

Experiences of Internalized and Enacted Stigma among Women with Obstetric Fistula in  
Tanzania

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Thesis submitted in partial fulfillment of  
the requirements for the degree of  
Master of Science in the Duke Global Health Institute  
in the Graduate School of Duke University

2016

ABSTRACT

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## **Abstract**

Background: Obstetric fistula is the development of a necrosis between the bladder and the vagina and/or the bladder and the rectum as a result of prolonged obstructed labor, resulting in urinary or fecal incontinence. In Tanzania surgical repair for obstetric fistula is provided freely by the government but it is estimated that there are over 25,000 women living with an untreated fistula. These women experience high degrees of psycho-social stresses exacerbated by the stigma surrounding their condition. There is a dire need to explore stigma within this population in order to better understand its impact, as stigma affects both treatment seeking behavior as well as long term recovery of those who access surgical repair.

Study Aims: This study aims to understand the experiences of stigma among women with obstetric fistulas by examining both internalized and enacted stigma, and by identifying pertinent correlates of internalized stigma.

Methods: This mixed-methods study utilized both quantitative and qualitative data collected in two related studies at a single hospital in Moshi, Tanzania. All study participants were women receiving surgical repair for an obstetric fistula. In the quantitative portion, cross-sectional survey data were collected from 52 patients. The primary outcome was fistula-related stigma, measured using an adaptation of the HASI-P stigma scale, which included constructs of both internalized and enacted stigma. In the qualitative portion, 45 patients participated in a semi-structured in-depth interview, which

explored topics such as stressors caused by the fistula, coping mechanisms, and available support. The transcripts were analyzed using analytic memos and an iterative process of thematic coding using the framework of content analysis.

Results: Expressions of internalized stigma were common in the sample, with a median score of 2.1 on a scale of 0 – 3. Internalized was significantly correlated with negative religious coping, social participation, impact of incontinence and enacted stigma. Qualitative analysis was consistent and demonstrated widespread themes of shame and embarrassment. Experiences of enacted stigma were not as common (median score of 0), although some items, like those pertaining to mockery and blame, were endorsed by up to 25% of the study sample. Themes of anticipated stigma (isolation and non-disclosure due to the possibility of stigmatization) were also evident in the qualitative sample and may explain the low enacted stigma scores observed.

Conclusion: In this sample of women receiving surgical repair for an obstetric fistula, stigma was evident, with internalized stigma resulting in psychological impacts for patients. Experiences of both anticipated and enacted stigma were also observed. There is a need to explore interventions that would decrease stigma while also increasing support for these women, as stigma may be a barrier towards accessing surgical repair and reintegration following surgery.

Keywords: Tanzania, obstetric fistula, stigma, maternal health

## **Dedication**

To my parents, without whom this would have never been possible

And

To my Fiancé; if we can survive this, we can survive anything.

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## **1. Introduction**

Obstetric Fistula is the development of a necrosis (hole) between the vagina and the bladder (VVF), or the rectum and the vagina (RVF), due to prolonged obstructed labor (Semere & Nour, 2008). An obstetric fistula results in urinary and/or fecal incontinence, and may also include other physiological problems like renal failure and secondary infertility (Arrowsmith, Hamlin, & Wall, 1996). Obstetric fistula is a multifaceted problem that does not only have physiological effects but also psychosocial effects. Women living with obstetric fistula have been known to have increased depression, anxiety and other mental health dysfunctions (Wall, 2006). They often internalize emotions of shame and negative self-perception, which can lead to self-instigated social isolation and exclusion from the community. This social avoidance maybe further exacerbated due to anxiety and guilt that results due to the active concealment of their condition, due to the shame associated (Alio et al., 2011; Hatzenbuehler, Phelan, & Link, 2013; Pachankis, 2007).

