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CRITICAL ISSUES

# Strengthening public health priority-setting through research on fistula, maternal health, and health inequities

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**KEYWORDS**
Health inequity;
Maternal mortality;
Obstetric fistula

**Abstract**

*Objective:* Findings from 4 studies conducted by the Women's Dignity Project and partners on the subjects of obstetric fistula, maternal mortality and morbidity, and health inequities are presented. *Methods:* The studies include qualitative and quantitative research, a survey, and an analysis of secondary data that examine women's experiences of fistula; constraints in service delivery for fistula treatment; factors shaping women's access to delivery care and constraints health workers face in providing care; and health inequities. *Results:* Findings from the studies are being used to improve fistula prevention and management, strengthen access to and provision of quality maternity care, and redress the health inequities that so adversely affect the poor. *Conclusion:* The studies provide policy makers, program managers, and service providers with evidence and the impetus to re-equilibrate policies, financial and human resources, and services in the interest of those in greatest need: women living in poverty.


## 1. Introduction

Obstetric fistula has finally emerged on the international public health agenda as an issue requiring-and deserving-concerted action. A fistula is a serious childbirth injury that leaves girls and women incontinent of urine and/or feces after prolonged and obstructed labor. It is estimated that approximately 2 million girls and women worldwide live with a fistula [1] and almost all of these girls and women live in resource-poor countries of Africa and South Asia. The condition is preventable and in most cases treatable. The medical and social impact of the condition demands that urgent attention be focused on dramatically decreasing the incidence of fistula as a matter of human rights and women's dignity.

A fistula is more than a woman's health problem. Its roots are embedded in economic, political, and social determinants that underlie poverty and vulnerability. These include limited financial expenditure on basic and maternal health care services for the poor; the absence of governance structures that bring the voices of marginalized people into public policy setting; the lack of transparency in the allocation of

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public funds, including for "priority" social sectors such as health; and the exclusion of women and girls from decision-making processes [2].

Clarifying the determinants of fistula sheds light on the overall health status of women living in poverty and on the factors that drive fundamental health inequities. Research into the continuum of these issues-fistula, maternal health among women living in poverty, and health inequities-can help shape public health interventions and resource allocation to better meet the needs of the poor.

## 2. Rationale and methods

Four research studies conducted, or currently underway, by the Women's Dignity Project (WDP) are presented. The summarized findings illuminate how research on a particular condition affecting the poor, together with analyses of the determinants of poor people's health, could be used to shape public health priorities.

These studies are on the following subjects: fistula and social vulnerability; hospitals providing fistula repairs; women's and providers' views of barriers to accessing high quality maternity care; and health inequalities in tanzania.

Women's Dignity Project ("Utu Mwanamke" in Kiswahili) is a nongovernmental organization (NGO) based in Dar es Salaam, Tanzania. It works at the local, national, and international levels to prevent and manage fistula within the broader context of health and gender equity and human rights. By working on the parallel paths of fistula and health equity, the determinants and impact of health conditions affecting the poor are addressed.

Women's Dignity Project has 4 key programs. *Community-based participatory research on fistula and social vulnerability* involves extensive research in 6 districts of Tanzania and Uganda with girls and women living with a fistula, their families and communities, and local health workers. *Institutional networking*, of which WDP is a lead organization, implements the National Fistula Program in Tanzania along with the Ministry of Health, the African Medical Research Foundation, and other stakeholders. Major activities include fistula prevention and the training of health workers in fistula treatment; research on issues concerning fistula; public education and advocacy; and reintegration of women after fistula repair. *Public engagement* mobilizes debate and action on fistula and the health rights of the poor, including media and strategic policy analysis of the determinants of health inequity. And *regional and global linkages* leverage actions against fistulas and health inequity among international agencies and donors, governments, local communities, health workers and health advocates, and the medical and scientific communities.

## 3. Four studies and their results

### 3.1. Study 1: Fistula and Social Vulnerability in Tanzania and Uganda [3]

The purpose of this study, begun in 2002, is to increase understanding of the social and health system determinants of fistula. It focuses on the challenges that women face when they need to access quality care at the time of delivery; on the impact of fistulas on women's lives; and on people's explanations for the appearance of fistulas. It also explores failures in the health and social systems that have resulted in fistulas, and emphasizes the personal experiences of girls and women.

The study, conducted by Women's Dignity Project, Engender Health, and three local groups in Tanzania and Uganda, involved 137 girls and women in the two countries. The families of many of these girls and women, as well as community members and local health workers, also participated in the study. In-depth interviews, group discussions, and problem trees were the key methods used, focusing on the pregnancy, labor, and delivery experience of the girls and women; their experience following fistula repair; and their recommendations for action to prevent and manage fistulas.

The girls and women identified for the study received treatment during and after the study, and additional girls and women identified by local research partners after the formal study ended also received treatment for their fistulas. In total, 142 girls and women received treatment with support from the Women's Dignity Project, 107 during the study period and 35 through the local partners after the study ended. Girls and women were identified for the study at the participating hospitals providing fistula repairs, with assistance from Reproductive and Child Health Coordinators in participating districts, and through field visits to communities in those districts. All participants consented to be interviewed for the study. The study was approved by the National Institute of Medical Research in Tanzania. The Ministry of Health in Uganda advised that the study could be implemented as a formal activity of the 3 Ugandan research partners, with communication to the Ministry of Health on the progress of the study.

Three key findings of the study challenge frequently held myths about girls and women affected with a fistula. The first key finding relates to the mean age at which the fistula occurred, 23 years in Tanzania and 22 years in Uganda. Fewer than half of the Tanzanian participants were 19 years or younger and most Ugandan participants were between the ages of 15 and 19 years. Most, therefore, were not adolescents when their fistula occurred, which is contrary to the general perception.

The second key finding is that many of the girls and women received financial and emotional support from their families, and some received help from their communities. Nearly all of the women mentioned being supported by at least 1 person, typically a family member, but also by people in the community or an employer. None of the women were totally isolated and unsupported. This may be a function of the method of recruitment, in that the whereabouts of the more isolated women might not have been be known by the health workers who participated in the study. Nonetheless, the fact that all women mentioned some type of support does indicate that they were not completely isolated.

Third, the study found that once they were healed of their fistulas, girls and women generally reintegrated themselves back into their families and communities. Almost all the women mentioned that after repair they were able to perform domestic chores, and that their relationships with the community improved.

### 3.2. Study 2: Tanzania Fistula Survey 2001 [4]

This survey was conducted in 2000 and 2001 in Tanzania by the Women's Dignity Project and the Tanzania Ministry of Health.