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**INCONTINENCE DATA FROM THE DEMOGRAPHIC  
AND HEALTH SURVEYS: COMPARATIVE ANALYSIS  
OF A PROXY MEASUREMENT OF VAGINAL FISTULA  
AND RECOMMENDATIONS FOR FUTURE  
POPULATION-BASED DATA COLLECTION**

**DHS ANALYTICAL  
STUDIES 17**



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- to provide decisionmakers in survey countries with information useful for informed policy choices;
- to expand the international population and health database;
- to advance survey methodology; and
- to develop in participating countries the skills and resources necessary to conduct high-quality demographic and health surveys.

## DHS Analytical Studies No. 17

# **Incontinence Data from the Demographic and Health Surveys: Comparative Analysis of a Proxy Measurement of Vaginal Fistula and Recommendations for Future Population-Based Data Collection**

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## Preface

One of the most significant contributions of the MEASURE DHS program is the creation of an internationally comparable body of data on the demographic and health characteristics of populations in developing countries.

The *DHS Comparative Reports* series examines these data across countries in a comparative framework. The *DHS Analytical Studies* series focuses on analysis of specific topics. The principal objectives of both series are to provide information for policy formulation at the international level and to examine individual country results in an international context.

While *Comparative Reports* are primarily descriptive, *Analytical Studies* comprise in-depth, focused studies on a variety of substantive topics. The studies are based on a variable number of data sets, depending on the topic being examined. A range of methodologies is used in these studies including multivariate statistical techniques.

The topics covered in *Analytical Studies* are selected by MEASURE DHS staff in conjunction with the U.S. Agency for International Development.

It is anticipated that the *DHS Analytical Studies* will enhance the understanding of analysts and policymakers regarding significant issues in the fields of international population and health.

Ann Way  
Project Director



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# Executive Summary

Until recently, the problem of gynecological fistula has been a low-priority issue on international agendas, in part because its prevalence is perceived to be low. In fact, however, the true prevalence of fistula is not known. This report represents an effort to begin to fill the gaps in knowledge about the prevalence and covariates of fistula, a condition that causes immense suffering and yet is completely preventable. Increasing knowledge about the condition, its prevalence, and its risk factors improves the chances that maternal health in general, and the issue of fistula specifically, will receive appropriate political, financial, and programmatic attention. Establishing a baseline for prevalence will allow for the possibility of an assessment of programmatic and policy interventions. The Demographic and Health Surveys (DHS) program has therefore initiated the collection of data on the problem of fistula. This document reports on that effort, including a critique of data collection methods and an analysis of the collected data on fistula symptoms and their covariates.

This report demonstrates the effects that methodological approaches to survey implementation have on self-reported prevalence of severe incontinence and its covariates, and it underscores the need for careful consideration in sample selection and questionnaire construction. As a remedy for the suboptimal approaches to data collection that have been used in the past in the DHS program, this report presents a newly developed fistula survey module. Above all, it must be understood that all women are at risk for developing fistula, and, therefore, in the collection of prevalence data on symptoms of fistula, all women must have the opportunity to respond to a carefully considered set of questions, such as the module presented here (Figure 1.3).

While the findings highlight the difficulties of data collection on fistula specifically and on maternal morbidity in general, they also indicate that, where data were correctly collected, the majority of the reported risk factors found in the literature on fistula in the developing world were indeed correlated with women's reported symptoms. Further, the fact that the prevalence of any incontinence in an unselected population of women can be quite high, when compared with the lower prevalence of fistula symptoms reported here, suggests that over-reporting of these symptoms in DHS surveys may not be egregious.

This report also serves to establish baseline levels of symptoms of fistula in several countries. Only through establishing the prevalence of fistula can contributing factors be identified, appropriate and sufficient resources be allocated, and interventions be evaluated at the national level. As the effort to collect data on fistula evolves, more standardized and appropriate data for analysis will become available, which will further assist the development of programmatic interventions (focused both on prevention and on repair and rehabilitation) and will better guide policymaking.

Findings from these analyses include both the expected and the unexpected. It was expected that, when women have limited access to health care, they will be at higher risk for experiencing symptoms of fistula. An association between stillbirth and reporting of fistula symptoms also was expected. In contrast, the fairly consistent association between sexual violence and fistula symptoms underscores the unexpected: resources to eradicate the suffering caused by fistula must be directed not only to improving maternal health care services, and access thereto, but also to supporting survivors of sexual violence and ultimately eradicating sexual violence against women.

Preventing pregnancy, specifically unwanted pregnancy, is a key primary prevention approach to maternal morbidity and mortality. The findings of this report indicate that, to the degree that fistulae develop through obstetric causes, there is a critical need to re-emphasize the role of family planning in ensuring maternal health and survival.

Finally, our results suggest that women who struggle with their labors do indeed seek medical care but too late to preclude severe morbidity. Women and families must be supported at the community, district, and national levels to recognize the signs of prolonged labor, to make appropriate and timely decisions about care during labor and delivery, and to have quick access to effective emergency care.

While the implementation of policy and programmatic strategies to eliminate fistula—whether of violent, obstetric, or iatrogenic derivation—will differ depending on national and subnational contexts, the driving element behind such efforts will be rooted in the same place: a sense of value and respect for the lives of women.

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## Introduction

Until recently, the problem of fistula has been a low-priority issue on international agendas, in part because its prevalence is perceived to be fairly low. However, the true prevalence of fistula is not known—both because it affects primarily the world’s most powerless and because those who suffer from the condition are stigmatized into silence. Recent efforts, such as the United Nations Population Fund (UNFPA) Campaign to End Fistula and the United States Agency for International Development (USAID) program for the prevention and treatment of vaginal fistula, have brought international attention to the issue. Still, it was noted at UNFPA’s 2003 South Asia Conference for the Prevention and Treatment of Obstetric Fistula that a lack of representative data on the problem of fistula was inhibiting progress in all key aspects of the Campaign (UNFPA, 2003).

This report represents an effort to begin to fill the gaps in knowledge about the prevalence and covariates of fistula, a condition that causes immense suffering and yet is completely preventable. Increasing knowledge about the condition, its prevalence, and its risk factors improves the chances that maternal health in general, and the issue of fistula specifically, will receive appropriate political, financial, and programmatic attention. Establishing a baseline for prevalence will allow for the possibility of an assessment of programmatic and policy interventions. The Demographic and Health Surveys (DHS) program has therefore initiated the collection of data on the problem of fistula. This document reports on that effort, including a critique of data collection methods and an analysis of the collected data on fistula symptoms and their covariates.

### 1.1 Background

#### 1.1.1 What Is Fistula?

Vaginal fistula is a medical condition consisting of an abnormal opening between the vagina and bladder (vesicovaginal fistula, or VVF) or between the vagina and rectum (rectovaginal fistula, or RVF)<sup>1</sup>. A woman with a fistula experiences an uncontrollable leakage of urine and/or feces from her vagina. It is a condition that has been essentially eradicated in the developed world, due primarily to improved access to and quality of obstetric care. In the developing world, however, fistula continues to have devastating effects on the physical, social, and economic lives of thousands of women.

#### 1.1.2 Causes of Fistula

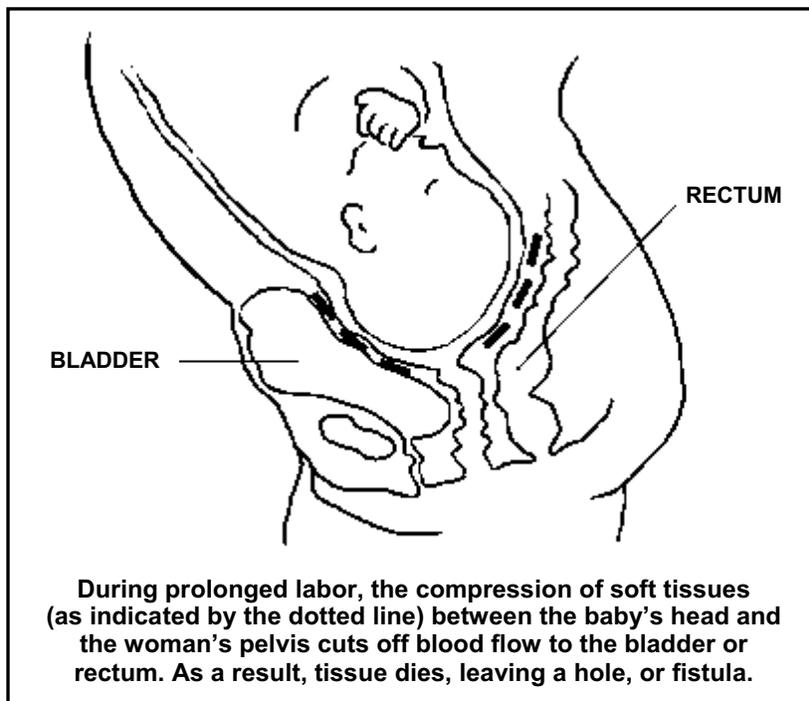
There are three sets of causes of vaginal fistula: obstetric, traumatic, and iatrogenic. In most parts of the developing world, vaginal fistulae usually result from the experience of prolonged obstructed labor (c.f. Muleta, 1997; Ramphal and Moodley, 2006; Rathee and Nanda, 1995). Obstructed labor occurs when the baby’s head cannot fit through the mother’s pelvis (e.g., the mother’s pelvic opening is too narrow or the baby has an abnormality causing a larger-than-usual head such as hydrocephalus), the baby is malpositioned in the uterus (for example, in a transverse lie), or there is an abnormal fetal presentation

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<sup>1</sup> A fistula is an abnormal passage or opening leading between two hollow internal organs or from a hollow internal organ to the surface of the body. A fistula often indicates pathology, but fistulae can also be created for therapeutic purposes; for example, a passage may be surgically created between an artery and a vein in order to enlarge the vein and so improve access to the bloodstream for hemodialysis. It is therefore important to specifically identify the type of fistula under discussion. This report covers only the topic of vesicovaginal or rectovaginal fistulae; for the sake of brevity, we often refer to VVF or RVF simply as fistula.

(for example, a shoulder or a hand presents first, rather than the usual back of the head). Obstructed labor results in obstetric fistula when the soft tissues of the bladder, vagina, and rectum are compressed between the baby's head and the woman's pelvis. This compression cuts off the flow of blood to these tissues (Figure 1.1). If circulation is not restored, the compressed tissues die (tissue necrosis) and are eventually sloughed away<sup>2</sup>, leaving an opening between the vagina and the bladder and/or between the vagina and the rectum. Urine or feces then leak continuously and uncontrollably through the abnormal opening and out of the vagina.

**Figure 1.1 How an obstetric fistula may develop**



*(Courtesy of UNFPA, Campaign to End Fistula)*

The tragedy - and the hope - of the problem of obstetric fistula is that it is completely preventable. While obstructed labor generally cannot be predicted or prevented, fistula as a result of obstructed labor can be avoided altogether if a woman has timely access to a health facility that can provide good quality emergency obstetric care, specifically caesarean section.

Iatrogenic fistulae - caused by errors made during the course of pelvic surgeries such as hysterectomy or caesarean section - may contribute more to the overall burden of fistula in some regions than previously recognized. Preliminary findings from East Africa indicate that as much as 10 percent of women seeking repair have an iatrogenic fistula (Raassen, 2008).

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<sup>2</sup> The tissue sloughing (and, therefore, the beginning of the leakage of urine) occurs during the week following delivery. Thus, a woman with an obstructed labor who arrives to a facility too late to prevent tissue damage but goes home within a day or two of delivery may not exhibit symptoms of fistula at the time of her visit to the facility. This may preclude immediate diagnosis and repair of the fistula.

Fistula can also result from being subjected to sexual violence (ACQUIRE, 2006; Human Rights Watch, 2002). While the public perception is that traumatic fistulae are particularly common in war-torn countries such as the Congo (Nordland 2007), initial reports in the peer-reviewed literature suggest rather that fistulae caused by sexual assault are rare relative to those from obstetric causes (Onsrud et al., 2008). It is unusual for rape by one man to result in a traumatic fistula; rather, it is gang rape or the violent introduction of foreign objects (sticks, bottles, barrels of guns) into a woman's vaginal canal that causes traumatic fistula. There is evidence, however, of fistula due to trauma within domestic relationships, signaling marital rape and intimate partner violence or else the effects of young age at first intercourse (Muleta and Williams, 1999; Sharma, 1991).

The northern Nigerian practice of gishiri cutting, consisting of random lacerations of a woman's lower genital tract in an effort to relieve obstructed labor, is estimated to contribute as much as 15 percent of fistula cases to the total in that region (Wall, 1998). Several other studies examining fistula in Nigeria estimate gishiri cutting to account for 6 to 13 percent of cases (Ampofo et al., 1990; Tahzib, 1983; Tahzib, 1985). In addition, there is speculation that invasive forms of female genital cutting (FGC) such as infibulation contribute to fistula through development of dense scar tissue, although conclusive evidence on this contentious issue is lacking (Wall et al., 2002; WHO Study Group on Female Genital Mutilation and Obstetric Outcome, 2006). Recent research using data from the DHS finds no association between female genital cutting and severe urinary incontinence (Peterman and Johnson, 2008).

