

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

Global Maternal and Child Health

Medical, Anthropological, and Public Health
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Series Editor

David A. Schwartz, Atlanta, GA, USA

Global Maternal and Child Health: Medical, Anthropological, and Public Health Perspectives is a series of books that will provide the most comprehensive and current sources of information on a wide range of topics related to global maternal and child health, written by a collection of international experts.

The health of pregnant women and their children are among the most significant public health, medical, and humanitarian problems in the world today. Because in developing countries many people are poor, and young women are the poorest of the poor, persistent poverty exacerbates maternal and child morbidity and mortality and gender-based challenges to such basic human rights as education and access to health care and reproductive choices. Women and their children remain the most vulnerable members of our society and, as a result, are the most impacted individuals by many of the threats that are prevalent, and, in some cases, increasing throughout the world. These include emerging and re-emerging infectious diseases, natural and man-made disasters, armed conflict, religious and political turmoil, relocation as refugees, malnutrition, and, in some cases, starvation. The status of indigenous women and children is especially precarious in many regions because of ethnic, cultural, and language differences, resulting in stigmatization, poor obstetrical and neonatal outcomes, limitations of women's reproductive rights, and lack of access to family planning and education that restrict choices regarding their own futures. Because of the inaccessibility of women to contraception and elective pregnancy termination, unsafe abortion continues to result in maternal deaths, morbidity, and reproductive complications. Unfortunately, maternal deaths remain at unacceptably high levels in the majority of developing countries, as well as in some developed ones. Stillbirths and premature deliveries result in millions of deaths annually. Gender inequality persists globally as evidenced by the occurrence of female genital mutilation, obstetrical violence, human trafficking, and other forms of sexual discrimination directed at women. Many children are routinely exposed to physical, sexual, and psychological violence. Childhood and teen marriages remain at undesirably high levels in many developing countries.

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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

Laura Briggs Drew • Bonnie Ruder
David A. Schwartz
Editors

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Editors

Laura Briggs Drew
Office of the Senior Vice
President and Provost
University of Maryland
College Park, MD, USA

Bonnie Ruder
Terrewode Women's Fund
Eugene, OR, USA
International Fistula Alliance
Sydney, Australia

David A. Schwartz
Perinatal Pathology Consulting
Atlanta, GA, USA

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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.

Edna Adan Ismail
Edna Adan Maternity Hospital
Hargeisa, Somalia

Edna Adan University
Hargeisa, Somalia

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.

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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.

Contributors

Mulat Adefris, MD, MPH Department of Obstetrics and Gynecology, University of Gondar, Gondar, Ethiopia

Alice Abokai Agana, RN, RM, MPhil Nursing and Midwifery Training College, Yeji, Bono East Region, Ghana

Saifuddin Ahmed, MBBS, PhD Department of Population, Family, and Reproductive Health, Johns Hopkins University Bloomberg School of Public Health, Baltimore, Maryland, USA

Robert Andrianne, MD, MMed Urology, PhD Department of Urology, University Hospital, University of Liège, Liège, Belgium

Aduragbemi Banke-Thomas, MD, PhD, MPH School of Human Sciences, University of Greenwich, London, UK

Justus K. Barageine, MBChB, MMed, PhD, FCOG (ECSA) Department of Obstetrics and Gynaecology, Makerere University College of Health Sciences, Kampala, Uganda

Meghan Beddow, MD Southcentral Foundation, Alaska Native Medical Center, Anchorage, AK, USA

Laurence Bernard, MD, MPH University of Ottawa, Ottawa, ON, Canada

Priscilla N. Boakye, RN, Mphil, PhD. (Cand.) Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, ON, Canada

Andrew Browning, AM, MBBS, FRCOG FRANZCOG (Hon) Maternity Africa, Arusha, Tanzania

Barbara May Foundation, Bowral, NSW, Australia

Bahir Dar Fistula Centre, Bahir Dar, Ethiopia

Ennet Banda Chipungu, MBBS, FCOG Freedom from Fistula Foundation, Freetown, Sierra Leone

Jacques Corcos, MSC, MD, FRCS(S) Department of Surgery (Division of Urology), McGill University, Jewish General Hospital, Montréal, QC, Canada

Karen D. Cowgill, PhD, MSc University of Washington Tacoma, Tacoma, WA, USA

University of Washington, Seattle, WA, USA

Alexandre Delamou, MD, MSc, MPH, PhD Department of Public Health & Africa Center of Excellence (CEA-PCMT), University Gamal Abdel Nasser of Conakry, Conakry, Guinea

Julie Désalliers, MD, MSc Espace Santé Nun's Island Clinical, Hôpital de LaSalle, Montréal, QC, Canada

Laura Briggs Drew, PhD, MPH Office of the Senior Vice President and Provost, University of Maryland, College Park, MD, USA

Alison M. El Ayadi, ScD, MPH Department of Obstetrics, Gynecology and Reproductive Sciences, University of California San Francisco, San Francisco, CA, USA

Alice Emasu, MBA, MSW TERREWODE and Terrewode Women's Community Hospital, Soroti, Uganda

Kathomi Gatwiri, PhD, M Couns Psych, BASW Faculty of Health, Centre for Children & Young People, Southern Cross University, Gold Coast, Australia

René Génadry, MD, FRCS (C) Department of Obstetrics & Gynecology, University of Iowa, Iowa City, IA, USA

Judith Goh, MBBS (Qld), FRANZCOG, PhD, AO Griffith University, Gold Coast, QLD, Australia

Greenslopes Hospital, QEII Hospital, Brisbane, QLD, Australia

Laura Jacobson, MPH, Doctoral Student Oregon Health & Science University-Portland State University, School of Public Health, Portland, OR, USA

Kimberly Jarvis, PhD, R.N Faculty of Nursing, Memorial University, St. John's, NL, Canada

University of Alberta, Edmonton Clinic Health Academy, Edmonton, AB, Canada

Caroline Johnson, MPH Independent Contributor, Washington, DC, USA

Jean-Baptiste S. Z. Kakoma, MD, MMed OG, PhD, AESM Department of Gynecology and Obstetrics, University of Lubumbashi, Lubumbashi, Democratic Republic of the Congo

University of Rwanda, Kigali, Republic of Rwanda

Prosper L. Kakudji, MD, MMed OG, PhD Department of Gynecology and Obstetrics, University of Lubumbashi, Lubumbashi, Democratic Republic of the Congo

Ivy Kalama Freedom from Fistula Foundation, Freetown, Sierra Leone

Weston Khisa, PhD Reproductive Health Department, Kenyatta National Hospital, Nairobi, Kenya

Xavier K. Kinenkinda, MD, MMed OG, PhD Department of Gynecology and Obstetrics, University of Lubumbashi, Lubumbashi, Democratic Republic of the Congo

Salam Kouraogo, MA Department of Sociology, Université de Ouagadougou, Ouagadougou, Burkina Faso

Hannah G. Krause, MBBS, FRANZCOG, AO Greenslopes Hospital, QEII Hospital, Brisbane, QLD, Australia

Ann E. Kurth, PhD, MSN, MPH Yale University School of Nursing, New Haven, CT, USA

Epidemiology of Microbial Diseases, Yale School of Public Health, New Haven, CT, USA

Tina Lavender, DBE, PhD Department of International Public Health, Liverpool School of Tropical Medicine, Liverpool, Great Britain

