broad understanding of obstetric fistula and the structural factors that disproportionally expose vulnerable women to this fate. They also reveal the tremendous breadth and depth of work that is being done to end fistula—from FIGO's fistula surgeons' training program, to clinical advancements in treatment, including greater attention to residual incontinence post-repair, to women's needs beyond surgery, including holistic reintegration and mental health services. The multidisciplinary nature of this volume provides a range of expertise and diverse perspectives to explore the complexity of obstetric fistula and potential solutions. The authors highlight targeted interventions, best practices, and key challenges, with the collective goal of moving toward the eradication of fistula and alleviating the suffering of hundreds of thousands of women. The editors of this book and its team of authors hope that this text will raise awareness of the continuing tragedy of obstetric fistula as an avoidable childbirth injury and galvanize efforts among the global public health, governmental, health care, and policymaking communities to take aggressive action to eliminate this debilitating condition.

## References

Adler, A., Ronsmans, C., Calvert, C., & Filippi, V. (2013). Estimating the prevalence of obstetric fistula: A systematic review and meta-analysis. *BMC Pregnancy and Childbirth, 13*(1), 246.

Ballard, K., Ayenachew, F., Wright, J., & Atnafu, H. (2016). Prevalence of obstetric fistula and symptomatic pelvic organ prolapse in rural Ethiopia. *International Urogynecology Journal, 27*(7), 1063–1067.

MEASURE Evaluation, i., b, The Maternal & Child Health Integrated Program, fistula care plus, and Johns Hopkins University. (2018). Prevalence of obstetric fistula and pelvic organ prolapse in Bangladesh: Summary of the 2016 National Estimates. https://www.measureevaluation.org/resources/publications/fs-18-290. Accessed 9 2019.

Stanton, C., Holtz, S., & Ahmed, S. (2007). Challenges in measuring obstetric fistula. *International Journal of Gynecology & Obstetrics, 99*, S4–S9.

Tunçalp, Ö., Tripathi, V., Landry, E., Stanton, C. K., & Ahmed, S. (2014). Measuring the incidence and prevalence of obstetric fistula: Approaches, needs and recommendations. *Bulletin of the World Health Organization, 93*, 60–62.

United Nations (2020). Intensifying efforts to end obstetric fistula within a decade. https://documents-dds-ny.un.org/doc/UNDOC/GEN/N18/445/45/PDF/N1844545.pdf?OpenElement. Accessed November 2020.

# 2 A Human Rights Approach Toward Eradicating Obstetric Fistula: Expanding Data Collection, Prevention, Treatment, and Continuing Support for Women and Girls Who Have Been Neglected

Laura Briggs Drew

## 2.1 Geographic Disparities in Maternal Health Outcomes: Unequal Prioritization of Women's Health and Human Rights Across the Globe

In the twentieth and twenty-first centuries, we have achieved great improvements in maternal health, including access to health care, nutrition, and hygiene. However, pregnancy and childbirth continue to be dangerous periods for women and their babies, particularly in resource-limited settings. In 2017, an estimated 295,000 women across the globe died during pregnancy or childbirth, and most of these deaths were preventable. Although this metric was a 35% reduction in global maternal mortality from 2000 (United Nations Population Fund et al., 2019), indicators of poor maternal health remain far too high. Maternal health disparities also elucidate significant inequities across the globe, with 94% of maternal deaths occurring in low and lower-middle-income countries (World Health Organization, 2019). In countries where access to family planning resources may be limited, the average number of pregnancies per woman is higher than it is in other settings, which further increases the lifetime risk of death and disability due to pregnancy (World Health Organization, 2019). Although reductions in maternal mortality have traditionally been used as indicators of progress in maternal health, maternal mortality estimates are dwarfed in comparison to the global burden of maternal morbidities. For every maternal death, an additional 20–30 women endure maternal morbidities, including life-threatening complications, infections, disabilities, and injuries, like obstetric fistula, which can negatively affect their quality of life (United Nations Population Fund, 2020).