Less commonly in the developing world, fistulas may result from radiation therapy. Schistosomiasis, which is known to affect the reproductive tract, has also been documented as a cause of vesicovaginal fistula (Richter et al., 2008). Finally, there is some prospective evidence to suggest that RVF can occur as a result of advanced HIV infection (Silva et al., 1998; Uba et al., 2004; Wiersma, 2003). How HIV infection leads to RVF remains unknown, however.

### 1.1.3 Effects of Fistula

Women with fistula suffer from a disability that prevents them from living a normal life physically, both because they are unable to control the leakage of urine and because fistula is associated with a range of other gynecologic, skeletal, neurologic, and dermatologic morbidities: amenorrhea, cervical injury, post-fistula pelvic inflammatory disease, foot-drop, kidney disease, ammoniacal dermatitis, and vulvar excoriation, among others (Cron, 2003; Kabir et al., 2003).

Not only a physical disability, fistula consigns the affected woman to a lifetime of social and economic disability if the injury is not repaired. Because of the associated odor, women suffering from fistula are often ostracized from their homes and communities. Because they generally cannot bear children as long as the fistula remains, they may be seen as having no value, particularly in societies where women's status is low and dependent on fertility. This social exclusion leads to psychological distress, sometimes so severe as to result in suicide (Wall et al., 2002).

#### Living with Fistula

*"The affected woman suffers from a continuous and uncontrollable stream of urine or feces coming out of her vagina. This is both a physical and a social catastrophe. No escape is possible from the constant trickle of urine, the constant ooze of stool, 24 hours a day. These women become physically and morally offensive to their husbands, their families, their friends, and their neighbors. Indelibly stigmatized by their condition, they are forced to the margins of society, where they live a precarious existence, unable to earn a living except through begging or by the cheapest and most degrading acts of prostitution."*

—Wall, 1998. Dead mothers and injured wives.

The physical, psychological, and socioeconomic consequences of obstetric fistula are compounded by emotional or psychological consequences stemming from the concomitant loss of the woman's baby: the vast majority of obstructed labors resulting in fistula also result in stillbirth. Perinatal loss is associated with considerable psychosocial distress (Scheidt et al., 2007). The experience of a late loss, as well as increased time between loss and a subsequent conception, are associated with particularly high levels of grief (Franché, 2001); late losses and extended time to subsequent conception (if ever) define the situation of most women coping with fistula. Women who suffer from fistula as a result of sexual assault are also likely to suffer emotional and psychological distress associated with the double violation of their bodily integrity (Boudreaux et al., 1998).

## 1.2 Content of This Report

The objectives of this report are methodological as well as research-oriented: we first present a methodological investigation into how best to obtain valid and representative statistics on fistula using survey methodology; we then analyze existing data in an effort to discern the prevalence and correlates of vaginal fistula. The report is organized accordingly: the remainder of Chapter 1 documents the DHS experience with collecting data on fistula symptoms using survey methodology. Chapter 1 also includes the new DHS survey module on fistula that was developed specifically to address the methodological shortcomings identified in this report. In Chapter 2, we report on direct and indirect estimates of the prevalence of fistula symptoms in eight countries for which such data are available. Chapter 3 explores the risk factors associated with fistula symptoms, using both bivariate and multivariate methods. In Chapter 4, we describe the context for the prevention of fistula. Chapter 5 is comprised of a discussion of the results and the conclusions drawn from the analyses presented in the report.

Table 1.1 DHS surveys on fistula symptoms

Description of the DHS surveys included in this report and the associated fistula-related variables available in each survey

	Ethiopia	DRC	Malawi	Mali	Niger	Pakistan	Rwanda	Uganda
<b>General information</b>								
Date collection started	4/2005	1/2007	11/2004	4/2006	1/2006	3/2006	1/2005	4/2006
Date collection ended (est.)	8/2005	5/2007	1/2005	11/2006	4/2006	6/2006	8/2005	10/2006
Data publicly available	x		x		x		x	x
Sample size (women 15-49)	14,070	12,000	11,698	13,260	9,223	10,023	11,321	8,531
<b>Fistula questions (content)</b>								
Fistula symptoms	x	x	x	x	x	x	x	x
Self-reported cause of symptoms		x		x	x	x		
Sought treatment				x	x		x	
Received treatment	x	x		x	x			
Success and description of repair				x	x			
<b>Supporting risk factors</b>								
Anemia (Hb)	x	x	x	x	x		x	x
Domestic violence module <sup>1</sup>		x	x	x			x	x
Sexual violence questions		x	x	x	x		x	x
Female genital cutting (FGC)	x			x	x			x

<sup>1</sup> Domestic violence module refers to module asked of a sample of ever-married women. Sexual violence questions refer to any other questions asked regarding any aspect of forced or unwanted sex.

Table 1.1 lists the countries included in this report, with the dates of fieldwork and individual sample sizes. Any differences between the DHS sample size and the sample size for the fistula analysis arise from variations in the survey instrument, which are discussed in the following section on DHS methodology. Not all of the countries in Table 1.1 have information on all variables examined in this report. For example, in some countries, women were asked about their experience of sexual violence, while in others these questions were not part of the survey. Similarly, some but not all countries asked questions about

female genital cutting. Therefore, Table 1.1 also indicates which surveys collected specific independent variables of interest. Given the variation in types of fistula-related data collected, some countries may be excluded from some of the tables in this report.

### **1.3 DHS Methodology: Fistula Measurement in the DHS Program**

This section discusses the issues that affect the measurement of maternal morbidity in general, the historical DHS experience with measuring the lifetime prevalence of fistula specifically, other potential problems associated with the use of household-based surveys for collecting data on fistula, and the direction that DHS will take in future data collection efforts.

#### **1.3.1 Measuring Maternal Morbidity: Estimation and Misestimation**

Measuring maternal morbidities in general. In countries where most births take place outside of facilities, and even facilities often keep poor records on births, reasonably reliable, nationally representative data on the incidence and prevalence of maternal mortality and morbidities are scarce. While women's self-reports of maternal morbidities are known to be problematic (see Fortney & Smith, 1999, for their useful discussion), there are few other data collection methods from which to select in order to obtain national estimates, and all methods have their drawbacks. Thus, in developing-country settings that lack national health information systems and where most women give birth outside of facilities, it is largely through surveys that nationally representative information about maternal morbidities can be captured.

The usefulness of survey methods to capture information from women on their pregnancy, labor, and delivery experiences is likely to vary depending on the specific morbidity under study. Some maternal morbidities such as pregnancy-induced hypertension may not have symptoms, or may have symptoms that women do not recognize as morbidities. Thus, women cannot report on them unless they have been told about their condition by a health professional. Postpartum hemorrhage is problematic to assess because the volume of blood lost is difficult to estimate even for experienced health professionals (Patel et al., 2006). Prolonged labor is also difficult to capture because establishing the onset of active labor is subjective, as are cultural expectations about how long labor is “supposed” to last; women's own perceptions of how long their labor lasted—and whether it seemed prolonged—are also subjective and not comparable with other women's responses (Gross et al., 2006). Survey questions on morbidity are often symptom-based, yet a given symptom could reflect more than one type of morbidity. For example, loss of consciousness could be associated with hemorrhage, shock, or an eclamptic seizure (Fortney and Smith, 1999).

Measuring fistula specifically. In some regards fistula may be one of the easier maternal morbidities to measure using survey methods. The symptoms associated with vaginal fistula—continuous, uncontrollable leakage of urine or stool day and night—are clearly observable and reportable by the respondent. Even if she has been repaired, a woman who has suffered from a fistula will not forget her experience. Thus, questions asking about lifetime experience of fistula symptoms are unlikely to be subject to recall bias.

Important sources of error do exist, however, some of which are specific to the condition of fistula. First, particularly if the respondent has been repaired, she may deny having ever had a fistula out of shame or fear of the stigma associated with the condition. Among women who have experienced a traumatic fistula, there is often an additional burden of shame and stigma, leading to the possibility of underreporting of fistulae among women with these experiences. Second, symptoms reported as fistula—essentially, incontinence of urine and/or feces—may actually be those of another condition with similar symptoms and consequences. For example, during the course of data collection in Bangladesh, Fronczak et al. (2005) encountered three cases that met their operational definition of fistula. After pelvic examination,

however, it was determined that two of the women suffered from severe urinary tract infections with incontinence, and one woman suffered from an old third-degree perineal tear that affected her anal sphincter, leaving her with fecal incontinence.

The first type of error—underreporting due to shame or fear of stigma—may be ameliorated to some degree through sensitivity training for fieldworkers, through assuring the respondent that her responses to the survey are confidential, and through assuring that both the interviewer and the respondent understand the purpose of the question being asked. The second source of error—reporting symptoms that seem to be VVF/RVF but are not—is less tractable. Pelvic exams are unlikely to be introduced into major nationally representative surveys, given the expense and the lack of trained local health care providers who are available and qualified to identify VVF/RVF. Thus, despite precautions taken during fieldwork to ensure accurate reporting, the figures presented here likely reflect some amount of inaccuracy.

Although the intent of the DHS questions (presented in Appendix A) is to collect information on the prevalence of VVF/RVF, the best that we can assert is that we have collected data on a specific, more serious type of urinary and/or fecal incontinence. Urinary incontinence not related to fistula is likely to be a source of overreporting. Some studies suggest that the prevalence among women of any urinary incontinence, including stress incontinence, is quite high. One British study found a prevalence of incontinence of 53 percent among a 10 percent sample of nonpregnant general clinic clients age 20 and above (prevalence was 47 percent among clients age 20-49) (Harrison and Memel, 1994). Swedish researchers also have found a high prevalence of urinary incontinence in a population-based study—22 percent among women age 18-50 (Hägglund et al., 1999). The fact that the prevalence of incontinence in an unselected population of women can be quite high, when compared with the lower prevalence of what are called in this report symptoms of fistula, suggests that overreporting of these symptoms in DHS surveys may not be egregious. Nevertheless, throughout the text we refer to our data on severe incontinence as “fistula symptoms,” rather than “fistulae,” so as not to overreach the limits of the data.

Qualitative validation studies are necessary to determine the sensitivity and specificity associated with this kind of question in a national health survey. Through work to improve available survey instruments, however, it should be possible to make some gains in specificity, that is, ruling out cases that are not fistula (the questions on experience of symptoms of fistula are likely to be sufficiently sensitive to the condition). Still, there will always be some level of inexactitude in any attempt to measure the prevalence of this particular morbidity using self-reports.

### **1.3.2 Past Approaches to Data Collection in the DHS**

DHS surveys began to collect data on symptoms of VVF/RVF in 2004. The early sets of fistula questions were essentially pilot questions on a topic that was not widely recognized as important at the time. Because of this, and because of justifiable reluctance to add questions to the already overburdened DHS survey instrument, the initial approach to data collection was to try to capture the most basic indicator of fistula prevalence using the minimum questions necessary. Thus, only lifetime experience of relevant symptoms was asked about, and no follow-up questions were included to ascertain additional information, such as whether a respondent reporting ever experiencing symptoms was still experiencing those symptoms.

These early efforts were not centrally coordinated, and a standard module to collect data on fistula had not yet been developed. As a result, the surveys that tried to collect information on fistula symptoms used varying samples and questionnaires, generating data that are not comparable across countries. Furthermore, not all samples or questionnaires were appropriate for the task of capturing data on fistula symptoms. This section describes the samples and questionnaires used for each of the countries included

in this report, and it discusses the ways that sample selection and questionnaire development can affect the findings of surveys that attempt to capture data on fistula.

Eligibility to respond to questions about fistula. Data on the experience of symptoms of fistula should be collected from all women. Because initial efforts to collect data on fistula were not centrally coordinated, questions on fistula symptoms were included in the DHS questionnaire without full consideration of the social and etiological context of this particular morbidity. Specifically, in most surveys where information on fistula was collected, women were excluded from being asked questions about fistula symptoms if they had not had a live birth or if they had never heard of “obstetric fistula.”<sup>3</sup>

Table 1.2 shows the variation in the eligibility criteria for questions about fistula symptoms according to country and associated sample sizes. Two countries—Malawi and Uganda—asked all women about fistula symptoms. The remaining six restricted the samples in a variety of ways. Ethiopia, the Democratic Republic of the Congo (DRC), Niger, and Mali first asked women if they had heard of the condition. Pakistan and Rwanda selected samples based on a history of live birth. Both approaches to restricting eligibility have significant problems, which are discussed below.

Table 1.2 Approaches to fistula-related data collection

Use of contingency questions or filters to select women to respond to questions on fistula symptoms

Approaches to data collection	Ethiopia	DRC	Malawi	Mali	Niger	Pakistan	Rwanda	Uganda
Use of contingency question	x	x		x	x			
Selection filter	Heard of fistula	Heard of fistula	No filter; all women eligible	Heard of fistula	Heard of fistula	Ever had live birth	Live birth in past 5 years	No filter; all women eligible
Sample size (% of total sample)	23.2	n/a	100	n/a	37.8	87.8	47.9	100
Sample size (absolute number)	3,907	n/a	11,698	n/a	3,863	8,798	5,386	8,531

n/a = not available

Problems with restricting eligibility to answer fistula symptom questions on the basis of knowledge of terminology. In some countries women were asked if they had ever heard of “obstetric fistula,” or, in francophone countries, “*maladie d’urine*.” Only respondents who had heard of the phrase were then asked the questions about their own experience of fistula symptoms. In terms of survey questionnaire development, this is called a “contingency question.”