Jordann Loehr, MD, MPH, FACOG University of Gondar, Gondar, Ethiopia

Heather Lytle, MD, MSPH, FACOG Department of Obstetrics and Gynecology, University of Utah Health, Salt Lake City, UT, USA

Marielle E. Meurice, MD Department of Obstetrics & Gynecology, University of California, Irvine, CA, USA

Stella Masala Mpanda, MSc, BNS Childbirth Survival International,
Dar es Salaam, Tanzania

Lilian Teddy Mselle, PhD, Mphil, BA, RNM Department of Clinical
Nursing, Muhimbili University of Health and Allied Sciences, Dar es Salaam,
Tanzania

Olivier Mukuku, MD Department of Maternal and Child Health, High
Institute of Medical Techniques of Lubumbashi, Lubumbashi, Democratic
Republic of the Congo

Prudence Mwini-Nyaledzigbor, RN, RM, PhD Catholic University
College, Fiapre, Sunyani, Ghana

Rahel Nardos, MD, MCR, FPMRS Division of Female Pelvic Medicine
and Reconstructive Surgery, Department of Ob/Gyn & Women's Health,
Center for Global Health and Social Responsibility, University of Minnesota,
Minneapolis, MN, USA

Joseph B. Nsambi, MD, MMed OG, PhD Department of Gynecology and
Obstetrics, University of Lubumbashi, Lubumbashi, Democratic Republic of
the Congo

Dorothy N. Ononokpono Department of Sociology and Anthropology,
University of Uyo, Uyo, Nigeria

Marie-Eve Paré, PhD Department of Anthropology, College Professor at
Cégep Edouard-Montpetit, Longueuil, QC, Canada

Beth S. Phillips, MPH Institute for Global Health Sciences, University of
California San Francisco, San Francisco, CA, USA

F. Beryl Pilkington, RN, PhD School of Nursing, Faculty of Health, York
University, Toronto, ON, Canada

Rachel Pope, MD, MPH University Hospital, Cleveland Medical Center,
Urology Institute, Cleveland, OH, USA
Fistula Care Center, Lilongwe, Malawi

Solina Richter, MCur, DCur, RN College of Nursing, University of
Saskatchewan, Saskatoon, SK, Canada

Bonnie Ruder, PhD, MPH, CPM Terrewode Women's Fund, Eugene,
OR, USA
International Fistula Alliance, Sydney, Australia

Nessa Ryan, PhD, MPH, MSCI New York University School of Global
Public Health, New York, NY, USA

Susan and Henry Samueli College of Health Sciences, Irvine, CA, USA

David A. Schwartz, MD, MS Hyg, FCAP Perinatal Pathology Consulting, Atlanta, GA, USA

Gillian Slinger, RN, RM, BSc, MSc Fistula Surgery Training Initiative, FIGO, London, UK

Theresa Spitznagle, PT, DPT, MHS, WCS Program in Physical Therapy, Department of Obstetrics and Gynecology, Washington University School of Medicine in St. Louis, St. Louis, MO, USA

Global Women's Health Initiative, Millis, MA, USA

Worldwide Fistula Fund, Schaumburg, IL, USA

Pooja Sripad, PhD, MPH Social Behavioral Science Research, Population Council, Washington, DC, USA

Mary J. Stokes, MD Department of Global Women's Health, Obstetrics and Gynecology, Baylor College of Medicine, Houston, TX, USA

Lilli Trautvetter, BA, MSc Fistula Surgery Training Initiative, FIGO, London, UK

Vandana Tripathi, PhD, MPH Fistula Care Plus, EngenderHealth, New York, NY, USA

Helen Vallianatos, PhD Department of Anthropology, University of Alberta, Edmonton, AB, Canada

Sabina Wakasiaka, PhD College of Health Sciences, University of Nairobi, Nairobi, Kenya

L. Lewis Wall, MD, DPhil Departments of Anthropology and Obstetrics & Gynecology, Washington University in St. Louis, St. Louis, MO, USA

Charlotte E. Warren, PhD, MEd, RSCN, RN, ON Social Behavioral Science Research, Population Council, Washington, DC, USA

Part I

Obstetric Fistula



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

1

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-

B. Ruder (✉)
Terrewode Women’s Fund, Eugene,
OR, USA
International Fistula Alliance, Sydney, Australia

L. B. Drew
Office of the Senior Vice President and Provost,
University of Maryland,
College Park, MD, USA
D. A. Schwartz
Perinatal Pathology Consulting, Atlanta, GA, USA

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 disproportionately 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.

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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

L. B. Drew (✉)
Office of the Senior Vice President and Provost,
University of Maryland, College Park, MD, USA
e-mail: lbdrew@umd.edu

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

repair, as well as the suffering and stigma that result from obstetric fistula, illuminate gross violations of human rights, which are intended to protect women's dignity (Cook et al., 2004). Therefore, if we are to achieve the United Nations' goal to eradicate obstetric fistula by 2030 (United Nations General Assembly, 2020), we must utilize an approach that prioritizes the SRHR of women and girls across the globe. From a human rights perspective, these efforts should focus on expanding data collection to accurately monitor progress, implementing programs to promote safe motherhood and prevent obstetric fistula development, increasing access to skilled obstetric fistula repair, and strengthening reintegration programs to address the totality of obstetric fistula consequences, including outcomes that pertain to SRHR.

2.2 Obstetric Fistula Development and Risk Factors

Obstetric fistula primarily occurs due to prolonged, obstructed labor without skilled care, and most women who develop an obstetric fistula labor at home between 2.5 and 4 days (Tebeu et al., 2012). During this extended period of time, the baby's head puts increasing pressure on tissues in the birth canal, which blocks blood supply to the surrounding tissues and leads to ischemia and necrosis. Consequently, a hole develops in the tissues that separate the vagina and the bladder (vesicovaginal fistula) and/or the vagina and the rectum (rectovaginal fistula). Once the obstetric fistula develops, the woman experiences chronic incontinence of urine and/or feces. In addition to this physical suffering, the prolonged, obstructed labor impacts the health of the baby; stillbirths occur in 90% of pregnancies in which the woman develops an obstetric fistula (Saifuddin Ahmed et al., 2016). Therefore, when the painful and prolonged labor ends, women are left uncertain of the cause of their incontinence and why their baby died.

Although prolonged, obstructed labor is the primary direct cause of obstetric fistula, a number of indirect factors contribute to maternal mortality and morbidity in resource-limited settings, including gender inequality, poverty, distance to healthcare facilities, lack of information, low education attainment, inadequate services, and cultural practices. These contributing factors reflect inequities in access to healthcare services and highlight the gap in maternal health outcomes between the rich and the poor (World Health Organization, 2019). In some countries where obstetric fistula is more common, fewer than one in three births are assisted by a skilled professional attendant, such as a midwife, nurse, or physician, and in rural areas, the rate of cesarean deliveries is often less than 2% (Velez et al., 2007). The international healthcare community has recommended the ideal rate for cesarean sections to be 10–15% since research has shown maternal and newborn deaths decrease when the cesarean section rate rises toward 10% (World Health Organization & Human Reproduction Programme, 2015); however, regional disparities, particularly within the “fistula belt,” reveal gross inequities in access to this life-saving emergency obstetric care.