### ***1.1 Prevalence and Treatment***

Although obstetric fistula has been virtually eliminated in high-income countries, it still carries a significant disease burden in low-income countries, where access to emergency obstetric care is scarce. A global burden of disease study in 1996 suggested that at least 7 million women face obstructed labor each year, with the large majority of these (6.5 million) living in the least developed regions of the world. Assuming that only 2% of these labors result in obstetric fistulas, that would result in

130,000 fistula cases each year (Wall, 2006). In Tanzania, obstructed labor is still one of the main causes of maternal mortality, as well as associated maternal morbidities, including obstetric fistula. It is estimated that there are between 1200 and 3000 new cases of obstetric fistula in Tanzania each year, and that over 25,000 women are currently living with an untreated fistula (UNFPA, 2016).

The treatment for fistula is reparative surgery; however, surgical ease and success depends on the duration the patient has had the fistula and the size of the necrosis. In low-income countries with under-developed medical systems, women may remain in obstructed labor for prolonged periods. The experience of prolonged labor, and resulting fistula, can be linked to three delays in the provision of emergency obstetric care, namely: delay in seeking care, delay in arriving at the facility, and the delay in receiving emergency obstetric care once a patient has reached a health facility (Thaddeus & Maine, 1994; Wall, 2006). Due to the large number of untreated fistulas in Tanzania, concerted efforts have been made by the Tanzanian government to provide surgical repair to women with fistula. Surgery is available free of charge at select hospitals, and a national community-based referral system has been implemented to increase the linkage to surgical repair (Fiander, Ndahani, Mmuya, & Vanneste, 2013). However, barriers to accessing surgical care are still predominant within the country, as seventy five percent of the total population in Tanzania lives in rural areas with minimal education and infrastructure, and most patients have to travel at least 500 km for fistula treatment (Bangser, 2002). All this combined with the

potential impact of stigma as a barrier to reaching surgical care helps explain why many suffer with fistula for many years before reaching care.

## *1.2 Defining Stigma*

Stigma is a complex social phenomenon, broadly defined as occurring due to a deviance from the norm and a violation of the order of social reality (REF: Berger and Luckman). In 1963, Goffman published ground-breaking work that described stigma as the relation between an attribute and its associated stereotype (Goffman, 1963; Scambler & Hopkins, 1986). Recently, Link and Phelan conceptualized stigma from historical definitions for the purposes of research in the social sciences, thereby providing a more holistic view of the topic. They describe stigma as the convergence of the components of labeling, stereotyping, status loss and discrimination that co-occur with existing power dynamics, a definition we will continue to utilize for the course of this paper (Link & Phelan, 2001).

Literature and language addressing the specifics and origins of stigma are varied, but suggest that stigma can be achieved (gained through conduct) or ascribed (gained through circumstances beyond the target's control), and is a result of the cognitive perceptions of those in power. Moreover, it is repeatedly suggested that stigma has a direct impact on the stigmatized individual's well-being and self-esteem, which, as Scambler's theory of stigma suggests, results in chronic and disabling conditions for the individuals who are stigmatized (Bangser, 2006; Link & Phelan, 2001; Scambler, 2004). Scambler suggests two kinds of stigma, enacted and felt.

Enacted stigma involves acts of discrimination against those who possess the discrediting attribute. Felt stigma, on the other hand, can be further divided into two categories: internalized stigma (feelings of shame) and anticipated stigma (fear of encountering enacted stigma) (Scambler, 2004). As there is no literature specifically describing stigma associated with obstetric fistula, we will now examine the above information in the context of the unique physical condition of an obstetric fistula.

### ***1.3 Stigma and Obstetric Fistula***

An obstetric fistula is a condition that has the potential to ascribe both enacted and felt stigma. Enacted stigma results via the direct discrimination of women at the hands of society and their families. Multiple studies have documented that many women with fistula are ostracized by society and divorced by their husbands, as they are thought to have brought shame to the family. Problems related to incontinence also serve to translate into severe troubles in their familial and intimate relationships, leading to further exclusion from their families and spouses (A. Islam & A. Begum, 1992; Wall, 2006). In Nigeria, a study found that the support given to fistula patients is often only limited to the provision of physical necessities, while keeping an emotional distance (Landry et al., 2013; Murphy, 1981). Enacted stigma also becomes apparent in the woman being blamed for her fistula, as members of the community may perceive the fistula as a punishment from God (Wall, 2006).