Use of contingency questions is appropriate when there is a need to ask more specific questions of a select group of respondents based on characteristics of the respondent that are directly relevant to the research question. For example, a researcher who is interested in asking questions to capture levels of knowledge about the different ways that HIV can be spread might appropriately use a contingency question asking respondents whether they have heard of HIV. If a respondent has never heard of HIV, then there is no need to ask about how it can be transmitted. Respondents who have never heard of HIV may skip to the next set of questions.

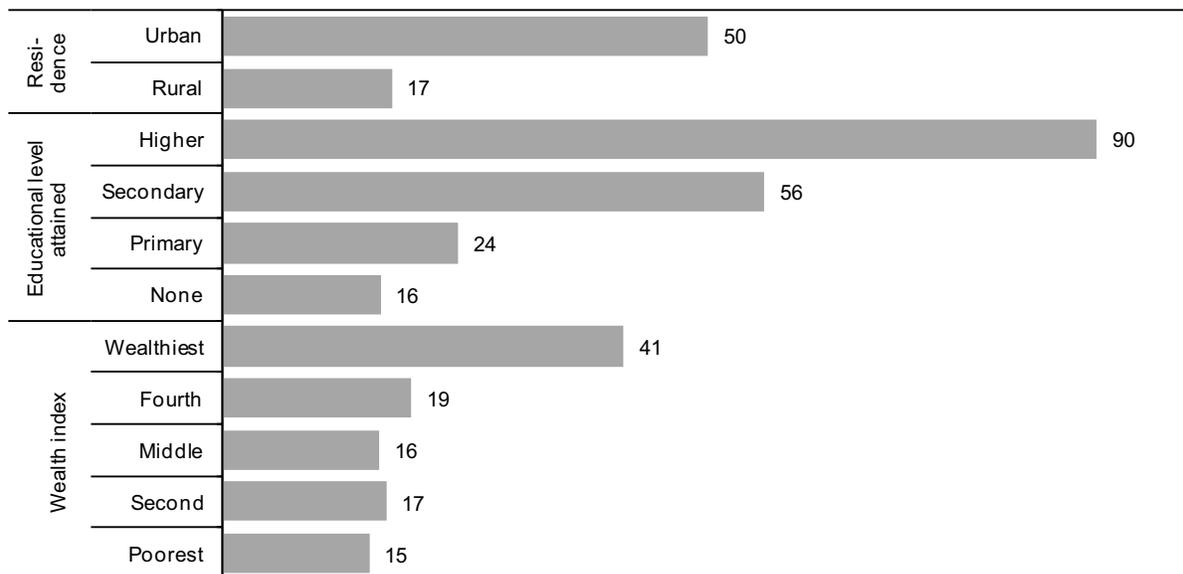
Contingency questions can be problematic, however, if they require that the respondent know specific terminology when knowledge is not the respondent characteristic of interest. This can be a particular problem where levels of literacy and education are low; people who live in remote areas may not be familiar with specific terminology that refers to a relatively rare event such as fistula. Recognizing symptoms is not equivalent to recognizing a name or label given to a disease or condition. Respondents

<sup>3</sup> In francophone countries the term “obstetric fistula” was replaced with the term “*maladie d’urine*.”

who cannot pass the “knowledge test” inherent in such a contingency question do not have the opportunity to answer the specific questions of interest regarding their own personal experiences—questions that require no knowledge of special terminology. Data collected using this approach are frequently biased towards the responses of those who are more urban or more educated.

This problem with knowledge-based contingency questions is clearly demonstrated with an example using the fistula-related data from the 2005 Ethiopia DHS<sup>4</sup>. Figure 1.2 shows the percentage of women in each category of residence, education, and household wealth who have ever heard of “obstetric fistula.”

**Figure 1.2 Percent of women in each category of wealth and education who have heard of “obstetric fistula,” 2005 Ethiopia DHS**



Only 23 percent of all Ethiopian women had ever heard of obstetric fistula, but 50 percent of urban women had heard the term compared with only 17 percent of rural women; 90 percent of women who had higher than secondary education had heard of obstetric fistula, but only 16 percent of uneducated women had heard the term; 41 percent of the wealthiest women knew the term, compared with only 15 percent of the poorest women. Thus, the women who were selected by the knowledge-based contingency question to answer the specific questions on their own experience of fistula symptoms were more likely to be urban, comparatively wealthy, and educated than the average for the entire population.

All available evidence, however, indicates that fistula is a condition of the rural, the poor, and those with no access to education. Indeed, the data in Table 3.1 indicate that, among those Ethiopian women who had heard of fistula, reporting of fistula symptoms was more than 2.5 times as high among the rural women who knew the term “obstetric fistula” as among urban women who knew the term. These results

<sup>4</sup> Ethiopia, the DRC, Mali, and Niger all asked knowledge-based contingency questions. Ethiopia added a probe, for those who said that they did not know the term obstetric fistula, which described the symptoms further (see Appendix A). Likely this allowed more women to cross the knowledge threshold and answer the questions on fistula symptoms, but the approach appears to have been insufficient to overcome the bias imposed by asking a knowledge-based question first. The assumption is that the probe was not used or was used incorrectly. The DRC, Mali, and Niger did not add any probe like the one used in Ethiopia. Only data from Ethiopia are analyzable at this time because (1) data from the DRC and Mali have not yet been made public and (2) the contingency question used in Niger produced data that are virtually unanalyzable—only 20 women reported symptoms of fistula.

indicate that the reported level of lifetime experience of fistula symptoms of 3.4 percent (among women who had ever heard of fistula) is biased and likely underestimates the prevalence of fistula symptoms in Ethiopia.

In this report we analyze the data from the countries that used knowledge-based contingency questions, but the results for these countries (Ethiopia and Niger) must be interpreted cautiously, given the bias inherent in these data.

Problems with restricting eligibility for fistula symptom questions on the basis of parity. It is inappropriate to collect data on fistula symptoms only from women who have ever had a live birth<sup>5</sup> because many women with fistula acquired the morbidity during their first pregnancy. If a woman's first pregnancy ends in unrelieved obstructed labor, which results in stillbirth in over 90 percent of cases and also frequently results in either the development of a fistula or maternal mortality, assuming the fistula remains unrepaired, the chances are high that she will never have a live birth. Thus, if we exclude women who have never had a live birth from the opportunity to answer questions about fistula symptoms, we exclude all women whose first and only pregnancies ended with both stillbirth and fistula. Additionally, in some war-torn regions, sexual violence may be a more frequent antecedent to VVF/RVF. Such violence can occur regardless of a woman's age or parity, and it can result in infertility. Thus, limiting questions about fistula symptoms to women who have had live births excludes nulliparous women who developed fistula and infertility as a result of violence. Finally, fistula may occur as a result of advanced HIV infection or schistosomiasis, which are other possible scenarios for fistula in a woman who has never had a live birth.

Thus, any restriction of a respondent's eligibility to answer questions on fistula symptoms on the basis of parity will result in the following three problems: a misestimation of the national prevalence of fistula due to methodological omission of potential problems, an incomplete understanding of the etiology of the morbidity due to biased sample selection, and distortions in the statistical associations between the experience of fistula symptoms and covariates of interest.

At the same time, including only women who have ever had a live birth also can bias the data, given that higher parity is associated with increased likelihood of incontinence from basic pelvic floor weakness (Nygaard et al., 2008).

This report does present analyses of the data from the countries that selected respondents based on parity (Rwanda and Pakistan), but the results must be interpreted with caution, given the likelihood of bias.

### **1.3.3 Other Survey-Related Sources of Misestimation**

Potentially problematic for this analysis is the fact that it avails itself of household survey data. The DHS is a household-based survey, and as such, it surveys only the housed population, excluding group quarters such as dormitories, barracks, and hospitals. Data on people who are homeless or who live in group facilities are not collected. It is frequently reported that women suffering from fistula are cast out of their homes and into the streets, no longer considered members of any household. In countries such as Ethiopia, where there is a well-known center<sup>6</sup> for the repair of VVF/RVF, women with fistula may take up residence on the grounds, remaining there or in affiliated group quarters after their surgeries if the repair was unsuccessful. It may be that societal treatment of women with this problem is context-specific; in some cultures, women may be abandoned, while in others they may remain members of the household

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<sup>5</sup> In the DHS, if one wants to select a subsample of women on the basis of fertility history, one can only select on the basis of whether or not a woman has ever had a live birth because, in most cases, respondents are not asked about stillbirths.

<sup>6</sup> The Addis Ababa Fistula Hospital is the only medical center in the world dedicated exclusively to fistula repair.

(c.f. Ezegwui and Nwoqu-Ikojo, 2005), at least for a time. The degree to which women with fistula are homeless is unknown in any of the countries included in this analysis. It is possible that women with fistula are underrepresented in the housed population and thus underrepresented in the survey data used in this analysis.

### **1.3.4 Revised DHS Fistula Module**

Led by the United Nations Population Fund (UNFPA) and the U.S. Centers for Disease Control and Prevention, the Data, Indicators, and Research Thematic Group of the International Obstetric Fistula Working Group (IOFWG) met in October 2006 and adopted an approach to survey-based data collection on the topic of fistula. Based on the recommendations of the participants in this meeting, which included fistula surgeons, physicians, epidemiologists, demographers, and leaders of organizations focused on repairing and reintegrating into society those women affected by fistula, a formalized fistula module has been developed for inclusion in DHS surveys for countries where fistula has been identified as a problem.<sup>7</sup>

The purpose of developing a formalized fistula module is to impose a rigorous standardization on data collection. This ensures that comparable data are collected from the correct samples of women across national settings within the DHS program. This approach also ensures that information on only the most important fistula-related indicators are consistently collected, and collected reliably, while excluding inessential questions from the overburdened DHS survey instrument. The development of the fistula module directly remedies the majority of methodological problems discussed in this chapter.

The instrument, presented in Figure 1.3, is to be administered to all women in the survey sample. It covers more fistula-related content than previous question sets on fistula, including questions on experience of symptoms, etiology of the problem, care-seeking behavior, and success of treatment.

Question Q01 elicits data on lifetime prevalence of severe urinary incontinence, which is interpreted as a symptom of fistula. For women who have never experienced such symptoms, the module asks whether they have ever heard of such a disorder (Q02)—an effort to capture the level of knowledge in the community about fistula. Understanding the level of knowledge of fistula in the community is helpful for programming information, education, and communication (IEC) campaigns.

Questions Q03-Q03A&B are asked in an effort to determine the circumstances leading to the reported severe incontinence. These questions may also enable researchers to generate more specific estimates of fistula prevalence: If a woman reports incontinence but does not report a precipitating event consistent with what is known about the etiology of fistula, it may be reasonable to omit her case from the prevalence estimates. Similarly, Q05, which asks respondents how long after the precipitating event the leakage began to occur, may help to generate more specific estimates: Women who report initial leakage several weeks or more after the reported precipitating event may be suffering from a condition other than fistula, which should become evident within about a week of an obstructed labor, and even sooner in the case of traumatic fistula. It should be noted that these questions may serve to inappropriately drop from the estimates cases of fistulae that occur as a result of AIDS or schistosomiasis. This is a problem that will require consideration when data from this module become available.

Q04 is intended to elicit information about when in her childbearing history the respondent began experiencing fistula symptoms. This information will contribute to an understanding of whether the risk of developing fistula varies according to parity. The question can be asked only in countries that collect a pregnancy history, however, and very few DHS surveys do so.

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<sup>7</sup> Participants in this working group are listed in Appendix C.

Questions Q06-Q09 ask affected women whether they have sought treatment. Those who have not sought treatment are asked why they have not done so. Those who do report seeking treatment are asked whom they consulted and whether treatment was effective.

This questionnaire module is expected to provide data on key fistula indicators as defined by the expert participants in the IOFWG. These data will give a more complete picture of women's experiences with severe urinary incontinence, provide better estimates of obstetric fistula, and avoid the methodological problems associated with earlier data collection efforts.



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# 2

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## National Contexts and Estimated Levels of Symptoms of Fistula

Below, in subsection 2.1, we describe the maternal health, gender equity, and poverty contexts of the countries that have collected data on fistula symptoms through the DHS program thus far.<sup>8</sup> This description sets the stage for the discussion of the estimates of fistula symptoms in each country in subsection 2.2.

### 2.1 Country Settings

It is important to consider the national contexts from which the data analyzed emerge. Given the focus of this report on better understanding the problem of fistula, summary data on three areas relevant to the problem of fistula are presented here:

- Maternal health indicators for each country, in order to better understand the degree to which access to good quality maternal care is limited;
- Selected indicators of gender equity for each country; gender equity is important when considering issues of maternal health because, when women are not valued equally in a society, their health needs are neglected;
- The national economic context, indicating the relative poverty of some of the countries where women are most likely to suffer from maternal morbidities such as fistula.