In some cases, there may be access to emergency obstetric care, but a number of factors contribute to why women may not receive it. The “Three Delays” model specifically attributes maternal mortality to delays in deciding to seek medical help for an obstetric emergency, delays in reaching an appropriate obstetric facility, and delays in receiving adequate care when an individual has reached the facility (Barnes-Josiah et al., 1998). Although this model was developed for maternal mortality, the framework can also be applied to maternal morbidities (Pacagnella et al., 2012), particularly obstetric fistula.

A cesarean section can relieve prolonged, obstructed labor and prevent an obstetric fistula from developing; however, for many women in resource-limited settings, this emergency obstetric service is often unavailable, unreachable, or unaffordable. Additionally, when women labor outside health-care facilities, women, their families, and traditional birth attendants (TBAs) may not recognize the signs of prolonged, obstructed labor and/or know that an emergency cesarean section is necessary.

Fig. 2.1 Women in rural Malawi return to their homes after a community meeting to promote safe motherhood, which announced construction of a nearby maternal waiting home and encouraged women with obstetric fistula to seek repair services at the Obstetric Fistula Repair Centre at Bwaila Maternity Hospital in Lilongwe, Malawi. (Photograph credit: Laura Briggs Drew)



When women try to labor at home but are unsuccessful, they are also more likely to reach a healthcare facility at a late stage, and this can be further delayed by lack of transportation, poor roads, heavy rains, great distances, and cost barriers (Tebeu et al., 2012). Therefore, obstetric fistula results from obstructed labor *and* obstructed transportation; the patient is often unable to access a hospital for delivery when labor stops progressing normally or the decision to seek a facility is made too late. For these reasons, key strategies to improve maternal health in rural and resource-limited settings include implementing community outreach programs that promote safe motherhood, increasing skilled attendance at birth, and constructing maternal waiting homes (Fig. 2.1).

In addition to limited access to skilled emergency obstetric care, many of the other risk factors for obstetric fistula development are tied to gender inequality, particularly poor nutrition for girls as well as marriage and childbearing at a young age. To begin, women who develop obstetric fistula are often small, short, and young. Characteristics of fistula patients reveal 40–80% of obstetric fistula occurs in women less than 150 cm tall (Tebeu et al., 2012; Wall et al., 2004), and a study in Nigeria found being less than 150 cm tall nearly doubles the risk of obstetric fistula occurrence (Ampofo et al., 1990). In many patriarchal societies, women and girls often eat their meals after men, and this can lead to chronic under-nutrition and ill health (Babiker, 2017). Additionally, poor nutrition is associated with small stature, pelvic immaturity, and chronic malnutrition, which can limit pelvic growth in young women (Zabin & Kiragu, 1998). Although growth in height stops or slows with the onset of menarche, the pelvis continues to grow through late adolescence and the birth canal is smaller the first 3 years after the onset of menarche than it is at age 18 (Moerman, 1982).

Although delaying pregnancy until pelvic structures have matured and grown to their full adult size can decrease the risk of cephalopelvic disproportion, early marriage and pregnancy are common among many cultures in sub-Saharan Africa. In 2018, West and Central Africa, which are within the “fistula belt,” had the highest regional adolescent birth rate in the world, with 115 births per 1000 girls aged 15–19 (UNICEF, 2019). Although adolescent birth rates have been decreasing across the globe, pregnancy at a young age is particularly dangerous, and adolescent mothers are less likely to receive skilled assistance during delivery or postnatal care compared to older mothers (UNICEF, 2019). Therefore, the risk of obstructed labor is greater in areas where both marriage and childbearing commonly occur at a young age (Wall, 2006), thereby increasing the risk of obstetric fistula development.

2.3 Long-Term Consequences and Quality of Life After Obstetric Fistula Development

When a woman or girl develops an obstetric fistula, her life is dramatically changed. She often does not know the cause of the incontinence, what contributed to the stillbirth, or that her condition can be resolved via surgery. In 1996, Arrowsmith and colleagues presented the “obstructed labor injury complex” to describe the multitude of factors that lead to obstructed labor, and consequently obstetric fistula development, as well as the physical and social injuries that result from obstetric fistula (Arrowsmith et al., 1996). In addition to obstetric fistula formation, obstructed labor can lead to fetal death, complex urologic injuries, vaginal scarring and stenosis, secondary infertility, musculoskeletal injury, and foot drop (Arrowsmith et al., 1996). For women who have obstetric fistula, nearly 80% will develop skin abrasions due to their urinary incontinence (Ahmed & Holtz, 2007).

In addition to the physical suffering of chronic incontinence, obstetric fistula is often a lifelong maternal morbidity that can impact a woman’s quality of life socially, psychologically, and economically. Because women with obstetric fistula are unable to manage their chronic incontinence and its subsequent odor, they are often stigmatized and shunned from their partners, families, and communities, which can negatively impact their quality of life in many ways. They may be unable to care for their family, share meals with their family, attend religious services, travel, and work because they are seen as “unclean” and unable to control their incontinence (Drew et al., 2016). Additionally, their social roles as women, wives, and mothers can be impacted; sexual dysfunction as well as fears and uncertainty about their ability to achieve a future pregnancy can lead to partner abandonment and isolation from their families (Drew et al., 2016; Mselle et al., 2011). This stigma and isolation often lead to loss of social support, worsening poverty and malnutrition, as well as suffering, illness, and premature death (Arrowsmith et al., 1996).

Because the physical, economic, and social consequences of obstetric fistula add difficulty and stress to the lives of these women, obstetric fistula can negatively affect psychiatric health (Weston et al., 2011). The pooled estimated prevalence of depression among women with obstetric fistula in African countries is greater than 50% (Duko et al., 2020), and high rates of suicidal ideation have been reported (Weston et al., 2011). These statistics are particularly concerning since access to mental health care is limited in areas where obstetric fistula is common. Therefore, when implementing holistic approaches to fistula management, programs should provide mental health care and family support to address the psychiatric dimensions of fistula patients’ well-being (Weston et al., 2011). Without appropriate care, women with obstetric fistula will continue to suffer physically, psychologically, socially, and economically. Therefore, the health and human rights of women who have endured obstetric fistula must be prioritized as we move toward eradicating obstetric fistula by 2030.

2.4 Progress Toward Obstetric Fistula Eradication

2.4.1 Expanding Data Collection: Challenges in Knowing the True Burden of Obstetric Fistula

In locations where most births occur outside of healthcare facilities and facilities may have poor record-keeping on births, accurate and nationally representative data on the incidence and prevalence of maternal mortalities and morbidities are scant (Johnson & Peterman, 2008). Additionally, hospital records are not nationally representative and they only capture women with obstetric fistula who reach a facility, which underestimates the true burden of this childbirth injury. Hospital records on births from facilities are also prone to selection bias, since these data are not representative of women who give birth outside facilities. Determining the burden of obstetric fistula worldwide is further compli-

cated because many of these women are marginalized and isolated from society with little economic, social, or political power (Baker et al., 2017); therefore, they often do not know that repair is possible or available. These challenges contribute to the paucity of reliable data on the incidence and prevalence of obstetric fistula, particularly at the national level.