Internalized stigma, on the other hand, refers to the patient's own feelings of shame and decreased self-esteem (Ahmed & Holtz, 2007; Alio et al., 2011; Gharoro &

Agholor, 2009; A. I. Islam & A. Begum, 1992; Landry et al., 2013; Siddle, Mwambingu, Malinga, & Fiander, 2013). As observed by studies conducted in multiple African settings, many women with fistula experience feelings of shame, loneliness, depression and decreased self-esteem (Ahmed & Holtz, 2007; Alio et al., 2011; Gharoro & Agholor, 2009; Siddle et al., 2013). Furthermore, women with religious affiliations may also experience negative cognitions (feelings of conflict, question, and doubt) regarding issues of God and faith, as well as a barriers towards practicing religion because of their fistula (A. I. Islam & A. Begum, 1992; M. H. Watt et al., 2014). These experiences of stigma (being labeled as outcasts, associations with negative stereotypes, and discrimination in their daily lives) are combined with the power dynamics of gender, where specifically in Tanzania a woman's worth is related to her role as mother, wife and farmworker. Women with obstetric fistula are clearly a group who meet the definition of stigmatized individuals described earlier (Link & Phelan, 2001; Mbilinyi, 1972).

#### ***1.4 Importance of Understanding Stigma of Obstetric Fistula***

Stigma is important to understand, not only because it causes delays in seeking care, but also because it compounds the effects of the disease due to the psychological stress that it generates (Corrigan, 2004; Keusch, Wilentz, & Kleinman, 2006; Pachankis, 2007). This stress is particularly heightened in illnesses and disabilities that require active concealment through behavior modifications, such as obstetric fistula and the concealment of incontinence. To fully understand and respond to the stigma



associated with fistula, it is necessary to explore enacted and internalized stigma separately. It has been suggested through studies on other health conditions that internalized stigma may have a much larger impact on one's overall well-being, due to the various psychological effects of possessing a potentially stigmatizing attribute (Scambler & Hopkins, 1986). As stigma may impact women's decision to seek care for the treatment of an obstetric fistula and may also has great impacts on recovery and reintegration following surgery, a thorough understanding of fistula-related stigma is imperative (Corrigan, 2004; Pachankis, 2007). Understanding the expressions and experiences of stigma among obstetric fistula patients can help to inform interventions to improve the quality of life and well-being of these women.

### ***1.5 The Study***

The goal of this study is to address the gap in knowledge with regards to the stigma associated with fistula, by describing the experience of both enacted and internalized stigma among women presenting at care for an obstetric fistula and identifying factors that are correlated with internalized stigma. It is hoped that this information can inform interventions to mitigate the suffering of women living with obstetric fistula, address the stigma-related barriers to accessing surgical repair, and support the successful reintegration of women following surgery

## **2. Methods**

### ***2.1 Study Design***

This is a mixed methods study, using data collected from two separate yet related research projects. The quantitative data is from the baseline data of a small randomized control trial of a mental health intervention for fistula patients conducted at the Kilimanjaro Christian Medical Center (KCMC) in Moshi from 2014-2015 (M. H. Watt et al., 2015). The qualitative data is from in-depth interviews conducted with women with fistula as part of an earlier descriptive study at KCMC from 2010-2012 (M. H. Watt et al., 2014; Wilson, Sikkema, Watt, & Masenga, 2015).

### ***2.2 Setting***

All data used for this study were collected in Moshi, Tanzania at the Kilimanjaro Christian Medical Centre (KCMC). KCMC is one of the five centers in Tanzania that specializes in fistula repair surgery. It is a referral hospital for over 11 million people in northern Tanzania and conducts approximately 50 fistula repair surgeries per year (KCMC, 2014). KCMC has a dedicated ward for fistula patients. Patients admitted for surgical repair of an obstetric fistula undergo surgery normally within one week after admittance and remain in the ward for 3-4 weeks after surgery.