#### 2.1.1 Maternal Health Indicators

Table 2.1 presents summary data on maternal health indicators for the countries that have collected data on fistula symptoms. All of the countries have extremely high estimated levels of maternal mortality, with Uganda having the lowest estimated ratio, at 435 maternal deaths per 100,000 live births, while the DRC and Malawi have the highest estimated ratios, both exceeding 900 maternal deaths per 100,000 live births. In most of these countries, less than half of births were attended by someone who was medically trained to provide delivery assistance. Ethiopia was the worst off, with only 6 percent of births attended by trained health personnel, while Malawi, at 57 percent, had the highest levels of attendance by trained health personnel. An indicator of lack of access to essential obstetric care is the national rate of caesarean section. Prevalence of caesarean section among all births should be no less than 5 percent (and no more than 15 percent) (UNICEF et al., 1997). Yet in countries of the sub-Saharan Africa region, 3 percent or fewer of live births in the five years preceding the survey were delivered by caesarean section, indicating that essential obstetric care is insufficiently available or used. When prevalence of caesarean delivery is disaggregated by household wealth status, access to such services among the poorest women can reach zero (Ronsmans et al., 2006). Of the caesarean operations that do occur, many are performed under less than ideal circumstances and are associated with a high rate of maternal and perinatal mortality (Fenton et al., 2003).

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<sup>8</sup> Data from Mali and DRC were not available for analysis at the time of the preparation of this report.

High total fertility rates (TFRs) are common in these countries, with women in Malawi, Mali, Niger, Rwanda, and Uganda all likely to give birth to six or more children over the course of their lifetimes, assuming current fertility rates. Pakistan has the lowest TFR, at 4.1 children per woman, followed by Ethiopia at 5.4 children per woman. The highest TFR is found in Niger, where on average a woman can be expected to give birth to seven children during her lifetime. The median age at first birth is about 18-19 years of age in most of these countries, with the exception of Rwanda, where the median age at first birth is 22 years. Female life expectancy is low in these countries, particularly in sub-Saharan Africa, where life expectancy ranges from just 40 years in Malawi to 50 years in Uganda. In contrast, Pakistani women have a life expectancy of 64 years.

### **2.1.2 Gender Equity**

Two indicators of the gender equity context in the selected countries are the female-to-male literacy ratio and the Gender-related Development Index (GDI) score and rank. There is more variation in the sex ratio for literacy than in the rankings for the GDI. In Malawi, Rwanda, and Uganda, at least 80 women per every 100 men can read, with the ratio nearly one-to-one in Rwanda. In contrast, in Mali and Niger, fewer than 50 women per every 100 men can read. Of 144 countries ranked in the GDI, however, no nation included in this analysis ranks higher than 117th (Uganda). Mali ranks 142nd in the GDI, and Niger ranks last in 144th position (UNDP, 2003).

### **2.1.3 Poverty**

Gross National Income (GNI)<sup>9</sup> serves as a cross-nationally comparable indicator of economic development for the countries in this analysis. Data are in current U.S. dollars. The per capita GNI is lowest in the Democratic Republic of the Congo at \$120 and is highest, among the sub-Saharan African countries, in Mali at \$380. The per capita GNI is highest overall in Pakistan at \$690. In comparison, the United States GNI per capita is \$43,740.

To summarize, indicators of both maternal health and survival and, relatedly, gender equity measures demonstrate considerable problems in all countries included in this report. All countries included in the analysis are among the poorest in the world, with the exception of Pakistan, which has at least twice the per capita GNI of nearly all of the other countries.

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<sup>9</sup> The World Bank defines GNI (formerly Gross National Product—GNP) as the sum of value added by all resident producers plus any product taxes (less subsidies) not included in the valuation of output plus net receipts of primary income (compensation of employees and property income) from abroad.

Table 2.1 Maternal health and welfare indicators

Setting the context: Maternal health and welfare indicators in countries with data on fistula symptoms

	Ethiopia (2005)	DRC (2006)	Malawi (2004)	Mali (2001)	Niger (2006)	Pakistan (2006)	Rwanda (2005)	Uganda (2006)
<b>Maternal health</b>								
Maternal mortality ratio (per 100,000 live births)	673	990 <sup>1</sup>	984	582	648	500 <sup>1</sup>	750	435
Percentage of births in the past 5 years with skilled attendance	5.7	n/a	57.0	40.6	32.9	38.8	38.6	42.0
Percentage of births delivered by caesarean section	1.0	n/a	3.1	1.1	1.0	8.5a*	2.9	3.1
Total fertility rate (TFR)	5.4	n/a	6.0	6.8	7.1	4.1	6.1	6.7
Median age at first birth (ages 24-49)	19.0	n/a	19.0	18.9	18.2	n/a	22.0	17.8
Female life expectancy at birth (years) <sup>1</sup>	49.0	44.9	40.1	49.1	44.9	64.0	44.1	50.0
<b>Gender equity</b>								
Ratio of literate women to men (ages 15-24)	0.62	n/a	0.91	0.44	0.42	n/a	0.96	0.83
Gender-related development index (GDI) value <sup>2</sup>	0.347	0.353	0.378	0.327	0.279	0.469	0.416	0.483
Gender-related development index (GDI) rank <sup>2</sup>	139	136	132	142	144	120	129	117
<b>Poverty</b>								
Per-capita gross national income (GNI) <sup>3</sup>	160	120	160	380	240	690	230	280

Notes: Unless otherwise indicated, all values are taken from the DHS. Values are representative of the adults in age group 15-49.

\* Percent of most recent births in the five years preceding the survey.

n/a = not available

<sup>1</sup> UNFPA & PRB, 2005.

<sup>2</sup> UNDP, 2003. The GDI index ranges from 0.941 to 0.279; the GDI rank is out of 144 countries with available data.

<sup>3</sup> World Bank, 2007. Atlas method, purchasing power parity as of 2005 in USD.

## 2.2 Estimates of Fistula Prevalence Based on Reports of Incontinence

There are many and varying estimates of the global prevalence of fistula. Some have estimated the global prevalence of fistula at about two million women (Waldijk and Armiya'u, 1993). More recent approximations of prevalence are over three million, with an additional 30,000 to 100,000 cases occurring each year on the African subcontinent alone (Wall, 2006). Ethiopia's Fistula Hospital in Addis Ababa treats approximately 700 new patients each year; however, these patients are a select group, not representative of the population of fistula sufferers as a whole, in that they have found the resources to cover transportation and other costs associated with the trip to the hospital. Other sources estimate a fistula rate of between 1 and 3 per 1,000 deliveries for West Africa in general (Elkins, 1994), 3.5 for Nigeria in particular (Harrison, 1985), and 5 to 10 per 1,000 deliveries in some rural areas of Ghana (Danso, 1996). Some suggest that a nation's rate of obstetric fistula is likely to be close to its maternal mortality ratio (Danso, 1996). Other research indicates that, for every woman who succumbs to maternal mortality, there are 100 women who experience a maternal morbidity (Koblinsky, 1995), with fistula being one such morbidity.

The history of the generation of these estimates—and their plausibility—is critically reviewed by Stanton et al. (2007). While there have been a variety of efforts to estimate the prevalence of fistula, no attempts have previously been made to collect national prevalence data on fistula through the use of survey methodology.<sup>10</sup> Measuring self-reported fistula symptoms through DHS surveys constitutes an effort to provide representative estimates of the prevalence of fistula in countries that are most affected by the problem.

Table 2.2 shows the estimated lifetime prevalence of fistula symptoms. Lifetime prevalence of symptoms reflects the proportion of respondents who reported ever having experienced the incontinence symptoms described by the survey question. Lifetime prevalence is expected to be somewhat higher than current prevalence because some women with fistula will have had the opportunity to have their fistulae repaired.

Note that, because of the diversity of the samples (discussed in Section 1.3), it is inappropriate to directly compare prevalence rates among countries. Therefore, we distinguish between prevalence in various subsamples for each country, where available. The two countries that collected symptom data from the full sample of women are Malawi (4.7 percent) and Uganda (2.6 percent). Pakistan has a lifetime prevalence of 4.6 percent among women who have ever had a live birth. Rwanda has a lifetime prevalence of 3.3 percent among women who had a live birth in the past five years. Finally, lifetime prevalence estimates in Ethiopia and Niger are 3.4 and 0.7 percent, respectively, among women who had ever heard of fistula. As noted earlier, Ethiopia had an extra probe describing the condition of fistula, while Niger did not (see Appendix A), resulting in an artificially low estimate in Niger.

Given the previously discussed methodological problems in most of the countries, only the data from Malawi and Uganda can be properly assessed. Uganda's prevalence estimates are about half of those of Malawi. This is interesting given that Uganda's maternal mortality ratio is also about half of that in Malawi (435 and 984, respectively). This correspondence supports the observation by some researchers that national prevalence of fistula is correlated with the national maternal mortality ratio (Danso, 1996).

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<sup>10</sup> However, Muleta et al. (2007) from the Addis Ababa Fistula Hospital have recently conducted a survey of rural Ethiopia that included validation (by way of pelvic exams) of women's self-reports of fistula symptoms. They found a prevalence of untreated fistula of 1.5 per 1,000 women age 15 and older.

Table 2.2 Fistula symptoms

Estimated lifetime prevalence of fistula symptoms among selected samples of women in countries with data on fistula symptoms (number of cases in parentheses)

	Ethiopia (14,070)	Malawi (11,698)	Niger (9,223)	Pakistan (10,023)	Rwanda (11,321)	Uganda (8,524)
Full sample sizes						
Full sample	---	4.7 (11,698)	---	---	---	2.6 (8,524)
Ever had a live birth	---	5.8 (9,298)	---	4.6 (8,798)	---	3.4 (6,410)
Never had a live birth	---	0.4 (2,400)	---	---	---	0.3 (2,114)
Gave birth in last 5 years	---	6.0 (7,309)	---	5.5 (5,724)	3.3 (5,386)	3.5 (4,997)
With knowledge of fistula	3.4 (3,907)	---	0.7 (3,863)	---	---	---
With knowledge and ever had a live birth	4.7 (2,300)	---	0.7 (3,143)	---	---	---
With knowledge and birth in last 5 years	5.1 (1,374)	---	0.6 (720)	---	---	---

Note: Pakistan sample is further limited to ever-married women ages 15-49.



## Factors Associated with the Experience of Fistula Symptoms

In order to best target policies and programmatic interventions aimed at reducing the incidence and prevalence of fistula, it is important to understand the factors associated with the condition. Most data on the characteristics of fistula sufferers come from fistula hospitals or other health care facilities that repair fistulae (e.g., Danso et al., 1996; Guirassy et al., 1995; Hilton and Ward, 1998; Ijaiya and Aboyeji, 2004). This analysis defines three main realms of factors associated with fistula and explores each using bivariate methods. These three realms are background socioeconomic characteristics, health-related factors, and birth-related characteristics that are thought to affect a woman's probability of experiencing fistula. Next, multivariate analysis using logit regression explores a subsample of indicators.

### 3.1 Bivariate Results

This section presents the results of the bivariate analysis. Results are broken out into three sets of tables reflecting socioeconomic, health-related, and birth-related covariates. For each category within each covariate, the mean value among that group is presented, as well as the p-value from the associated  $\chi^2$  test. Dark type denotes significance at the 5 percent level or better. Analysis is conducted using survey weights provided in the DHS.

Although we present the results of the bivariate analyses side -by-side, it must be kept in mind that the results are not comparable, save for the fact that the same independent variables are used for all analyses (where data exist). Nevertheless, the discussion of the bivariate results will take a broad and summary approach, while the discussion of the multivariate results will be more detailed, accounting for survey-specific characteristics.

#### 3.1.1 Socioeconomic Characteristics

The literature indicates that fistula is more prevalent in rural areas; this is probably due to urban women's closer proximity to health services. Fistula is also reported to be associated with poverty (Onolemhemen and Ekwempu, 1999), lack of education (Hilton and Ward, 1998; Muleta, 1997; Onolemhemen and Ekwempu, 1999), and lack of women's empowerment in general as well as specifically to the inability to seek health care when needed (Cook et al., 2004). In this section we discuss the association between these characteristics and women's experience of symptoms of fistula.

Table 3.1 presents results for bivariate associations with background characteristics (age, education, marital status, wealth, rural-urban residence, and access to health care) in the six countries with available data. Many of the characteristics show significance in the expected direction. For example, with increasing education, women are significantly less likely to report fistula symptoms (Ethiopia, Malawi, Uganda). Unmarried women are significantly less likely, while widowed or separated women are more likely, to report symptoms (Ethiopia, Malawi, Rwanda, Uganda). Generally, as wealth increases, the percentage of women reporting symptoms decreases, although this indicator is not always significant. Rural women are significantly more likely than urban women to report fistula symptoms in all countries except Niger (where the relationship is in the expected direction but is not significant) and Pakistan (where there is no statistical difference by residence in the prevalence of symptoms).