The most common data sources on obstetric fistula are medical records, which are not nationally representative and remain dependent upon women with obstetric fistula reaching a healthcare facility, and self-reported surveys (Saifuddin Ahmed & Tunçalp, 2015), including Demographic and Health Surveys (DHS), which gather incontinence data as a proxy measure of obstetric fistula on nationally representative household surveys (Johnson & Peterman, 2008). The true prevalence of obstetric fistula is unknown as this number could only be calculated if all women with obstetric fistula were diagnosed upon clinical examination. Additionally, hospital-based studies fail to elucidate the magnitude and geographic distribution of obstetric fistula (Stanton et al., 2007). Therefore, the DHS attempted to establish baseline national-level prevalence estimates by including questions on symptoms, etiology of the problem, care-seeking behavior, and treatment outcomes in their household surveys (Johnson & Peterman, 2008). These efforts are applauded as they provide baseline prevalence estimates that are nationally representative and can be used to assess the impact of programmatic and policy interventions on obstetric fistula over time (Johnson & Peterman, 2008).

Compared to other maternal morbidities, the symptom of fistula, i.e., unrelenting incontinence after labor, is unlikely to be subject to recall bias; it is easy for women to accurately report compared to other symptoms that may be less apparent and/or associated with multiple maternal morbidities (Johnson & Peterman, 2008), which makes household surveys a useful method to capture this information. However, the DHS questions do have limitations. Notably, respondents, including women who have received obstetric fistula repair, may deny ever experiencing incontinence after labor due to shame (Johnson & Peterman, 2008), which would lead to underreporting. Additionally, overreporting could occur because a woman's incontinence may actually be due to urinary tract infections, stress incontinence, and in some cases, perineal tears (Johnson & Peterman, 2008). Therefore, the proxy measurement of incontinence symptoms for obstetric fistula in DHS may contribute to some inaccuracy in national-level obstetric fistula estimates. Additionally, misestimation may occur because DHS is a household-based survey; therefore, women who are either at fistula repair facilities or have been shunned and are subsequently homeless are not captured by DHS's survey administration methods (Johnson & Peterman, 2008).

Although there may be some inaccuracy in the estimations, the data from DHS do provide meaningful and informative lifetime obstetric fistula prevalence estimates that may be fairly accurate. For example, the lifetime prevalence of fistula in Malawi in 2006 and Uganda in 2004 was estimated to be 4.7% and 2.6%, respectively (Johnson & Peterman, 2008). This aligns with Malawi's maternal mortality ratio also being double that in Uganda (984 and 435 per 100,000 live births, respectively) and supports previous observations that obstetric fistula prevalence is correlated with national maternal mortality ratios (Danson et al., 1996; Johnson & Peterman, 2008). Nevertheless, in settings without national health information systems and where the majority of women give birth outside of facilities, DHS remains the primary method to capture representative information on maternal morbidities, including obstetric fistula, and to ensure comparable data are collected across national settings (Johnson & Peterman, 2008).

Estimating the global prevalence of obstetric fistula has been challenging, and the estimates have varied greatly. A literature review on population-based estimates of obstetric fistula found the original estimates were quoted from studies, background sources, and introductions (Stanton et al., 2007); however, these were secondary and tertiary citations, and in some cases, the original reference was personal communication (Bangser et al., 2002; United Nations Population Fund & EngenderHealth, 2003; Wall, 2002). Other population-based estimates were based upon surgeons' estimations and

studies that described estimation methods with varying degrees of transparency (Stanton et al., 2007). Previously, the most commonly cited estimates of global obstetric fistula prevalence varied between two and three million cases with 50,000–100,000 incident cases per year (Bangser et al., 2002; Browning, 2004; Cook et al., 2004; Danso et al., 1996; Donnay & Weil, 2004; Hilton, 2003; United Nations Population Fund, 2012; United Nations Population Fund & EngenderHealth, 2003; Wall, 1998, 2006). Additionally, the review by Stanton et al. found global fistula prevalence estimates are sometimes incorrectly used to describe the prevalence of obstetric fistula in Africa and Asia (Kelly, 2004; World Health Organization, 2021a), which has added more inconsistencies to prevalence estimates across publications.

Although most publications have previously stated there are two to three million estimated cases of obstetric fistula across the globe, recent research suggests this number overestimates the true burden. A recent meta-analysis and systematic review found a pooled prevalence of 0.29 obstetric fistula per 1000 women of reproductive age in all regions, and in sub-Saharan Africa the prevalence was 1.60 obstetric fistula per 1000 women of reproductive age (Adler et al., 2013). Given there were approximately 1.865 billion women of reproductive age across the globe in 2015 (World Health Organization, 2021b), the global prevalence of obstetric fistula among women of reproductive age at that time would have been closer to 540,000 using the pooled prevalence estimate from Adler et al. The most recent estimate is closer to this number and suggests 500,000 women and girls are currently suffering from obstetric fistula (Ahmed, 2020; United Nations General Assembly, 2020). This remarkable reduction from two to three million to 500,000 estimated prevalent cases suggests significant progress has been made in the eradication of obstetric fistula, including increasing access to obstetric fistula repairs (United Nations General Assembly, 2020). However, new, preventable cases will continue to develop each year without significant improvements in access, quality, and affordability of maternal health services, including emergency obstetric care, which may lag behind incident cases of obstetric fistula (Wall, 2006). As we move forward in our efforts to eradicate obstetric fistula, epidemiologic data and population-based estimates on the incidence and prevalence of obstetric fistula continue to be needed (Stanton et al., 2007). This data is the only way we can accurately measure the impact of our efforts toward achieving obstetric fistula eradication.

2.4.2 Preventing Obstetric Fistula

The medical and social impacts of obstetric fistula on women's lives elucidate the urgent need to reduce fistula incidence as a matter of human rights and women's dignity (Bangser, 2007). Therefore, we must prevent incident cases of obstetric fistula through targeted interventions that promote safe motherhood and increase access to skilled attendance at birth (Fig. 2.2). The WHO classifies fistula prevention strategies into the following categories: 1) prevention strategies that focus on contraception and family planning; 2) secondary prevention strategies to ensure women have access to skilled care during delivery; and 3) tertiary prevention strategies, which focus on early fistula screening among women at increased risk (de Bernis, 2007). Collectively, these prevention strategies recognize obstetric fistula persists solely because structural factors, including gender inequality and inequity in healthcare access and quality, allow this preventable childbirth injury to continue. Therefore, any efforts that focus on obstetric fistula prevention must prioritize the SRHR of women and girls.

Successful strategies to prevent obstetric fistula include educating communities about the cultural, social, and physiologic factors that increase risk of obstetric fistula (Miller et al., 2005). Because cephalopelvic disproportion increases risk of obstructed labor and obstetric fistula development, delaying childbearing for several years after menarche can prevent the sequelae of prolonged, obstructed labor (Miller et al., 2005). Therefore, while being sensitive to social and cultural factors,

Fig. 2.2 Aberdeen Women's Centre outside Freetown, Sierra Leone. The facility provides comprehensive maternal health care, including family planning, skilled attendance during delivery, and obstetric fistula repair. (Photograph credit: Laura Briggs Drew)



prevention efforts should focus on working with communities to emphasize the need to delay marriage and childbearing at a young age. Additionally, the special nutritional needs of girls should be emphasized to prevent chronic malnutrition and improve the physical maturity of young mothers (Miller et al., 2005).