### ***2.3 Sample***

The target population for both studies were women who had developed a fistula during childbirth and were admitted to KCMC for surgical repair. Both studies had the same inclusion criteria:

- 18 or older and able to give informed consent
- VVF or RVF as a result of childbirth
- Able to understand and communicate in Swahili

All women who met the inclusion criteria and were admitted to KCMC during the study periods were invited to participate. The quantitative portion of the study included 52 participants, and the qualitative portion included 45 participants.

### ***2.5 Quantitative Procedures***

When an eligible woman was admitted to KCMC for an obstetric fistula (confirmed by a dye test), a recruitment nurse informed the study coordinator at KCMC. The study coordinator explained the study to the participant, and, if the woman was interested in participating, she obtained written informed consent.

Once the participant was enrolled in the study, the coordinator established a time to meet with the participant in a private space. The survey was orally administered in Swahili. Visual response aids were used with scaled measures to facilitate accurate responses. The survey took approximately 60-90 minutes. As compensation each participant was given a toiletry bag and a supply of adult diapers.

## ***2.6 Measures***

The following measures were used for analysis in this paper.

### **2.6.1 Outcome variable: Fistula-related stigma**

To measure fistula-related stigma, the HIV Stigma Index (HASI-P) was adapted for fistula patients (Holzemer et al., 2007). The HASI-P measures 6 stigma domains: 1) verbal abuse, 2) fear of contagion, 3) healthcare neglect, 4) social isolation, 5) workplace stigma and 6) negative self-perception (Holzemer et al., 2007). In order to adapt HASI-P to measure stigma faced by fistula patients, the subscales “workplace stigma” and “healthcare neglect,” along with three items in the subscale “fear of contagion” were eliminated due to their irrelevance. The final measure included 19 items. Each item (question) asked whether the participant had had a specific experience in the past six months related to her fistula, and had answer choices ranging from 0 (“never”) to 3 (“all the time”). For this study, all five items of the subscale “negative self-perception” were used to measure internalized stigma ( $\alpha=0.78$ ). The other 14 items were combined to measure enacted stigma ( $\alpha=0.94$ ).

### **2.6.2 Predictors of Internalized Stigma**

In order to identify factors that are associated with internalized stigma, we examined demographics, obstetric history, and constructs at the individual and interpersonal levels.

## **Demographics**

Participants reported their age, years of education, and monthly household income.

## **Obstetric history**

Participants reported the number of months they had lived with a fistula and the number of living children they had, if any.

## **Individual-level constructs**

### *Severity of incontinence (SI)*

A pictorial incontinence scale was used to assess the severity of women's incontinence. An African artist was employed to make drawings depicting various sizes of urine puddles (ranging from 0 – 7) for a woman transitioning from a sedentary to a standing position after being seated for a fixed time. Participants were then asked to point towards the puddle that would roughly correspond to their own level of incontinence.

### *Incontinence Quality of Life (QoL)*

The Rockwood Quality of Life (QoL) survey for fecal incontinence was adapted to be specific to urinary incontinence (Rockwood, 2004). The measure contained 13 questions, 12 of which explored behavioral changes due to a fear of leakage on a scale of 1 (“none of the time”) to 4 (“most of the time”). Items on the scale explored fear of leaving the house, avoiding friends and family, and modifications to social and personal

schedules. The higher a participant's sum score for this measure, the higher the impact of incontinence on their quality of life ( $\alpha=0.79$ ).

*Social participation (PS)*

The participation scale (PS) was developed to measure social participation among people with disabilities and/or stigmatized conditions. The measure consists of 18 items in which participants rank their social participation in comparison to their peers (Van Brakel et al., 2006). Items explore questions related to domains such as work opportunities, social attendance, and participation in recreational activities. Participants respond on a scale of 1 ("definitely no") to 4 ("definitely yes"), with a high sum score indicating equal social participation in comparison to their peers and vice versa ( $\alpha=0.91$ ).