Table 3.1 Fistula symptoms and socioeconomic characteristics

Percentage of women reporting fistula symptoms in six DHS surveys, according to age group and socioeconomic characteristics, bivariate associations

Characteristic	Ethiopia (N = 3,907)		Malawi (N = 11,698)		Niger (N = 3,863)		Pakistan (N = 8,798)		Rwanda (N = 5,393)		Uganda (N = 8,524)	
	%	p-value	%	p-value	%	p-value	%	p-value	%	p-value	%	p-value
<b>Age (in years)</b>												
15-19	2.07	0.140	<b>5.37</b>	<b>0.000</b>	0.62	0.921	4.59	0.994	1.59	0.286	<b>0.65</b>	<b>0.000</b>
20-24	3.00	0.640	5.47	0.123	0.58	0.850	5.45	0.217	<b>5.15</b>	<b>0.001</b>	2.78	0.725
25-29	2.09	0.094	5.32	0.107	1.32	0.059	4.86	0.580	3.74	0.327	3.27	0.187
30-34	2.68	0.482	5.52	0.279	0.55	0.832	4.31	0.642	2.63	0.192	<b>4.27</b>	<b>0.001</b>
35-39	4.25	0.477	6.60	0.197	0.65	0.992	4.78	0.722	2.53	0.197	2.94	0.597
40-44	<b>5.83</b>	<b>0.043</b>	<b>3.66</b>	<b>0.010</b>	0.00	0.162	3.64	0.153	2.33	0.170	2.62	0.972
45-49	<b>7.19</b>	<b>0.004</b>	6.35	0.201	0.48	0.713	4.40	0.801	1.82	0.171	3.51	0.226
<b>Formal education</b>												
None	<b>5.23</b>	<b>0.000</b>	<b>6.35</b>	<b>0.000</b>	0.73	0.445	4.63	0.791	2.80	0.228	<b>3.60</b>	<b>0.027</b>
Primary only	3.35	0.931	4.80	0.513	0.64	0.969	5.67	0.101	3.61	0.125	2.74	0.575
Secondary and above	<b>0.73</b>	<b>0.000</b>	<b>1.80</b>	<b>0.000</b>	0.20	0.180	3.62	0.092	2.70	0.481	<b>1.52</b>	<b>0.002</b>
<b>Marital status</b>												
Currently in union	3.91	0.157	<b>5.61</b>	<b>0.000</b>	0.68	0.629	4.66	0.165	<b>3.00</b>	<b>0.015</b>	<b>3.22</b>	<b>0.000</b>
Never in union	<b>0.98</b>	<b>0.000</b>	<b>0.62</b>	<b>0.000</b>	0.77	0.785	n/a	n/a	1.38	0.144	<b>0.63</b>	<b>0.000</b>
Separated/divorced	5.85	0.120	4.33	0.597	0.00	0.490	1.31	0.098	<b>5.76</b>	<b>0.002</b>	<b>4.17</b>	<b>0.018</b>
Widowed	<b>8.60</b>	<b>0.005</b>	6.28	0.151	0.00	0.581	3.32	0.414	<b>0.00</b>	<b>0.042</b>	2.09	0.525
<b>Wealth quintile</b>												
Poorest	<b>6.58</b>	<b>0.009</b>	<b>5.80</b>	<b>0.021</b>	0.73	0.878	4.59	0.975	3.09	0.679	3.01	0.362
Second	4.84	0.194	<b>6.16</b>	<b>0.001</b>	1.07	0.283	4.68	0.838	3.36	0.910	3.39	0.082
Middle	2.78	0.517	5.46	0.085	1.09	0.335	5.19	0.267	3.39	0.851	2.69	0.903
Fourth	<b>5.79</b>	<b>0.016</b>	4.15	0.227	0.27	0.253	4.81	0.642	3.56	0.616	2.88	0.581
Wealthiest	<b>1.58</b>	<b>0.000</b>	<b>2.33</b>	<b>0.000</b>	0.43	0.238	3.63	0.090	3.07	0.681	<b>1.58</b>	<b>0.002</b>
<b>Place of residence</b>												
Urban	<b>1.70</b>	<b>0.001</b>	<b>2.83</b>	<b>0.001</b>	0.43	0.239	4.62	0.906	2.28	0.062	<b>1.68</b>	<b>0.028</b>
Rural	<b>4.47</b>	<b>0.001</b>	<b>5.09</b>	<b>0.001</b>	7.69	0.239	4.55	0.906	3.46	0.062	<b>2.84</b>	<b>0.028</b>
<b>Health care access<sup>1</sup></b>												
Sufficient access	2.84	0.214	<b>3.51</b>	<b>0.000</b>	<b>0.31</b>	<b>0.008</b>	n/a	n/a	<b>2.32</b>	<b>0.000</b>	2.39	0.237
Limited access	3.88	0.214	<b>5.48</b>	<b>0.000</b>	<b>1.12</b>	<b>0.008</b>	n/a	n/a	<b>4.82</b>	<b>0.000</b>	2.86	0.237

Notes: Bold type denotes significance at the 5 percent level or better. Pakistan sample is ever-married women.

n/a = not available

<sup>1</sup> This is a composite variable reflecting a woman's reports of whether she finds access to health care a major problem.

### **3.1.2 Health-Related Characteristics**

A number of general health-related indicators have been linked to the experience of fistula. Amenorrhea and dysmenorrhea have been reported as a co-morbidity of fistula (Kabir et al., 2003). In some contexts the cultural practice of FGC, specifically the gishiri cut and infibulation, has been associated with increased risk for obstructed labor and subsequent fistula. As previously noted, sexual violence is a reported antecedent of vesicovaginal and rectovaginal fistula. Although the literature has not specifically described linkages between nutritional status and fistula, there is reason to believe that such a relationship might exist. Poor nutritional status is likely to be part of the complex of circumstances that predisposes a woman to fistula, but it could also be a result of having fistula (because women with fistula tend to have reduced access to social networks and employment, thus reducing their ability to obtain high-quality foods). Thus, although the directionality of any discovered relationship would be unclear, we chose to examine the data for any association between nutritional status (anemia and low body mass index--BMI) and fistula.

The results in Table 3.2 indicate that lack of menstruation is significantly and positively associated with experience of symptoms of fistula in half of the countries analyzed (Ethiopia, Malawi, Uganda). Of the three countries that asked questions on FGC, only in Niger is FGC significantly and positively associated with fistula symptoms. There is no relationship in either Ethiopia or Uganda. In two of the four countries where data on sexual violence were collected, the relationship is positive and significant in Malawi and Rwanda and is not significant in Uganda or Niger. Finally, the indicators of nutritional status do not have a significant relationship with fistula symptoms except in Uganda, where anemia is positively associated with symptoms of fistula.

In sum, no health-related risk factor was consistently associated with fistula symptoms across all six countries studied. Nonetheless, lack of menstruation and experience of sexual violence are associated with fistula symptoms in half the countries with available data, lending legitimacy to their designation as risk factors.

Table 3.2. Fistula symptoms and general health conditions

Health condition of interest	Ethiopia (N = 3,907)		Malawi (N = 11,698)		Niger (N = 3,863)		Pakistan (N = 8,798)		Rwanda (N = 5,386)		Uganda (N = 8,524)	
	%	p-value	%	p-value	%	p-value	%	p-value	%	p-value	%	p-value
No menstruation last six weeks	<b>4.74</b>	<b>0.013</b>	<b>5.66</b>	<b>0.000</b>	0.58	0.679	4.66	0.817	3.33	0.857	<b>3.29</b>	<b>0.006</b>
Any female genital cutting	3.48	0.786	n/a	n/a	<b>4.36</b>	<b>0.003</b>	n/a	n/a	n/a	n/a	5.20	0.423
Ever experienced sexual violence <sup>3</sup>	n/a	n/a	<b>6.89</b>	<b>0.000</b>	0.00	0.253	n/a	n/a	<b>5.39</b>	<b>0.000</b>	2.83	0.452
Anemic <sup>1</sup>	4.41	0.503	3.73	0.691	0.66	0.499	n/a	n/a	2.76	0.658	<b>3.64</b>	<b>0.048</b>
Underweight (BMI < 18.5) <sup>2</sup>	3.47	0.947	4.50	0.599	0.76	0.694	n/a	n/a	<b>0.00</b>	<b>0.039</b>	2.11	0.618

Notes: Bold type denotes significance at the 5 percent level or better. Pakistan sample is ever-married women.

n/a = not available

<sup>1</sup> Anemia indicator includes mild, moderate, and severe forms. Valid measurements available for reduced sample of 2,749 for Malawi; 2,684 for Rwanda; 1,494 for Ethiopia; 1,780 for Niger; 2,816 for Uganda.

<sup>2</sup> Valid anthropometric measurements available for reduced sample of 9,744 for Malawi; 2,343 for Rwanda; 1,628 for Niger; 2,518 for Uganda. In addition, this measurement excludes women who report currently being pregnant.

<sup>3</sup> Indicator was constructed from the intersection of three potential indicators: (1) report of husband ever forced sex, (2) report of first sex forced, (3) report of forced sex within specific time frames (ever, last sex, last 12 months). Indicator availability varies by country, but all are considered potential sources of trauma to the woman's vaginal canal. Valid measurement available for reduced sample of 9,707 for Malawi; 2,283 for Rwanda; 2,087 for Uganda.

### 3.1.3 Birth-Related Characteristics

Obstructed labor is the typical antecedent of VVF/RVF. The medical literature points to small stature (less than 145 cm tall), and a resultant mismatch between the size or shape of the woman's pelvis and the size of the baby's head, as a key variable predicting obstructed labor (Konje and Ladipo, 2000; Philpott, 1982). Labor can also be prolonged by malpresentation or malposition of the fetus.

Young age at first pregnancy is often cited as a predisposing factor for the experience of both obstructed labor and fistula (Muleta, 2004). Many young women who present for fistula repair do so in the aftermath of their first pregnancy. DHS collects information only on age at first live birth and not on age at first pregnancy. Because fistulae and stillbirth are more likely to occur together in first pregnancies than in subsequent pregnancies, and, when they do, they often preclude subsequent pregnancies, we include a variable on both age at first sex and age at first birth. It is expected that including age at first sex will allow an indirect assessment of the association between early childbearing and the development of fistula symptoms. This expectation is based on the following assumptions:

1. that most sexual activity is unprotected (this assumption is supported by contraceptive use data from the DHS), and
2. that unprotected sex will result in pregnancy within the first year of sexual activity.

Under these assumptions, age at first sex serves as a proxy for age at first pregnancy when data on age at first pregnancy are unavailable. In a situation where approaches to data collection on births rule out the possibility of reporting a first birth as being born still rather than alive, age at first sex is a more reasonable variable to use in an analysis of risks factors for fistula than age at first live birth. We include both age at first live birth and age at first sex in the analysis. However, while we designate a young age at first birth as a maternal age less than 18 years, we designate a young age at first sex as less than 16 years. This difference accommodates reasons for delays in the timing of first labor/delivery such as possibly infrequent sex around the time of sexual debut and the nine-month gestational period. These considerations ensure more congruity between the variables reflecting age at first birth and age at first sex.

As most babies (and many women) do not survive an unassisted obstructed labor, there is an association between fistula and stillbirth (Adhikari et al., 2005). We look at experience of stillbirth, as well as additional indicators of women's access to skilled maternity care (delivery by Caesarean section, delivery outside of a health facility, skilled attendance and receipt of a postpartum check) in the bivariate analysis. While the maternity care indicators refer only to the respondent's most recent birth in the five years preceding the survey, we make the assumption that access to skilled maternity care for the most recent birth serves as a rough proxy for the respondent's access to skilled maternity care for previous pregnancies.

While a young age at first live birth (less than 18 years of age) is not associated with experience of fistula symptoms in any of the study countries, an age at first sex of 15 or younger was positively and significantly associated with the experience of fistula symptoms in Ethiopia, Malawi, and Uganda (Table 3.3).

Experience of stillbirth is associated with incontinence at the level of  $p < 0.05$  in two countries, Malawi and Niger, and is associated at the  $p < 0.10$  level in Uganda. The lack of consistent association across all the countries is likely due to the sample selection criteria applied in Pakistan and Rwanda (experience of live birth).

Table 3.3 Fistula symptoms and childbirth indicators

Percentage of women reporting fistula symptoms in six DHS surveys, according to indicators related to childbirth, bivariate associations

Childbirth-related indicator of interest:	Ethiopia (N = 2,300)		Malawi (N = 9,298)		Niger (N = 3,143)		Pakistan (N = 8,789)		Rwanda (N = 5,386)		Uganda (N = 6,410)	
	%	p-value	%	p-value	%	p-value	%	p-value	%	p-value	%	p-value
(1) Age of first (live) birth (< 18 years)	5.79	0.130	6.33	0.131	0.52	0.367	4.58	0.989	2.75	0.434	3.34	0.922
(2) Age at first intercourse (< 16 years)	<b>5.14</b>	<b>0.003</b>	<b>5.97</b>	<b>0.000</b>	0.66	0.982	5.01	0.327	2.90	0.656	<b>3.88</b>	<b>0.000</b>
(3) Ever had still birth <sup>1</sup>	0.00	0.474	<b>10.06</b>	<b>0.014</b>	<b>5.40</b>	<b>0.007</b>	5.25	0.522	2.62	0.691	7.37	0.063
(4) Delivery by caesarian section last birth	7.23	0.494	<b>9.52</b>	<b>0.051</b>	1.57	0.346	6.89	0.286	2.47	0.561	4.87	0.451
(5) Delivered outside health facility last birth	<b>5.56</b>	<b>0.033</b>	6.07	0.856	0.67	0.406	5.54	0.944	3.40	0.573	3.91	0.180
(6) No skilled attendance last birth <sup>2</sup>	5.12	0.935	6.05	0.932	0.69	0.571	5.55	0.960	<b>2.87</b>	<b>0.047</b>	2.17	0.108
(7) Postpartum check last birth	3.39	0.242	<b>7.17</b>	<b>0.015</b>	n/a	n/a	5.55	0.966	<b>7.45</b>	<b>0.004</b>	3.87	0.984
(8) Under 145 cm in height <sup>3</sup>	0.00	0.381	5.25	0.361	0.00	0.903	n/a	n/a	0.00	0.205	4.27	0.203

Notes: Bold type denotes significance at the 5 percent level or better. Pakistan sample is ever-married women. Samples include only women who report ever having a live birth, except for indicators (4)-(7), which have the following as their denominators: Ethiopia, 1,373; Malawi, 7,305; Niger, 2,426; Pakistan, 5,700; Rwanda, 5,383; Uganda, 4,995.

n/a = not available

<sup>1</sup> Indicator was constructed from reports of having ever lost a pregnancy at the 7th, 8th, or 9th month.