Efforts to prevent obstetric fistula must also focus on ensuring women who are in need of modern contraception have access to these methods. In 2019, 1.9 billion women were of reproductive age (15–49 years), of which 1.1 billion had a need for family planning, yet 270 million women who wanted family planning methods did not have access to modern contraceptive methods (Kantorová et al., 2020). Ensuring access to and use of preferred contraceptive methods advances the human right of people to determine the number and spacing of their children (World Health Organization, 2020). For adolescent girls in particular, contraception use can prevent pregnancy-related health risks, including obstructed labor and obstetric fistula, and it offers a range of potential non-health benefits, including education opportunities which can advance women's empowerment and gender equality (World Health Organization, 2020).

In rural areas, midwives have a critical role in obstetric fistula prevention efforts as they can promote preventative health practices within communities. Additionally, midwives' training and skills allow for early detection of cephalopelvic disproportion, malpresentation, and prolonged, obstructed labor (Miller et al., 2005), which can encourage a family's decision to transport a mother to a maternity waiting home prior to delivery or a healthcare facility when complications arise during labor. In areas where obstetric fistula is common, increasing access to skilled attendance at birth is critical, and curriculums on obstetric fistula prevention have been developed for nurses and midwives in these settings (East, Central, and Southern African Health Community (ECSA-HC) and Fistula Care/EngenderHealth, 2012).

The absence of skilled attendants during delivery and the lack of accessible high-quality emergency obstetric care perpetuate obstetric fistula development in resource-limited settings. For many countries within the "fistula belt," less than half of live births occur with the assistance of skilled birth attendants (World Health Organization, 2021c). The World Health Organization has prioritized the need to expand skilled attendance at delivery, particularly in countries where coverage of skilled

attendance at birth is below 85% (World Health Organization, 2004). For many women, TBAs—non-formally trained and community-based providers of care during pregnancy, childbirth, and the postnatal period who are independent of the health system—are often the only available source of care during pregnancy (World Health Organization, 2004), and their assistance may be preferred for cultural, traditional, and financial reasons. Because skilled attendance at birth can threaten the livelihood of TBAs and since they work outside of the healthcare system, TBAs may have tense relationships with government healthcare systems and vice versa (World Health Organization, 2004). Therefore, it has been difficult to successfully incorporate their involvement in safe motherhood strategies (World Health Organization, 2004). Additionally, training TBAs has not been effective in reducing maternal mortality (World Health Organization, 2004).

Although it may be challenging to incorporate TBAs into safe motherhood strategies, they have a longstanding role and cultural importance in their communities, and TBAs can serve as partners to increase the number of births that occur in the presence of a skilled birth attendant (World Health Organization, 2004). The WHO points to Malaysia as an example of how to successfully incorporate TBAs into safe motherhood strategies; TBAs were registered in a separate section of the Midwives' Register, trained in avoidance of harmful practices, and given delivery allowances and hygienic childbirth kits, and they contributed valuable services, such as postnatal massages, while government midwives oversaw the delivery process (Pathmanathan et al., 2003). Additionally, TBAs reported cases to the government midwife and had their supplies renewed, and under this strategy, home deliveries shifted from being TBA-assisted to being under the supervision of government-trained midwives (Pathmanathan et al., 2003). Therefore, when trying to ensure safe motherhood, it is important to recognize that TBAs, although not formally trained, can be incorporated into such strategies. Indeed, creative and holistic solutions are needed if we are to achieve sustainable impact in reducing global maternal mortality and morbidity, including eradicating obstetric fistula by 2030.

2.4.3 Increasing Access to Obstetric Fistula Repair

When discussing the progress that has been made toward the eradication of obstetric fistula, it would be remiss to fail to highlight the work of Dr. Catherine Hamlin and her husband, Dr. Reg Hamlin, who were pioneers and devoted their lives to providing obstetric fistula repair surgery in Ethiopia. In 1974, they cofounded the Addis Ababa Fistula Hospital, which is a global center of expertise and training on obstetric fistula repair (Hamlin & Fleck, 2013). Through their work, they dramatically remodeled the maternal healthcare landscape for women in Ethiopia; more than 60,000 women with obstetric fistula received skilled surgical repair and had their lives transformed (Catherine Hamlin Fistula Foundation, 2018). Similar models have been replicated in other settings where fistula is common, which have provided life-changing surgeries for women who have suffered from obstetric fistula. More recently, the Hamlin College of Midwives was founded to ensure more women in Ethiopia have skilled attendance during their deliveries. This program recruits high school graduates from the provinces to receive midwifery training so they can return to the provinces and work with the regional fistula centers (Hamlin Fistula Ethiopia, 2014). Their pioneering work has propelled positive action to address obstetric fistula, and without their dedicated efforts, obstetric fistula would not be internationally recognized as a neglected public health and human rights issue.

As obstetric fistula has gained more prominence as a public health issue, the surgical community has also shown increased attention to improving access to obstetric fistula treatment, and these services are almost always at no cost to the patient. When women and girls have access to skilled fistula surgeons, obstetric fistula repair is successful in more than 90% of cases (Barone et al., 2015; Nardos et al., 2009, 2012; Sori et al., 2016). Therefore, the International Federation of Gynecology and

Obstetrics (FIGO) established a standardized global fistula training program to ensure surgeons can be trained in the latest techniques (Browning & Syed, 2020). This education and training program will improve women's access to high-quality fistula repair surgery and make strides toward bridging the obstetric fistula treatment gap. FIGO's effort is promising, since although the exact prevalence of obstetric fistula is unknown, there is general agreement that it considerably outweighs the number of local, skilled fistula surgeons who can repair this childbirth injury (Slinger & Trautvetter, 2020). However, in addition to these efforts, resources must be mobilized and countries should be empowered to develop their own sustainable fistula eradication plans, including access to safe delivery and emergency obstetric care (Slinger & Trautvetter, 2020).

As we expand training for the next generation of fistula surgeons, we must also continue to evaluate novel surgical techniques and ways to improve continence and sexual health after repair (Browning & Syed, 2020). Currently, there is a research gap in obstetric fistula repair techniques, and in settings where obstetric fistula is more common, there are unique challenges that may preclude the feasibility of such research studies (Pope & Beddow, 2020). Additionally, iatrogenic fistula is on the rise in settings where obstetric fistula is common, which indicates a need for additional research on the prevention and treatment of these injuries (Pope & Beddow, 2020). As international efforts are employed to gather evidence on successful surgical techniques while training local fistula surgeons to bridge the fistula treatment gap, the number of women who suffer lifelong consequences of obstetric fistula will shrink, and we will be one step closer toward eradicating this preventable and treatable childbirth injury.

However, availability of skilled fistula surgeons does not equate to accessibility; women who need fistula repair may be unable to reach these services due to barriers such as poverty, distance, and social isolation. For many women, the absence or cost of transportation is a significant barrier to reaching and receiving obstetric fistula repair services (United Nations General Assembly, 2020). Additionally, they may not know that their condition is treatable or they may be unfamiliar with healthcare services and reluctant to seek treatment. Sociocultural factors, including use of cultural and traditional practices to treat fistula, have also been identified as reasons that can contribute to delays in seeking obstetric fistula repair (Lyimo & Mosha, 2019). In some settings, decision making may be predominantly made by men, and this can lead to unequal opportunities in women's health education as well as women's lack of decision-making authority on where they can seek healthcare services (Lyimo & Mosha, 2019). To reduce these barriers to fistula repair, a number of programs have been implemented, including hospital outreach programs, mobile surgical outreach programs, community-based screening for obstetric fistula, fistula ambassador programs to identify women in need of repair, and programs to reduce financial transportation barriers (Fiander et al., 2013; Freedom from Fistula Foundation, 2016; Maroyi et al., 2020; Tunçalp et al., 2014; Umoiyoho et al., 2012; United Nations Population Fund, 2019). As similar programs are implemented in additional settings, their feasibility and impact should be evaluated, so we can achieve progress in identifying women who are in need of obstetric fistula repair and ensure that they are able to reach these life-changing services.