*Negative religious coping (RCOPE)*

The Brief RCOPE instrument was adapted for this population (Pargament, Smith, Koenig, & Perez, 1998). Seven of the original 14 items were selected due to their perceived relevance to obstetric fistula. Items were related to negative cognitions women may have had in the past one month (e.g., "I have been wondering whether God has left me," "I've been wondering what I did for God to punish me like this"). Participants respond on a scale of 1 ("none of the time") to 4 ("most of the time"), with a higher sum score indicating a higher level of negative religious cognitions ( $\alpha=0.83$ ).

## **Interpersonal-level constructs**

### *Social support (MOS)*

Social support was measured with the 19-item Medical Outcomes Study (MOS) Perceived Social Support Questionnaire (Broadhead, Gehlbach, De Gruy, & Kaplan, 1988). Participants are asked to indicate how often they had access to various forms of social support in four domains: emotional (e.g., “Someone who understands your problems”), tangible (e.g., “Someone to help you if you were confined to the bed”), affectionate (e.g., “Someone who shows you love and affection”), and positive interaction (e.g., “Someone to have a good time with”). Participants respond on a scale of 1 (“none of the time”) to 5 (“all the time”), with a higher score indicating more available social support ( $\alpha=0.94$ ).

### *Enacted Stigma*

Enacted stigma, as described above, was also examined as a predictor of internalized stigma.

## **2.7 Qualitative Methods**

When an eligible woman was admitted to KCMC for an obstetric fistula (confirmed by a dye test) during the study period of Aug 2010 to Feb 2012, a recruitment nurse informed the study coordinator at KCMC. The study coordinator then explained the study to the participant and obtained written informed consent. All participants in the study completed an in-depth interview, conducted in Swahili by a community health nurse who had received extensive training on qualitative methods.

A semi-structured interview guide was used to facilitate the interview, focusing on topics such as stressors caused by fistula, coping mechanisms, and available support. Examples of specific questions that elicited data on stigma were: “What memories do you have from developing or living with a fistula that you remember the most?” and “How have your relationships with those people changed since you began leaking?”. The interviews lasted for approximately 30 minutes each. They were digitally recorded, transcribed in Swahili, and then translated into English. As compensation, each participant was provided with a small quantity of household goods.

## ***2.8 Data Analysis***

### **2.8.1 Quantitative Analysis**

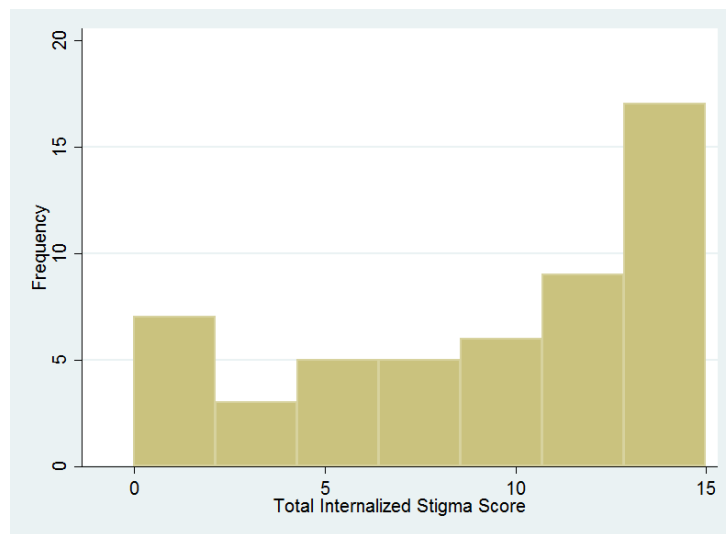
The survey data were entered using Epi Info and cleaned for data analysis. The data were then entered and analyzed in STATA 13. Due to the limited sample size and the variability of responses, non-parametric tests were selected for the analysis, as the data were not normally distributed.

The analysis was conducted in two steps. The first step of analysis was to describe the fistula experiences of the sample. As initially described, two subscales were created to represent internalized and enacted stigma. A dichotomous variable for each item was then created representing “never (response of 0)” and “at least once (response of 1, 2 or 3)”. For each item in the stigma measure, the proportion of the sample who endorsed the item and the median score across participants was calculated. A subscale score was then calculated by averaging the individual items for the scale. A Wilcoxon signed rank test



was conducted to determine significance of the difference between the median scores reported for the internalized and enacted stigma subscales. Three participants had no data for single items on the enacted stigma scale, and the missing values were imputed with the mean score of the remaining items.