<sup>2</sup> Skilled attendance included delivery by doctor, nurse, midwife, or trained birth attendant. Attendance by a traditional birth attendant is not considered skilled attendance.

<sup>3</sup> Height measurements available for a reduced sample of 11,143 for Malawi; 2,695 for Rwanda; 989 for Ethiopia; and 2,168 for Uganda.

There is inconsistent support for the role of variables reflecting recent utilization of maternal health service. In Malawi, there is a positive association between delivery by caesarean section and fistula symptoms. This is not unexpected, because caesarean section is the only way to relieve an obstructed labor, but in circumstances where women labor for days before presenting at a health facility capable of rendering appropriate care, the intervention may come too late to prevent the development of a fistula. Another explanation of this association arises from the fact that poorly performed caesareans can themselves result in fistulae. In Ethiopia, delivery outside of a health facility is associated with an increased risk of fistula symptoms, while in Rwanda, delivery without the assistance of a trained provider is significantly associated with increased risk. In both Rwanda and Malawi, postpartum checks are significantly positively associated with increased risk for fistula symptoms. Again, this is not unexpected in contexts where postpartum care is not yet routinely taken up for preventative purposes but rather is more likely to be sought for curative purposes.

Short stature is not significantly associated with increased risk for fistula symptoms. Other studies have also failed to find a significant relationship between height and fistula (Onolemhemhen and Ekwempu, 1999) or between height and caesarean section (Kara et al., 2005; Kelly et al., 1996).

### **3.2 Multivariate Results**

The multivariate logit analysis was conducted for every country except Niger, which had too few cases of fistula symptoms to support the analysis. Coefficients are reported as odds ratios, and standard errors are clustered at the community level. Control variables used in the multivariate analysis were selected based on several criteria. First, a distinction was made between variables that are thought to be determinants of fistula and those that may be in part caused by development of the fistula itself. For example, it may be expected that married women will have higher rates of fistula because they have higher birth rates than women who are not in union. At the same time, however, marital status could be influenced by development of the fistula itself because of the resulting high divorce or separation rates. Likewise, lack of menstruation could be indicative of a fistula. It is more likely, however, that this condition developed after rather than prior to the development of the fistula. Although both types of variables are interesting from a policy perspective, to avoid potential confounding associations with certain variables, we included only indicators that are clearly determinants of fistula rather than possibly a result of fistula. Second, we include determinants which are significant for at least two of the six countries in the bivariate analysis. An exception is made for FGC because of its specific policy interest, even though the variable was significant for only one country in the bivariate analysis.

The final model includes age (grouped), education levels, wealth quintiles, health indicators (sexual violence, FGC, stillbirth), and community-level indicators (urban-rural residence and access to health care). Similarly, experience of sexual violence is replaced by the sample mean for women who were not selected for the violence module, and an indicator is included to represent the missing information. Details on the components and limitations of the sexual violence variable are described in further detail in Appendix B. Limited access to health care is indicated by a community (cluster)-level mean of women's self-reports of difficulty in accessing health care for themselves. Results are presented in Table 3.4.

Again, although we present the results of the multivariate analyses side by side in Table 3.4, the results are not comparable across countries. While we did not highlight the methodological distinctions of each survey in the discussion of the bivariate results, the approach to discussing the multivariate results is to address each country separately, with specific reference to the survey methodology used in each country.

### **3.2.1 Ethiopia**

In the Ethiopia DHS all women were asked, “Have you ever heard of ‘obstetric fistula’ [LOCAL TERM]?” If the woman responded in the negative, the interviewer was instructed to probe: “Have you ever heard of a condition in which a woman continuously leaks urine and/or faeces following childbirth?”

As discussed previously, the use of the knowledge-based contingency question creates an urban and educational bias in the pool of women who are eligible to answer the question on whether they have experienced obstetric fistula. Furthermore, the construction of the question specifies that this condition occurs after childbirth, leaving out the possibility that fistula could have other etiologies such as sexual violence or HIV infection.

These circumscriptions likely affected the strength of the relationship of the covariates to the dependent variable. For example, because the sample of women is biased towards more urban, educated, and affluent respondents, poorer, rural respondents excluded from answering the relevant questions, and thus cases of fistula symptoms, are excluded from the sample. Furthermore, the effect of variables such as difficulty in accessing health care will be diluted or distorted in such a sample, because relatively well-off respondents are less likely to have difficulty obtaining health care for themselves. Questions on sexual violence were not asked in Ethiopia.

The multivariate model for Ethiopia indicates that there are few significant risk factors for the experience of fistula symptoms, given the problematic survey methodology. Only women who are in the oldest age groups are significantly more likely to report fistula symptoms than other women, suggesting that age-related incontinence is particularly overreported in this sample. (It is expected that the odds of fistula will increase upon women’s entry into their childbearing years, rather than only at the close of their childbearing years.) As expected, even in such a circumscribed sample, the wealthiest and most educated women are significantly less likely to report fistula symptoms than others.

### **3.2.2 Malawi and Uganda**

In Malawi and Uganda all women had an opportunity to answer a question intended to elicit reporting of fistula symptoms. Thus, the data from these surveys are the most appropriate for analysis. In Malawi there were two opportunities for women to be asked about fistula symptoms, once in response to a question on postpartum problems (asked only of women who had given birth in the five years preceding the survey) and, for all women who did not answer that question in the affirmative or who were not asked that question, once as follows: “Sometimes a woman can have a problem, usually after a difficult childbirth, such that she experiences leakage of urine or stool from her vagina. Have you ever experienced this problem?” The Uganda survey provided one opportunity to answer the following nearly identical question on fistula symptoms: “Sometimes a woman can have a problem, usually after a difficult childbirth, such that she experiences an uncontrollable leakage of urine or stool from her vagina. Have you ever experienced this problem?” While these questions do refer to the association between fistula and difficult childbirth, they do not imply that an affirmative response should refer only to obstetric experiences (although it is not possible without qualitative research to know how the survey respondents actually interpret the word “usually” in the question).

In both Malawi and Uganda, age is associated with reporting of fistula symptoms throughout the life course. Compared with 15-19 year olds, many of whom have not yet borne children, all subsequent age groups are significantly more likely to report fistula symptoms. This finding is in line with expectations and provides some support for the methodological approach taken in these two countries. In Malawi, the wealthiest and most educated women are significantly less likely than the poorest and least educated women to report symptoms, while in Uganda, there is no significant relationship with these variables. In Malawi, experience of fistula symptoms is 75 percent higher among women who report sexual violence.

In Uganda, there is no significant relationship between sexual violence and fistula, perhaps due to the sampling considerations described in Appendix B. Women’s experience of stillbirth confers a 63 percent higher risk of fistula in Malawi and more than doubles the odds of experiencing fistula symptoms in Uganda. Malawian women who live in communities that face considerable problems in obtaining health care are 30 percent more likely to report symptoms than those who do not. For Ugandan women this variable is not significant.

### **3.2.3 Pakistan**

In Pakistan, women were asked a comprehensive set of questions on their experience of symptoms, starting with the following: “Sometimes a woman can have a problem, usually after a difficult childbirth, such that she continuously dribbles urine even during sleep that wets her clothes too and/or leaks stool from her vagina. Have you ever experienced this problem?” Subsequent questions inquired about the survival of the baby and treatment of the fistula. Unfortunately, at some point during questionnaire development, the decision was made to restrict eligibility for these questions to women who had ever had a live birth. As previously discussed, this excludes from analytical consideration the women who experienced both stillbirth and fistula with their first pregnancy and who have not subsequently had a live birth. Additionally, many of the questions on important covariates such as experience of sexual violence and problems faced in accessing health care were not asked in Pakistan.

As a result of these issues, and given the likelihood that prevalence of fistula is lower in Pakistan (due to higher prevalence of caesarean section) than it is in sub-Saharan Africa (resulting in fewer cases of incontinence to analyze), there are no significant covariates in the model.

### **3.2.4 Rwanda**

Rwanda limited eligibility to answer questions on fistula to women who had delivered a live birth in the five years preceding the survey. This may explain the resemblance between Rwanda’s and Pakistan’s results: None of the basic sociodemographic risk factors for experiencing fistula symptoms are significant. Experience of sexual violence, however, nearly triples women’s odds of reporting fistula symptoms compared with women who did not experience sexual violence. The statistical significance of this finding likely reflects the recent history of genocidal civil war in Rwanda. Additionally, women who live in communities where access to health care is limited are nearly twice as likely to experience symptoms of fistula as those who have better access to health services.

## **3.3 Discussion of Results**

While the results of the analysis themselves are not strictly comparable, it is possible to highlight some findings that are nevertheless fairly consistent across countries.

First, experience of sexual violence is a covariate that is significantly associated with the experience of fistula symptoms in two of the three countries where questions on violence were asked. This reaffirms a focus on this etiology that has been suggested in previous analyses (Johnson, 2007a) and strengthens the argument that sexual violence contributes to more cases of fistula—or conditions with similar symptoms—than previously understood.

Second, where stillbirth is significant—in Malawi and Uganda, the only countries with an unbiased sample of respondents—it has a strong association with fistula symptoms. It is expected that, as more appropriately collected data on fistula become available, the consistency of the relationship across countries will improve. This association serves as a measure of validation of the use of survey methods to capture information on VVF/RVF.

One unexpected finding is that residence (urban or rural) is not significant in any country's analysis. In the two countries that had unbiased samples available for analysis, Malawi and Uganda, previous analysis (Johnson, 2007a) indicates that the effect of the residence variable is captured by the wealth variable in Malawi, while in Uganda the residence variable is simply nonsignificant in the multivariate model.

During analysis, it was noted that the Malawi data performed the best in terms of generating the expected associations among fistula symptoms and likely correlates. Possible reasons for this include the facts that Malawi did not have a selected subsample for the fistula questions, that subsampling for the sexual violence questions was minimal, and that many respondents had more than one opportunity to respond to questions on both fistula symptoms and sexual violence.

Table 3.4 Logit results (odds ratios) for risk factors for fistula symptoms

Independent variables	Ethiopia (3,907 )	Malawi (11,698)	Pakistan (8,798)	Rwanda (5,393)	Uganda (8,524)
<b>Age (ref: 15-19 years)</b>					
20-24	1.648	2.416***	1.294	2.140	3.377***
25-29	1.603	2.364***	1.388	1.577	3.373***
30-34	1.738	2.281***	1.143	1.057	4.701***
35-39	2.236*	2.655***	1.081	1.245	3.283***
40-44	3.446***	2.831***	0.936	1.007	3.192***
45-49	2.706**	1.604*	1.063	0.883	4.327***
<b>Education (ref: no schooling)</b>					
Primary only	0.866	0.871	1.183	1.204	1.215
Secondary and above	0.192***	0.461***	0.816	1.046	0.939
<b>Wealth quintiles (ref: poorest)</b>					
Second quintile	0.840	1.097	1.053	1.031	0.959
Middle quintile	0.549	0.937	1.079	1.251	0.921
Fourth quintile	0.891	0.835	1.108	1.145	0.898
Wealthiest quintile	0.354*	0.628**	0.846	1.085	0.669
<b>Health indicators</b>					
Experienced sexual violence (ref: no)	n/a	1.754***	n/a	2.808***	1.331
Missing information on sexual violence (ref: no)	n/a	0.952	n/a	1.621***	1.245
Underwent FGC (ref: no)	0.833	n/a	n/a	n/a	1.302
Experienced stillbirth (ref: no)	0.000	1.630*	1.207	0.883	2.415**
<b>Community-level variables</b>					
Has limited access to health care (ref: no)	0.792	1.304**	n/a	1.912***	0.925
Urban (ref: rural)	1.142	0.929	1.175	0.710	0.777
Pseudo R <sup>2</sup>	0.100	0.040	0.005	0.038	0.030

Note: Sample sizes reflect sub-samples for fistula questions: Ethiopia (ever heard of fistula), Pakistan (married; ever had live birth) and Rwanda (live birth in last five years). Coefficients reported as odds ratios and robust standard errors (not reported) are clustered at the PSU level.

n/a = not available

\* significant at 10%; \*\* significant at 5%; \*\*\* significant at 1%

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# 4

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## Prevention

Given the large numbers of women reporting symptoms suggesting fistula, there is a clear imperative to devote attention and resources to the issue. Since most fistulae result from childbirth, policies and programs that prevent early and unwanted pregnancies and that avoid delays in obstetric care could reduce the incidence of the problem. This section presents data from the DHS that indicate opportunities for policy and program interventions aimed at preventing fistula.