2.4.4 Strengthening Reintegration: Providing Continuing Support and Prioritizing SRHR After Obstetric Fistula Repair

In recent years, access to obstetric fistula repair has improved in sub-Saharan Africa and many women report improvements in physical and mental health after repair (Drew et al., 2016; El Ayadi et al., 2020). However, because of the stigmatizing nature of obstetric fistula, which a woman may have endured for many years before surgery, reintegration may be more challenging for some women than others as they adjust to new circumstances and attempt to resume their prior roles. Depending on the

severity of their fistula and surgical outcomes, some women may experience ongoing physical and psychological challenges when they reintegrate into their communities, and they may need additional medical care and continuing follow-up (El Ayadi et al., 2020). For a woman who has an unsuccessful fistula repair and continues to suffer from incontinence, stigma and discrimination may worsen because her fistula is considered irreparable, and this may lead to ongoing social, economic, and psychological suffering. For women who have a successful repair but continue to suffer from incontinence (stress, urge, or low capacity), they may require further follow-up to determine and address the cause of their incontinence (Drew et al., 2016). Therefore, in addition to capacity building and strengthening health systems to prevent and treat obstetric fistula, fistula care should be comprehensive and holistic to facilitate the reintegration process and restore women's dignity (Bomboka et al., 2019). Such efforts should be based on individualized assessments of women's social reintegration needs (Emasu et al., 2019), including economic security, social support, health education, relationship desires, and family planning. A number of programs incorporate education, training in income-generating skills, and group therapy as part of obstetric fistula treatment (El Ayadi et al., 2020); however, it is imperative that women's SRHR also be prioritized as they reintegrate into their communities after obstetric fistula repair.

Interviews with women in sub-Saharan Africa have revealed that resuming their social roles as wives and mothers is a predominant positive experience during reintegration after fistula repair (Lombard et al., 2015). However, many factors may influence how quickly and successfully these roles can be resumed, particularly sexual activity, pregnancy, and childbirth. A challenging part of the discharge process is encouraging women to abstain from sexual activities for up to 6 months to allow the vaginal tissues to heal; however, this extended period of abstinence may unintentionally discourage some women from seeking obstetric fistula repair (Drew et al., 2016). Additionally, because women are encouraged to abstain from sexual activity during this prolonged period, they may be less likely to seek and use family planning methods, which could lead to unintended pregnancies and increased risk of future labor complications among women who have undergone obstetric fistula repair (Drew et al., 2016). Although many women may be able to re-establish intimate relationships after repair, the surgery can reduce vaginal caliber and women commonly report sexual dysfunction, including painful intercourse, after repair (Anzaku et al., 2017; Drew et al., 2016; Pope et al., 2018). Sexual activity can be a stigmatized health care topic; however, obstetric fistula repair centers can be used as safe spaces to discuss such issues (Mernoff et al., 2020), and these discussions may be helpful for women as they attempt to resume their intimate relationships after obstetric fistula repair. Therefore, comprehensive discharge processes that include family planning and discussions on sexual activity are encouraged. Counseling and treatment to address sexual dysfunction after obstetric fistula repair are also warranted.

In many contexts, motherhood is a critical component of a woman's identity; it defines her position in her kinship group and community (Mselle et al., 2011). Therefore, it is not surprising that a recent review on women's reintegration experiences after obstetric fistula repair found most women were concerned over their fertility (Lombard et al., 2015). However, contrary to reintegration recommendations expressed by healthcare providers (Mselle et al., 2012), women did not recommend for services that address fertility to be part of the discharge and reintegration process after obstetric fistula repair (Lombard et al., 2015). This dichotomy suggests that although healthcare providers may be able to address this need, women from low-income backgrounds may not be informed about clinical options to address their fertility concerns (Lombard et al., 2015). Indeed, most family planning services in settings with high fertility, like sub-Saharan Africa, focus on contraceptive access and promoting women's agency and decision-making for delaying and/or preventing future pregnancies, while little resources are allocated toward addressing infertility. This finding further reflects institutional failures to address the totality of issues pertaining to the SRHR of women and girls, including their fertility desires.

As we gain progress toward eradicating obstetric fistula, additional research is needed to better understand women's needs during reintegration and long-term outcomes after obstetric fistula repair, including their sexual and reproductive health. To inform the development and implementation of effective reintegration programs, such research should include patients' perspectives and recommendations rather than solely focusing on institutional perspectives (Lombard et al., 2015). Researchers and service providers should additionally implement more robust evaluations of their programs, and standardization of objectives and patient outcomes would enable evaluations of reintegration programs to be compared with one another (El Ayadi et al., 2020).

2.5 Increasing Public Awareness, Advocacy, and Action on Obstetric Fistula Through a Human Rights Approach

Although great progress was achieved in the United Nations' Millennium Development Goals, which sought to significantly decrease global maternal mortality and morbidity by 2015, disparities continue to persist across the globe, particularly in resource-limited settings. Therefore, more work needs to be done in order to achieve the United Nations' Sustainable Development Goals that pertain to advancing the health of women and girls by 2030. These targets include improving maternal health, achieving universal healthcare coverage, the eradication of child and early marriage, and ensuring universal access to sexual and reproductive healthcare services, including family planning, education, and integrating reproductive health into national strategies and programs (United Nations, 2015). In addition to these targets, the United Nations Secretary-General has put forward the goal to eradicate obstetric fistula by 2030 (United Nations General Assembly, 2020). While this goal is ambitious, it is also achievable if we prioritize the SRHR of women and girls.

If we fail to propel positive action toward preventing severe birth injuries, like obstetric fistula, women will continue to suffer from lifelong disabilities and poor quality of life. In addition to the United Nations, many partners, including EngenderHealth, FIGO, Freedom from Fistula Foundation, the Fistula Foundation, the Hamlin Hospital, Mercy Ships, Médecins Sans Frontières, and others have called for increased action to improvements in maternal health, including addressing obstetric fistula (United Nations General Assembly, 2020). In order to successfully eradicate obstetric fistula by 2030, global strategies must be developed to strengthen health systems to provide cost-effective fistula surgery, and the many risk factors that lead to prolonged, obstructed labor in low- and lower-middle income countries must be addressed (Epiu et al., 2018), including issues of human rights and social justice.

The upsetting and troubling reality is most maternal mortalities, and morbidities, including obstetric fistula, are often entirely preventable (United Nations Population Fund, 2020), but factors at the individual, interpersonal, and societal levels perpetuate the problem. For these reasons, it is imperative that there are collaborative efforts to recognize the importance of ensuring safe motherhood across the globe and prioritize women's health issues as issues of human rights. Additionally, accelerating progress in SRHR is recognized as being essential to people's health and survival, to global economic development and to the overall well-being of humanity (Starrs et al., 2018). However, despite the evidence of these benefits, progress in prioritizing SRHR has historically been stalled due to weak political commitment, inadequate resources, gender inequality, discrimination against women and girls, and hesitation to address issues that pertain to women's sexuality (Starrs et al., 2018). Given many of the United Nations' Sustainable Development Goals are targeted toward advancing the health of women and girls by 2030, it is imperative that governments and institutions collaborate to prioritize the SRHR of women and girls.