Among the many factors that can lead to death from pregnancy, the primary direct causes of maternal mortality in Africa include hemorrhage (33.9%), sepsis/infections (9.7%), hypertensive disorders (9.1%), complications from unsafe abortion (3.9%), and obstructed labor (4.1%) (Khan et al., 2006). Although obstructed labor can be alleviated via a cesarean section, many women labor outside of healthcare facilities and they do not have access to emergency obstetric care. In addition to being a

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L. B. Drew et al. (eds.), *A Multidisciplinary Approach to Obstetric Fistula in Africa*, Global Maternal and Child Health, https://doi.org/10.1007/978-3-031-06314-5_2

leading cause of maternal mortality, obstructed labor is a major cause of neonatal morbidity and mortality, and it can also lead to devastating maternal complications and morbidities (Dolea & AbouZahr, 2000). One of the most severe and debilitating long-term complications of obstructed labor is obstetric fistula: a hole that forms when tissues in the vaginal wall are damaged during prolonged, obstructed labor, which leads to chronic incontinence of urine and/or feces.

The true number of maternal morbidity cases across the globe is not known. However, maternal deaths are often referred to as the tip of the iceberg with maternal morbidity its base (Firoz et al., 2013). Additionally, estimates suggest the global burden of severe maternal morbidity (SMM), which is defined as an unintended outcome of labor and delivery that leads to significant short-term and long-term consequences to a woman's health, is increasing over time, with sub-Saharan Africa having the highest burden of SMM at 198 per 1000 live births (American College of Obstetricians and Gynecologists, 2016; Geller et al., 2018). Estimating the prevalence and incidence of maternal morbidities is challenging because in some contexts the majority of births and subsequent maternal morbidities occur outside hospital settings, and for women in these areas who successfully access healthcare facilities, there is often poor record-keeping.

Until the early 1900s, when advancements in obstetric care to prevent and treat obstructed labor were achieved in America and Europe, obstructed labor was one of the leading causes of both maternal mortality and morbidity across the globe (EngenderHealth, 2015), but today it rarely contributes to maternal deaths in developed countries (Khan et al., 2006). As access to safe delivery care improved and the need for obstetric fistula repair became unnecessary, the first obstetric fistula hospital in the United States closed its doors, and the site became the Waldorf Astoria Hotel in New York City (EngenderHealth, 2015). Continuing advancements in modern obstetric care have almost universally eliminated obstetric fistula in settings with adequate access to these services. However, an estimated 500,000 women and girls are currently enduring untold suffering from obstetric fistula (Ahmed, 2020; United Nations General Assembly, 2020), and almost all of these cases are within the "fistula belt," which extends across countries in the northern half of sub-Saharan Africa (Tebeu et al., 2012). In addition to poor healthcare access and quality, other factors that contribute to the prevalence of unrepaired obstetric fistula in this region include a shortage of trained providers for fistula repair, limited awareness about repair possibilities, poor integration of services, and the marginalization of women (Cook et al., 2004).

Geographic disparities in the prevalence of obstetric fistula elucidate injustices and human rights violations that affect women who are young, poor, and in resource-limited settings with inadequate access to skilled emergency obstetric care. In low and lower-middle income countries, obstetric fistula cases occur due to early marriage and childbearing before a girl's pelvis is fully developed, as well as inadequate prenatal and obstetric care access, which stems from poverty and living in remote and rural areas (Cook et al., 2004). Social determinants of health, including inadequate nutrition, limited education, and low health literacy additionally contribute to obstetric fistula development, and many of these factors are tied to gender inequality. Although a number of proximal and distal factors influence why obstetric fistula continues to occur in these settings, it would be remiss to fail to recognize how lack of political will also contributes, including failure to prioritize healthcare services and neglecting the sexual and reproductive health and rights (SRHR) of women and girls. The consequences of these failures are profound, particularly in developing regions. Each year, more than 30 million women give birth outside of a healthcare facility, more than 45 million women receive no or inadequate antenatal care, and more than 200 million women who want to avoid pregnancy are not using modern contraception (Starrs et al., 2018).

Although obstetric fistula is almost completely preventable, it persists due to gross societal and institutional neglect of women and girls, which is an issue of rights and equity (Donnay & Weil, 2004). Collectively, the continuing occurrence of obstetric fistula, inadequate provision of timely