The second step of the analysis was to analyze and identify associations between internalized stigma and the above stated variables. Spearman correlations were calculated in order to ascertain associations between the internalized stigma score and the potential correlates. Spearman correlation tests were chosen given that the data was not normally distributed (Figure 1).



**Figure 1: Distribution of the Internalized Stigma Score across Study**

**Participants**

### **2.8.2 Qualitative Analysis**

English transcripts of the qualitative interviews were used to create analytic memos, which served to summarize and organize each transcript into themes (Birks, Chapman, & Francis, 2008). Representative quotes from the participant transcripts were included for each theme in order to ensure accuracy of the participants' views. The memos were then uploaded into NVIVO 10 (QSR-International, 2013).

Content analysis of the transcripts was carried out using the theory of enacted and internalized stigma to generate appropriate codes (Hsieh & Shannon, 2005). Common themes between the participants were noted along with discrepancies among the transcripts. Patterns both within and across participants pertaining to stigma were then recorded, and representative quotes were identified to illustrate the emerging themes.

### 3. Results

#### 3.1 Description of the Samples

Table 1 presents the basic demographic information of the women included in the two study samples. The two samples were similar in all of their demographic characteristics. Differences were noted in duration of fistula across the two groups; however, the intra-quartile range (IQR) revealed that the two samples were quite similar. The similarities between the two groups allows for the successful integration of the qualitative and quantitative results of this study.

**Table 1: Sample Demographics**

	Quantitative Dataset (n=52)	Qualitative Dataset (n=45)
Mean Age (sd)	40.9 (16.4)	39.1 (14.8)
% Primary school completion	65.4%	57.8%
Median # of months lived with fistula (IQR)	168 (12 -232)*	46.5 ( 3 – 212.5)*
% living with spouse/partner	50	57.8
Religion: <ul style="list-style-type: none"><li>• % Christian</li><li>• % Muslim</li></ul>	38.5 59.6	62.2 31.1
Mean # of living children	1.9 (2.0)	2.0 (2.0)

\* = 1 missing value

### 3.1 Quantitative Results

#### 3.1.1 Descriptions of Stigma Experiences

Table 2 describes the expressions of internalized stigma in the population. All items on the internalized stigma subscale were endorsed by over 50% of the participants. A large majority (84.6%) reported that they had some experience of feeling that they did not deserve to live because of their fistula and 75.0% expressed feeling ashamed of their condition. Feelings of worthlessness and perceiving oneself as bringing trouble to the family were endorsed by 63.5% and 61.5%, respectively, while feeling that one was no longer a person was endorsed by 53.8%.

**Table 2: Summary Statistics of the Internalized Stigma Subscale**

Stigma Scale	Proportion Endorsed (%)	Median (range 0-3)
<b>Internalized Stigma</b>		<b>2.1</b>
I felt that I did not deserve to live.	84.6	3.0
I felt ashamed of having this condition.	75.0	3.0
I felt completely worthless.	63.4	3.0
I felt that I brought a lot of trouble to my family.	61.5	2.0
I felt that I am no longer a person.	53.8	1.5

Table 3 describes the experiences of enacted stigma in the population. The most common experiences of enacted stigma appear to be getting mocked in public and being