### 4.1 Preventing Early and Unwanted Pregnancies

By advocating later ages at first pregnancy, ensuring that all women have access to contraceptive methods, and ensuring appropriate care for women during pregnancy, delivery, and postpartum, it is possible to reduce the incidence of a variety of maternal morbidities, including obstetric fistula, as well as to reduce maternal mortality (Campbell and Graham, 2006). Family planning efforts have recently lost financial and technical resources, due to diminishing support from donor countries and the redirection of resources to address the AIDS epidemic. Restoring some of the focus to family planning is a key element in reducing the chances of unwanted pregnancy and thereby reducing the risk of developing obstructed labor and hence obstetric fistula.

Table 4.1 presents data, for the six countries in this analysis, on contraceptive prevalence, levels of unmet need for contraception, and the percentage of births in the past five years that were mistimed or unwanted at the time of conception. In most of the countries, the levels of unmet need and mistimed/unwanted pregnancies are very high, exceeding 20 percent in all countries save for Niger. Unmet need for contraception is the condition that policymakers and safe motherhood programs should seek to alleviate in order to lower maternal morbidity and mortality rates.

Additionally, reducing early childbearing is likely to reduce the incidence of maternal morbidities such as fistula, as well as a host of other negative outcomes (e.g., Buvinic, 1998). Data on median age at first birth in these countries appears in Table 2.1.

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Table 4.1 The context of prevention: Use of and need for family planning

The percentage of currently married women who are currently using a modern contraceptive method, the percentage of currently married women with an unmet need for family planning, and the prevalence of mistimed or unwanted pregnancy in six DHS surveys with data on fistula symptoms

Indicator	Ethiopia	Malawi	Niger	Pakistan	Rwanda	Uganda
Contraceptive prevalence	13.9	28.1	5.0	21.7	10.3	17.9
Unmet need for contraception	33.8	27.6	15.8	23.8	37.9	40.7
Percent of births mistimed or unwanted	34.9	40.4	9.6	27.0*	39.8	45.8

### 4.2 Preventing Delays in Treating Obstructed Labor

While obstructed labor can be neither predicted nor prevented in most cases, it can be treated—usually through a caesarean delivery. There are many factors that affect whether a woman can get access to a health facility that can provide emergency obstetric care, including the availability of such facilities in the country. DHS data make possible an examination of certain individual-level characteristics that may

influence the likelihood that a woman will obtain the necessary obstetric care when faced with the obstetric emergency of obstructed labor: the percentage of women who deliver in health facilities, the proportion of women for whom access to health care is difficult, the proportion of women who know the danger signs of pregnancy, and the proportion of women who have received postpartum care. These data are presented in Table 4.2.

Table 4.2 The context of prevention: Obstetric care

Percentage of women with a birth in the past five years, in six DHS surveys with data on fistula symptoms, who were told about pregnancy complications; whose access to a health facility was difficult, and why; who had caesarean sections; and, among those delivering outside of a facility, who had postnatal checks

Indicator	Ethiopia	Malawi	Niger	Pakistan	Rwanda	Uganda
Percent who were told of complications of pregnancy	8.9	67.0	12.3	n/a	5.8	33.7
Percent who were told where to go in event of a pregnancy complication	7.7	64.2	10.8	n/a	5.3	31.5
Percent with difficult access to health facility	94.9	80.4	78.6	n/a	80.7	84.3
Trouble getting permission to go	37.1	8.5	8.8	n/a	1.9	8.3
Trouble getting money for treatment	80.2	63.5	66.6	n/a	71.8	68.3
Too far	73.2	62.1	54.1	n/a	39.1	58.5
Would have to take transport	78.0	57.3	52.9	n/a	38.5	51.9
Did not want to go alone	64.1	25.8	24.6	n/a	15.9	24.7
No female health care provider	75.1	12.7	15.6	n/a	5.5	16.5
Percent delivering in a health facility	5.2	58.0	18.2	37.3	29.3	44.6
Percent of women who had a caesarean section	1.2	3.3	1.2	8.5	3.1	3.6
Percent of women delivering outside a facility who had postnatal check by health professional within 0-6 days postpartum	4.7	23.4*	10.7	16.7	2.9	14.5
Number of women with a birth in the 5 years preceding the survey	7307	7270	6301	5675	5425	5035

n/a = not available

\* Percent of all women reporting a postnatal check

*“To prevent fistula, a lot more needs to be done to educate not just the women, but the men, because they control the resources needed to access the services that would prevent fistula.”*

—Dr. Ileogbem Sunday Adeoye, Obstetrician/Gynecologist, Ebonyi State University Teaching Hospital, Abakaliki, Nigeria

Women who know the complications of pregnancy are more likely to go to a health facility for delivery (Johnson, 2007) and are assumed to know to get to a facility more quickly if they begin laboring at home but experience a complication. Knowledge of signs of complications and where to go in the event of a complication varies considerably across the six countries, with women in Malawi most likely to have been told about complications (67 percent) and women in Ethiopia and Rwanda least likely (9 percent and 6 percent, respectively). Given that most women attend at least one antenatal care visit during the course of their pregnancies, health care providers should not miss this opportunity to give their clients this critical information. Additionally, ensuring that women and their families—particularly husbands—can promptly recognize the signs of prolonged labor and understand that it is a life-threatening situation could be a key objective of IEC programming. Maintaining partograms in the community could be one way to facilitate community-based recognition of prolonged labor.

More than three-quarters of women in these countries (omitting Pakistan for lack of data) report that they have serious problems obtaining health care for themselves. Getting money for treatment and distance to the facility or need to use transport to get to a health facility are the primary obstacles to women seeking health care for themselves. Given the problems posed by distance and travel, ensuring that an emergency transportation system is in place for rural women who otherwise plan to labor and deliver at home is an essential component of ensuring timely access to emergency obstetric services, particularly given that less than half of women in four of the six countries studied do deliver in health facilities.

As previously discussed in Section 2.1, the prevalence of caesarean section in all of the sub-Saharan African countries is extremely low, leading to the informed assumption that many women and babies who need the life-saving surgery are instead dying in the peripartum. Increasing the number of facilities able to perform caesarean sections and upgrading the quality of care provided are essential to reducing maternal mortalities and morbidities such as fistula.

Finally, few women in any of these countries who deliver outside of a health facility receive a timely postpartum check on their own health. Early identification and treatment of a fistula may improve the likelihood of successful repair (Raassen et al., 2008), helps the woman return to a normal life more quickly, and may help to preclude some of the more severe social and economic consequences of fistula.



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# 5

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## Conclusions and Next Steps

This report documents early efforts to collect national lifetime prevalence data on vaginal fistula. It demonstrates the effects that methodological approaches to survey implementation have on self-reported prevalence of severe incontinence and its covariates, and it underscores the need for careful consideration in sample selection. A new approach to survey-based data collection, recommended here, should remedy the problems of past approaches to data collection. Above all, it must be understood that all women are at risk for developing fistula, and therefore, in the collection of prevalence data on symptoms of fistula, all women must have the opportunity to respond to a carefully considered set of questions, such as the module presented here (Figure 1.3).

While the findings highlight the difficulties of data collection on fistula specifically and maternal morbidity in general, they also indicate that, where data were correctly collected, the majority of the reported risk factors found in the literature on fistula in the developing world were indeed correlated with women's reported symptoms. Further, the fact that the prevalence of incontinence in an unselected population of women can be quite high, compared with the lower prevalence of fistula symptoms reported here, suggests that over-reporting of these symptoms in DHS surveys may not be egregious. These findings should provide motivation to improve efforts in questionnaire construction, sample selection, data collection, and analysis. There is a need for sequential data collection in the form of pregnancy and fistula histories to enable researchers to sort out cause and effect. The findings also provide a reasonable basis for thinking that many women reporting symptoms of fistula have indeed suffered or are currently suffering from this condition—or, as Fronczak et al. (2005) have shown, a condition with indistinguishable symptoms and socioeconomic consequences.

This report also serves to establish baseline levels of symptoms of fistula in several countries. Only through establishing the prevalence of fistula can contributing factors be identified, appropriate and sufficient resources be allocated, and interventions be evaluated at the national level. As the effort to collect data on fistula evolves, more standardized and appropriate data for analysis will become available, which will further assist the development of programmatic interventions (focused both on prevention and on repair and rehabilitation) and will better guide policymaking.

Although Fortney and Smith (1999) have demonstrated the statistically unsatisfactory nature of self-reports on maternal morbidity, they also note that, “short of all births taking place in institutions and comprehensive data collection on all deliveries, there is little choice but to continue to use self-reports.” There does appear to be promise in the use of survey methods to capture national prevalence data on fistula. Thus, there is justification for continued collection of survey data. Establishing the sensitivity and specificity of the questions on fistula, particularly through the use of qualitative methods and physical exams, is a key next step in the development of improved survey instruments.

Findings from these analyses include both the expected and the unexpected. It was expected that, when women have limited access to health care, they will be at higher risk for experiencing symptoms of fistula. The association between stillbirth and reporting of fistula symptoms also was expected. In contrast, the fairly consistent association between sexual violence and fistula symptoms underscores the unexpected. Resources to eradicate the suffering caused by fistula must be directed not only to improving maternal health care services, and access thereto, but also to supporting survivors of sexual violence and ultimately eradicating sexual violence against women.

Preventing pregnancy, specifically unwanted pregnancy, is a key primary prevention approach to maternal morbidity and mortality. The descriptive analysis in Section 4 highlights the critical need, given that fistulae develop largely through obstetric causes, to re-emphasize the role of family planning in ensuring maternal health and survival.

Finally, the results here suggest that women who struggle with their labors do indeed seek medical care, but often too late to preclude severe morbidity. Women and families must be supported at the community, district, and national levels to recognize the signs of prolonged labor, to make appropriate and timely decisions about care during labor and delivery, and to have quick access to effective emergency care.

While the implementation of policy and programmatic strategies to eliminate fistula—whether of violent, obstetric, or iatrogenic derivation—will differ depending on national and subnational contexts, the driving element behind such efforts will be rooted in the same place: a sense of value and respect for the lives of women.

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## Appendix A Questionnaires by Country

### *Malawi (2004)*

432A	After this birth, did you experience a problem such as:	YES	NO	DON'T KNOW	
	Heavy bleeding?	1	2	3	
	High blood pressure?	1	2	3	
	Stroke/convulsions?	1	2	3	
	Infection/fever?	1	2	3	
	Uncontrollable leakage of urine or stool from your vagina?	1	2	3	
	Post-partum depression/blues?	1	2	3	
494B	Sometimes a woman can have a problem, usually after a difficult childbirth, such that she experiences an uncontrollable leakage of urine or stool from her vagina.  Have you ever experienced this problem?	YES ..... 1 NO ..... 2 DON'T KNOW ..... 8			

Note: Question 432A was asked only of women who had received postpartum care for a birth in the past five years. Question 494B was asked of all women regardless of childbearing status.

### *Ethiopia (2005)*

1021	Have you ever heard of obstetric fistula (USE LOCAL TERM)?  IF NO PROBE: Have you ever heard of a condition in which a woman continuously leaks urine and/or faeces following childbirth?	YES ..... 1	NO ..... 2	→ 1101
1022	Have you yourself experienced obstetric fistula?	YES ..... 1	NO ..... 2	→ 1024
1023	Have you ever been treated for obstetric fistula?	YES ..... 1	NO ..... 2	
1024	Are there any (other) women in your household who suffer from obstetric fistula?	YES ..... 1	NO ..... 2	→ 1101
1025	How many (other) women in your household suffer from obstetric fistula?	NUMBER ..... <input style="width: 20px; height: 15px;" type="text"/> <input style="width: 20px; height: 15px;" type="text"/>		DON'T KNOW ..... 98

Note: Question 1021 was asked of all women ages 15-49.

**Rwanda (2005)**

433A	Avez-vous jamais souffert d'une fistule obstétricale ? (MALADIE CARACTÉRISÉE PAR L'ÉCOULEMENT INCONTRÔLÉ DES URINES OU/ÉT DES SELLES DU VAGIN À CAUSE DE LA PERFORATION DE LA PAROI DU VAGIN QUI LE MET EN COMMUNICATION AVEC LA VESSIE ET/OU LE RECTUM)	OUI..... 1 NON..... 2  PASSER A 434 ←	
433B	Avez-vous recherché des soins pour ce problème ?	OUI..... 1 NON..... 2	

Note: These questions were asked only of women who had delivered a live birth in the past five years.

**Uganda (2006)**

643C	Sometimes a woman can have a problem, usually after a difficult childbirth, in which she experiences uncontrollable leakage of urine or stool from her vagina.  Have you ever experienced this problem?	YES ..... 1 NO ..... 2 DON'T KNOW ..... 8	
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Note: Question 643C was asked of all women ages 15-49.