Furthermore, given that a woman's health is inextricably linked to that of her family, advancements in women's health will not only improve health and well-being for women, but they will also extend to their families. Specifically, maternal morbidities often affect more than the mother's health, as her morbidities can impact the health and development of the next generation, as well as the well-being of the family, including its social and economic standing (Koblinsky et al., 2012). This relationship is particularly evident in cases of obstetric fistula, as women who suffer from this childbirth injury are often stigmatized, abandoned, and unable to work because of their chronic incontinence. Therefore, the consequences of obstetric fistula can also affect the social and economic well-being of her family. For too long, reducing maternal morbidities has been a neglected agenda in maternal health (Koblinsky et al., 2012). However, if we prioritize and protect the SRHR of women and girls, we can achieve discernible impact and progress (Liljestrand, 2006), including making strides toward the eradication of obstetric fistula. These efforts will lead to improvements in women's health as well as the health of their families.

2.6 Conclusion

In order to successfully eradicate obstetric fistula by 2030, the human rights of women and girls must be protected, and the social determinants of health that lead to regional disparities in maternal mortality and morbidity should be addressed. As a first step, governments must make concerted efforts to prioritize the SRHR of women and girls. Governments, agencies, and organizations must also address the myriad of direct and indirect factors that negatively impact women's health. In addition to inadequate healthcare access, quality, and affordability, these factors include social and economic inequities, gender inequality, low education attainment, poverty, child marriage, and pregnancy at a young age (Anastasi et al., 2020). Obstetric fistula eradication also depends upon building and strengthening programs that target prevention and treatment (Capes et al., 2011), and research is needed to evaluate the impact and effectiveness of these programs. As we move toward eradicating obstetric fistula by expanding data collection to monitor progress, implementing strategies to prevent obstetric fistula development, and strengthening systems to ensure women's reintegration needs are met, fistula treatment must be accessible, affordable, and evidence-based. Unfortunately, there remains a backlog of women who need obstetric fistula repair, and more evidence-based practices are needed to provide high-quality, accessible, and comprehensive care (Pope, 2018).

At the core of these efforts, it must be recognized that obstetric fistula is a problem of gross inequity; it persists only because systems have failed to prioritize and protect the human rights of women and girls. Therefore, programs and policies must address the underlying determinants of obstetric fistula, including gender inequality, poverty, and disempowerment of women in these settings (Lombard et al., 2015). Moreover, if the SRHR of women and girls are not protected and prioritized, preventable maternal mortality and morbidity will continue across the globe. Obstetric fistula eradication can be achieved by 2030, but meeting this goal will only be possible if collaborations and political will recognize human rights violations perpetuate global disparities in maternal health outcomes, including obstetric fistula.

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Archeological Basis for Obstetrical Fistula: A Condition That Is as Ancient as Human Themselves

3

David A. Schwartz

3.1 Evolutionary Origins of Obstructed Delivery

Obstructed labor occurs more frequently in humans than in any other animals. The development of bipedalism in human evolution resulted in skeletal changes together with enlargement of the human brain that together are responsible for this birth complication. Even compared with other primates, childbirth in humans is slow and particularly difficult as a result of the small size of the maternal pelvis and the large size of the fetal head. Bipedal locomotion together with encephalization has resulted in increased demands placed on the human female pelvis. This process of decreased size of the human birth canal resulting from maintaining an upright bipedal mechanism of locomotion and the progressively larger human cranial capacity throughout evolution has been termed the “obstetric dilemma” by Sherwood Washburn (Washburn, 1960; Wittman & Wall, 2007). The resulting “tight fit” between the dimensions of the fetal head and the maternal birth canal is the result of millions of years of human evolution, but has led to rates of cephalopelvic disproportion and consequently obstructed labor in from 1% to 8% of all childbirths in different regions of the world (Dolea & AbouZahr, 2003; Wittman & Wall, 2007). If obstructed labor is not relieved, maternal exhaustion, dehydration, infection, and ketosis can develop. Obstructed labor is a major cause of maternal death in resource-poor nations of the world, in which cases the immediate causes of death include sepsis, uterine rupture, hemorrhage, and shock. Fetal death is also a common occurrence, and if the fetus and placenta are left in situ, maternal complications and death can also ensue (Pavličev et al., 2020; Schwartz, 2015). In those mothers who survive an obstructed delivery, a frequent complication is the development of an obstetric fistula.

3.2 Archeology of Obstetric Fistula and Obstructed Birth

The archeological record provides evidence for a number of diseases in antiquity that includes both infectious and noninfectious conditions. Paleopathology, the study of ancient diseases, utilizes a number of tools to identify these conditions. They include examination of human remains to identify

D. A. Schwartz (✉)
Perinatal Pathology Consulting, Atlanta, GA, USA
e-mail: davidalanschwartz@gmail.com

osteological disease, analysis of preserved soft tissues, chemical analysis, pathology and histological examination, radiological methods, and, most recently, molecular biology techniques.

For the overwhelming majority of human history, pregnancy and childbirth have been dangerous, and even life-threatening, conditions for girls and women (Schwartz, 2018). Although fetal and newborn skeletal remains are not as well preserved as are adult osteological materials, there still exist physical anthropology and archeology evidence of obstetrical death as a result of childbirth in many parts of the ancient world (Wells, 1975; Wells et al., 2012). Examples include the occurrence of a third-trimester fetus associated with the body of the famed “rich Athenian lady” who was cremated c.a. 850 BCE in Greece (Liston & Papadopoulos, 2004); death of a young mother and her unborn full-term breech fetus at the Neolithic site of An Son in Vietnam c.a. 2100–1050 BCE (Willis & Oxenham, 2013); three maternal deaths in medieval Stockholm (Högberg et al., 1987); two maternal deaths from ancient Egypt in which each woman had a deformed pelvis and a fetal head present within the pelvic cavity (Elliot-Smith & Wood Jones, 1910); a woman having a “coffin birth” in medieval Aebelholt, Denmark (Moller-Christensen, 1958; Wells, 1975); and an obstetric death from Kings Worthy, Great Britain, in which a Saxon woman was interred with an infant that appeared to lie half in and half out of her vagina (Hawkes & Wells, 1975; Wells, 1975).

It should not be surprising that one of the leading causes of pregnancy-related death both in ancient and contemporary times is obstructed delivery. As a result, in ancient times the mortality rate of pregnant women with obstructed deliveries was extremely high, and if the dead fetus was not quickly removed (often by decapitation and withdrawal of the remains piece by piece), there would be a high likelihood of maternal sepsis, coagulopathy, hemorrhage, shock, and death. Those who survived the immediate period of childbirth would frequently develop obstetric fistula. In more recent times, still prior to the advent of cesarean section and anesthesia in the nineteenth century, the sole potential treatment for an obstructed delivery was by use of the obstetrical forceps, a tool that had been invented in the seventeenth century and used in secrecy by members of the Chamberlen family of surgeons (Dunn, 1999).