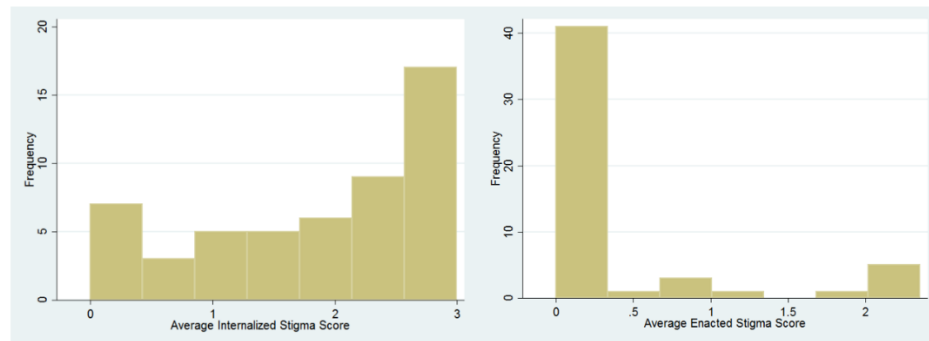
called bad names, with 25% of the participants endorsing the relevant items. These experiences were closely followed by items that conferred personal blame for the fistula: 23% endorsed the item, which asked whether they had ever been told that their fistula was a result of God punishing them, and 22% reported that they had been blamed for their fistula. Although the median of the observed items were all zero, the importance of enacted stigma should not be disregarded as the spread of the data indicates.

**Table 3: Summary Statistics of the Enacted Stigma Subscale**

Stigma Scale	Proportion Endorsed (%)	Median (range 0 – 3)
<b>Enacted Stigma Subscale (Median Score)</b>		<b>0</b>
Someone mocked me when I passed by.	25	0
I was called bad names.	25	0
I was told that God is punishing me.	23.1	0
I was blamed for my fistula and leaking.	21.6*	0
People sang offensive songs when I passed by.	19.2	0
I was made to sleep in a different part of the house.	17.6*	0
I was told that I have no future.	17.3	0
Someone stopped being my friend.	11.5	0
People avoided me.	9.8*	0
People ended their relationships with me.	9.6	0
A friend would not chat with me.	7.7	0
People cut down visiting me.	7.7	0
I stopped eating with other people.	5.8	0
I was made to eat alone.	3.8	0

\* 1 missing value

The median score calculated for the enacted stigma subscale was zero, because the majority of the participants had an average score close to zero, as illustrated in Figure 2. However, it should be noted that the median score is not representative of the entire population, as almost 10% of the population had very high enacted stigma scores.



**Figure 2: Distributions of the Enacted and Internalized Stigma Scores**

Comparing the two domains of enacted and internalized stigma (Figure 2), it is clear that experiences of internalized stigma were much more common than enacted stigma. The difference in the median scores was examined using the Wilcoxon signed-rank test and proved to be extremely significant ( $p < 0.001$ ). This indicates that the experiences of internalized stigma were significantly more common than experiences of enacted stigma within the study population.

### 3.1.2 Correlates of Internalized Stigma

For the individual level variables, all variables except severity of incontinence had a weak to moderate but significant, correlation with internalized stigma. This can be seen in table 2 via rho values greater than 0.3 and a p-values less than 0.05. Negative religious coping and quality of life affected due to incontinence, showed moderate positive correlations with internalized stigma, and social participation showed moderate negative correlations with internalized stigma.

From the interpersonal-level category, only enacted stigma had a significant positive correlation, indicating that higher enacted stigma scores corresponded with higher internalized stigma score.

No demographic or obstetric history variables were associated with internalized stigma.

**Table 4: Spearman’s Correlation Test; testing correlation with internalized stigma (n=52)**

Variable	Spearman's rho	p- value
<b>Demographic Variables</b>		
Age	0.1962	0.1962
Education	0.1864	0.1859
Income/month (TZ Shillings)	-0.1155	0.4148
<b>Obstetric History Variables</b>		
Duration of Fistula (months)	-0.0591	0.6802
Number of Living Children	-0.0527	0.7136
<b>Individual-level Variables</b>		
Negative religious coping	0.338	0.0142
Social participation	-0.3318	0.0243
Severity of Incontinence	0.2302	0.1078
QoL Incontinence	0.5032	0.0003
<b>Interpersonal-level Variables</b>		
Enacted Stigma	0.3751	0.0062
Social Support	-0.135	0.3401