**Mali (2006) and Niger (2006)**

No.	QUESTIONS ET FILTRES	CODES	PASSER À
925	Connaissez-vous la maladie dénommée « fistule » c'est-à-dire, la « maladie de l'urine » ?	OUI ..... 1 NON ..... 2	→ 1001A
926A	Quelles sont selon vous, les causes de cette maladie ?	SORCELLERIE OU ENVOUTEMENT MYSTIQUE ..... A MAUVAIS SORTS, FATALITE..... B TROP JEUNE POUR ACCOUCHER ..... C TROP VIEILLE POUR ACCOUCHER ..... D TROP MAIGRE POUR SUPPORTER UNE GROSSESSE ..... E TROP D'ACCOUCHEMENTS SUCCESSIFS..... F MALADIES FREQUENTES DURANT LA GROSSESSE ..... G ACCOUCHEMENT D'UN GROS BEBE ..... H ACCOUCHEMENT A DOMICILE SANS ASSISTANCE MEDICALE ..... I VOLONTE DE DIEU ..... J AUTRES ..... X (PRÉCISER) NE SAIT PAS ..... Y	
926B	Quelles sont selon vous les principales manifestations de cette maladie ?	AMAIGRISSEMENT CONTINU ..... A PERTE INVOLONTAIRE DES URINES ..... B PERTE INVOLONTAIRE DES SELLES ..... C PERTE INVOLONTAIRE DES URINES ET DES SELLES ..... D CONSTAMMENT MOUILLEES ..... E ODEURS NAUSEABONDES ..... F INFIRMITE LOCOMOTRICE RELATIVE ..... G	
927	Peut-on soigner, selon vous, cette maladie et en guérir ?	OUI ..... 1 NON ..... 2	
928	Avez-vous déjà contracté cette maladie ?	OUI ..... 1 NON ..... 2	→ 935
929	Si oui, comment, selon vous, avez-vous contracté cette maladie ?	_____ _____ _____	
930	Comment faites-vous ou comment avez-vous fait pour vous soigner ?	CENTRE DE SANTÉ ..... A MATERNITÉ ..... B HOPITAL ..... C CLINIQUE PRIVÉE ..... D AUTRE STRUCTURE MÉDICALE (A PRÉCISER) ..... E SOINS TRADITIONNELS AU VILLAGE ..... F AUCUN TRAITEMENT ..... G	→ 935
931	Si vous suivez ou vous avez suivi un traitement en relation avec votre fistule dans un centre de santé moderne, combien d'opérations chirurgicales, avez-vous subies ?	NOMBRE DE FOIS <input type="text"/> <input type="text"/> SI AUCUNE FOIS 00	→ 933
No.	QUESTIONS ET FILTRES	CODES	PASSER À
932A	Cette opération chirurgicale ou la dernière opération chirurgicale subie, a-t-elle été selon vous une réussite ?	OUI ..... 1 NON ..... 2	
932B	Pourquoi pensez-vous que cette opération est réussie ?	CESSATION TOTALE DES PERTES D'URINES ..... A REPRISE NORMALE DES ACTIVITES QUOTIDIENNES..... B SENSATION DE DELIVRANCE ET DE MIEUX ETRE..... C RETOUR A LA VIE DE FAMILLE ..... D	
932C	Pourquoi pensez-vous que cette opération n'est pas réussie ?	AGGRAVATION : PERTES D'URINES TROP FREQUENTES ..... A	

**Democratic Republic of the Congo (2006)**

726	Connaissez-vous la maladie dénommée "fistule" c'est-à-dire, la maladie qui fait que la femme perd de l'urine et/ou défèque continuellement ?	OUI ..... 1 NON ..... 2	→ 801
726A	Selon vous, quelle est la principale cause de cette maladie ?	ACCOUCHEMENT ..... 1 INTERV. CHIRURGICAL ..... 2 TRAUMATISME ..... 3 NE SAIT PAS ..... 8	
727	Connaissez-vous (souffrez-vous) actuellement de pertes d'urines et/ou de selles par le vagin en dehors des "mictions /défécations" ?	OUI ..... 1 NON ..... 2	→ 729
728	Avez-vous déjà connu (souffert) de pertes d'urines et/ou de selles par le vagin en dehors des mictions /défécations ?	OUI ..... 1 NON ..... 2	→ 801
729	Comment cela est-il arrivé ?	APRÈS ACCOUCHEMENT ..... 1 APRÈS AGRESSIONS SEXUELLE... 2 APRÈS INTERVENTION CHIRURGICALE ..... 3 AUTRE ..... 6 (PRÉCISER)	→ 731
730	Vous avez dit que cela est arrivé après un accouchement. Était-ce à votre 1er, 2ème, 3ème ... accouchement ?	RANG ACCOUCHEMENT ... <input type="text"/> <input type="text"/>	
731	Quel âge aviez-vous au moment où cela vous est arrivé (pour la première fois) ?	ÂGE ..... <input type="text"/> <input type="text"/> NSP ..... 98	
732	Avez-vous reçu (suivez-vous actuellement) un traitement ?	OUI ..... 1 NON ..... 2	

**Pakistan (2006-07)**

906	<b>CHECK 212:</b>	ONE OR MORE LIVE BIRTH <input type="checkbox"/>	NO LIVE BIRTHS <input type="checkbox"/>	→ 911
907	Sometimes a woman can have a problem, usually after a difficult childbirth, such that she continuously dribbles urine even during sleep that wets her clothes too and/or leaks stool from her vagina. Have you ever experienced this problem?	YES, DRIBBLING OF URINE ..... 1 YES, STOOL COMING FROM VAGINA ..... 2 YES, BOTH ..... 3 NO ..... 4  DON'T KNOW ..... 8	→ 911	
908	Do you still have this problem?	YES ..... 1  NO ..... 2		
909	Please tell me how did this problem start:	AFTER A DIFFICULT CHILDBIRTH ..... 1  AFTER A RAPE/SEXUAL ASSAULT ..... 2  OTHER _____ 6 (SPECIFY)		
910	What happened to baby?	LIVE BIRTH: DIED IN SEVEN DAYS ..... 1 DIED AFTER SEVEN DAYS ..... 2 STILL LIVING ..... 3 STILL BIRTH ..... 4		

473	<p>During the delivery or in the 40-day period after the delivery of (NAME), did you experience any of the following problems?</p>	<table border="0"> <thead> <tr> <th></th> <th style="text-align: center;">YES</th> <th style="text-align: center;">NO</th> </tr> </thead> <tbody> <tr> <td>Severe headaches?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Blurred vision?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Swelling of your hands?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Swelling of your face?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>High fever?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Fits or convulsions?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Labor for more than 12 hours?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Baby's feet came first?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Placenta came first?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Continuous dribbling of urine even during sleep</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Bad-smelling vaginal discharge?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Inability to control motions.</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> <tr> <td>Heavy vaginal bleeding?</td> <td style="text-align: center;">..... 1</td> <td style="text-align: center;">..... 2</td> </tr> </tbody> </table> <p>(SKIP TO 474) ←</p>		YES	NO	Severe headaches?	..... 1	..... 2	Blurred vision?	..... 1	..... 2	Swelling of your hands?	..... 1	..... 2	Swelling of your face?	..... 1	..... 2	High fever?	..... 1	..... 2	Fits or convulsions?	..... 1	..... 2	Labor for more than 12 hours?	..... 1	..... 2	Baby's feet came first?	..... 1	..... 2	Placenta came first?	..... 1	..... 2	Continuous dribbling of urine even during sleep	..... 1	..... 2	Bad-smelling vaginal discharge?	..... 1	..... 2	Inability to control motions.	..... 1	..... 2	Heavy vaginal bleeding?	..... 1	..... 2
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473A	<p><b>IF YES:</b> When did you experience this:</p>	<p>Immediately after birth of baby 0 In the first 24 hours 1 Later 2</p>																																										
474	<p><b>CHECK 473:</b> ANY YES <input type="checkbox"/> ALL NO <input type="checkbox"/> (SKIP TO 480)</p>																																											
475	<p>Were any of these problems so severe that you were afraid you might die?</p>	<p>YES ..... 1 NO ..... 2 CANNOT REMEMBER 8</p>																																										
476	<p>Did you seek advice or treatment for the problem(s)?</p> <p><b>IF YES:</b> Whom did you see?</p> <p>Anyone else?</p> <p><b>PROBE FOR THE TYPE(S) OF PERSON(S) AND RECORD THE ALL MENTIONED.</b></p>	<p><b>HEALTH PERSON</b> DOCTOR ..... A NURSE/MIDWIFE/LHV ..... B</p> <p><b>OTHER PERSON</b> DAI-TBA ..... C LADY H. WORKER ..... D HOMEOPATH ..... E HAKIM ..... F OTHER ..... X (SPECIFY)</p> <p>NO ONE ..... Y (SKIP TO 479) ←</p>																																										
477	<p>Where did you seek treatment for the problem(s)?</p> <p>Anywhere else?</p> <p><b>PROBE TO IDENTIFY TYPE(S) OF SOURCE(S) AND RECORD ALL MENTIONED.</b></p>	<p><b>HOME</b> YOUR HOME ..... A OTHER HOME ..... B</p> <p><b>PUBLIC SECTOR</b> GOVT. HOSPITAL ..... C RHC/MCH ..... D BHU/FWC ..... E OTHER PUBLIC ..... F (SPECIFY)</p> <p><b>PRIVATE MED. SECTOR</b> PVT. HOSPITAL/CLINIC ..... H PVT. DOCTOR ..... I HOMEOPATH ..... J DISPENSER / COMPOUNDER ..... K HAKIM ..... L OTHER PRIVATE MED. .... M (SPECIFY)</p> <p>OTHER ..... X (SPECIFY)</p>																																										

## Appendix B Components of the Sexual Violence Variable

Appendix Table B: Construction of sexual violence indicators by country

For countries where the sexual violence indicator was a composite variable, the questions were asked according to eligibility (if the woman had ever been married or sexually active). All questions are asked within the domestic violence module, which is administered to a subsample of the original sample of women. Only one woman per household is eligible to answer questions on domestic violence. In Rwanda and Uganda, a subsample of households was selected out of the original household sample for data collection on domestic violence. It is expected that the results for the sexual violence variable will be more robust for Malawi (minimal subsampling) than for Uganda and Rwanda (where only about a fifth of the sample had the opportunity to answer questions on violence).

*Questions asked by country:*

Malawi (2004)	<p><b>Intimate partner SV:</b> 71 percent (ever married).</p> <p><b>Forced sex:</b> 76 percent (sexually active).</p>	<p>(QDV06A (h)): (Does/did) your (last) husband/partner ever: (i) physically force you to have sexual intercourse with him even when you did not want to?</p> <p>(QDV21B): The first time you had sexual intercourse, would you say that you had it because you wanted to, or because you were forced to have it against your will?</p> <p>(QDV21C): In the last 12 months, has anyone forced you to have sexual intercourse against your will?</p>
Rwanda (2005)	<p><b>Intimate partner SV:</b> 22 percent (ever married).</p> <p><b>Forced sex:</b> 34 percent (sexually active).</p>	<p>(Q1106A (i)): (Does/did) your (last) husband/partner ever: (i) physically force you to have sexual intercourse with him even when you did not want to?</p> <p>(Q 542): The first time you had sexual intercourse, did you want to have sex or you were forced against your will?</p> <p>(Q 543): In the last 12 months, did someone force you to have sex against your will?</p>
Uganda (2006)	<p><b>Intimate partner SV:</b> 20 percent (ever married).</p> <p><b>Forced sex:</b> 22 percent (sexually active).</p>	<p>(Q1105 (h)): (Does/did) your (last) husband/partner ever do any of the following things to you: (h): physically force you to have sexual intercourse with him even when you did not want to?</p> <p>(Q1121): The first time you had sexual intercourse, would you say that you had it because you wanted to, or because you were forced to have it against your will?</p> <p>(Q1125): At any time in your life, as a child or as an adult, has anyone ever <u>forced you in any way</u> to have sexual intercourse or perform any other sexual acts?</p>

## **Appendix C Participants in the 2006 International Obstetric Fistula Working Group Data, Indicators, and Research Group, October 11-13, 2006, Geneva, Switzerland**

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Saifuddin Ahmed	John Hopkins Bloomberg School of Public Health
Maggie Bangser	Women's Dignity Project
Mark Barone	EngenderHealth
Karen Beattie	EngenderHealth
Gervais Beninguisse	Institut de Formation et de Recherches Démographiques (IFORD)
Cynthia Berg	US Centers for Disease Control (CDC)
Luc de Bernis	United Nations Population Fund (UNFPA)
Vincent Fauveau	United Nations Population Fund (UNFPA)
Barbara E. Kwast	Averting Maternal Death and Disability (AMDD)
Kiersten Johnson	Demographic and Health Surveys (DHS)
Patricia MacDonald	US Agency for International Development (USAID)
Mario Marinaldi	World Health Organization/Reproductive Health and Research (WHO/RHR)
Matthews Mathai	World Health Organization/Making Pregnancy Safer (WHO/MPS)
Subhi Mehdi	US Agency for International Development (USAID)
Pervin Meherji	National Institute for Research in Reproductive Health/Indian Council of Medical Research
Mulu Muleta	Addis Ababa Fistula Hospital
Richard Dackam Ngatchou	United Nations Population Fund (UNFPA)
Arvind Pandey	National Institute for Medical Statistics/Indian Council of Medical Research
Thomas J.I.P. Raassen	African Medical Research Foundation
Kate Ramsey	United Nations Population Fund (UNFPA)
Jennifer Harris Requejo	World Health Organization/University of Texas at Austin
Charles-Henry Rochat	Geneva Foundation for Medical Education and Research (GFMER)
Florina Serbanescu	US Centers for Disease Control

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