Mummies can be especially rewarding to study in documenting the spectrum and patterns of disease in antiquity, including disorders of pregnancy. This is because in many cases the body, especially the soft tissues including organs, has been preserved due to mortuary rituals or, in some cases, climatological factors. An analysis of female mummies representing seven pre-Columbian Andean populations of Arica, Chile, ranging in age from the Early Formative Period in the Azapa Valley (1300 BCE) up to the Gentilar period (1400 CE), revealed that 18 (14% of the total) had died from childbirth-complicated death. The majority of these women appear to have died during the puerperium, including three without completing delivery (Arriaza et al., 1988).

The best evidence for obstetrical fistula in the archeological record comes from ancient Egypt—a time and place where mummification reached its zenith as a method for preserving human remains. The well-preserved mummy of Queen Henhenit from 4000 years ago demonstrates the type of obstetrical fistula that still occurs today, and the condition is likely discussed in the Ebers Papyrus. Avicenna, a Persian polymath and physician and the Father of Early Modern Medicine, also described the association between obstructed birth and vesicovaginal fistulas in the eleventh century.

3.3 Queen Henhenit

The mummy of Queen Henhenit (also Henhenet) is the oldest physical evidence of obstetric fistula. She lived during the Eleventh Dynasty, around 2025 BCE, the start of ancient Egypt’s Middle Kingdom period (2040–1710 BCE) and immediately following the First Intermediate Period (2081–2040 BCE). As a young woman, Henhenit was a priestess of the goddess Hathor. This deity was a loving mother

figure, a protectress, goddess of childbirth and fertility, and the patroness of music, dance, and wine (Wall, 2018). She became the wife of Pharaoh Nebhepetre Mentuhotep (Mentuhotep II), also known by his prenomen Nephepetre, who ruled Egypt for 51 years as the first pharaoh of the Middle Kingdom. He had many wives who were interred with him or near his mortuary temple located in the Theban necropolis at Deir el-Bahri. Henhenit, in addition to Sadeh, Ashayet, and Kemsit, was a secondary wife of the pharaoh, and all were priestesses of Hathor. They were titled *Hmt-nswt mryt.f*, meaning “King’s wife, his beloved” and *khkrt-nswt-w3tit*, “Unique embellishment of the King.”

Beginning in 1893, excavations began at Deir-al-Bahri by Henri Édouard Naville and his team of archaeologists and workmen on behalf of the Egypt Exploration Fund (Fig. 3.1). After working for 10 years, they discovered the funerary temple of the Pharaoh Mentuhotep II. Further work identified the “pit tomb number 11” located beneath a column in a colonnaded court on the Western aspect of the temple. The sarcophagus and mummy of Henhenit were discovered in this tomb, termed DBXI.11 (Figs. 3.2 and 3.3) (Winlock, 1942; Wall, 2018; Zacharin, 1988; Naville et al., 1907). Five other women, probably priestesses of Hathor, were entombed nearby. A wooden coffin was present within Queen Henhenit’s sarcophagus and in this was her mummy that had apparently been robbed in antiquity. Naville stated,

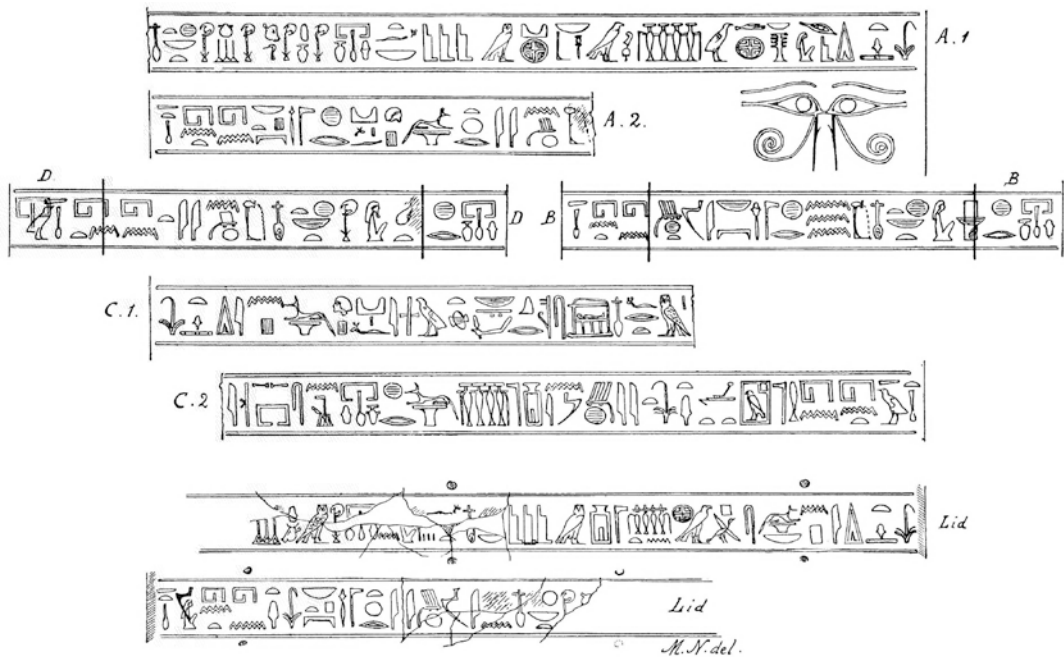
The lid had been broken into three pieces, which lay on the rubbish accumulation at the bottom of the chamber. Fragments of a large square wooden coffin were found in the shaft, with a line of hieroglyphs painted in green on a white ground; this, like the sarcophagus, bore the name of Henhenit, priestess of Hathor, and only royal favorite.

Within the sarcophagus was the mummy of a woman, no doubt Henhenit, lying on the cloth wrappings. Her hands and feet are small and delicately formed, her hair short and straight. It is a very interesting mummy. It and the sarcophagus have been assigned to the Metropolitan Museum of New York.

Fig. 3.1 The tomb of Henhenit (DBXI.11) and a small decorated chapel were found in the mortuary temple of King Mentuhotep II and Queen Hatshepsut (reigned 1498–1483 BCE, Dynasty XVIII), Deir el-Bahri, Thebes. The temple is a partly rock-cut and partly free-standing terraced structure. During the Graeco-Roman Period (332 BCE–CE 395), the temple became a center for healing and the upper terrace was consecrated to Imhotep. Numerous graffiti are evidence of the large number of invalids who visited it until the second-century CE. (Credit: Reeves, 1989. Licensed under the terms of the Creative Commons Attribution 4.0 International License, <http://creativecommons.org/licenses/by/4.0/>)



Fig. 3.2 Massive stone sarcophagus of Queen Henhenit on display at the Metropolitan Museum, New York. It was buried in a shaft tomb beneath the platform of King Mentuhotep II's temple at Deir el Bahri. (From the Metropolitan Museum of Art. <https://www.metmuseum.org/art/collection/search/100000424>, licensed under the terms of the Creative Commons Zero (CC0) License, <https://creativecommons.org/publicdomain/zero/1.0/>)



INSCRIPTIONS OF THE SARCOPHAGUS OF HENHENIT.

Fig. 3.3 Hieroglyphic inscriptions on the sarcophagus of Queen Henhenit. (From Naville et al., 1907)

In 1907, Naville sent both Queen Henhenit's mummy and her sarcophagus to the Metropolitan Museum of Art in New York in gratitude for having received financial support for his archeological work. Once at the Metropolitan Museum, the mummy was observed that a 10 cm long portion of tis-