\*Highlighted cells indicate noteworthy associations

## ***3.2 Qualitative Results***

### **3.2.1 Internalized Stigma**

In the qualitative interviews, the majority of participants expressed feeling shame due to their fistula. Participants indicated that their shame stemmed from their fear of wetting themselves in public and of smelling of urine. This fear seemed to be a product of their lack of control and of underlying feelings of dirtiness. As a result of feelings of shame, women reported symptoms of anxiety and restlessness, as one woman described her condition: “I feel restless and have no peace of mind sister, I wet clothes all the time (Patient 3, 1 month with fistula).” In addition to embarrassment, feelings of hopelessness and bitterness were also expressed by participants. One woman described these feelings: “I just feel bitter and sorry for myself because I live in a state of unhappiness due to the problem of urine flow from time to time (Patient 4, 21 years with fistula).” These feelings of intense shame demonstrate a high degree of internalized stigma.

Internalized feelings of stigma contributed to behaviors of avoidance, self-isolation, and concealment of their condition from others. Many participants expressed feeling so ashamed of their condition that they no longer attended their mosque or church for fear of discovery. As one woman explained: “Since I got this fistula problem I feel shy to attend church. I go once in a while, but it is not like in the past (Patient 5, 12 years with fistula).” This behavior also extended to their social relationships, with women choosing to stay inside the house because of their shame and embarrassment, as this woman expressed: “I feel embarrassed because I cannot mingle with other people for



long. Even if there is a party, I attend, drink a little, and leave at once (Patient 9, 39 years with fistula).” Another participant echoed this self-isolation: “I usually feel bad, and there are certain times I hide inside (Patient 5, 12 years with fistula).”

Lastly, all of these participants emphasized that their feelings of shame and embarrassment had led to their being very selective in revealing their fistula within their social networks. In many cases, only close family members knew about their fistula, and the participants repeatedly expressed their desire to not share this information beyond their immediate family circle. The reasons given for the selective and limited disclosure, accompanied by self-imposed isolation, were rooted in feelings of shame. For example, patient 5 (12 years with fistula) reported feelings and experiences such as: “It is shameful and you cannot tell anyone;” “I never tell anybody and I never talk to anyone;” and “Sister I cannot [talk to my religious community] because I feel shy and these are shameful matters that don’t deserve to be told to anybody.”

### **3.2.2 Enacted Stigma**

About one-fourth of the qualitative participants revealed that they had directly experienced a form of enacted stigma as a result of their fistula. These stigmatizing experiences included being left by a partner, being gossiped about or ridiculed, and being excluded from spaces and events.

Many participants who had been separated from their partners believed that it was because of their fistula. They reported that their spouses had complained about the smell of urine around them, and viewed them with animosity and resentment. In some cases,

these feelings of animosity resulted in an unstable familial environment, with frequent arguments and taunts towards the patients. One participant said, “After I got this problem, my husband changed. He seemed offended and hated me for it. After I noticed the change, I decided to leave and returned to my family (of origin) (Patient 32, 3 years with fistula).” Another recounted the verbal abuse from her husband: “Words (taunts) were [spoken] from my husband as he started to see me as a bother because of the urine smell (Patient 33, 12 years with fistula).”

The smell of urine also seemed to be the underlying reason for participants being excluded from a variety of settings. Exclusion of the participant from social activities normally occurred during meal times, or by friends and family who refused to visit because of the fistula. In many of these cases the smell of urine was the primary reason the participant was isolated. A participant described one of these instances: “Some of the people who came to my aunt’s where I stayed said they would not eat because I smelt of urine (Patient 16, < 1 month with fistula).” Other participants described their friends and neighbors staying away by reporting things like: “They already realize that I have a problem; that is why they do not come (Patient 21, 4 months with fistula);” and “My friends also get offended by the urine smell (Patient 15, 5 years with fistula).”

Some participants also reported that they had faced malicious gossip due to their condition. A participant talked about how there were some people who would stigmatize her and discriminate against her because of her fistula. She said that whenever she was out in the community, she would hear people gossip about her and many would choose not to sit near her because of the smell (Patient 40, 18 years with fistula). This seemed to

be a common experience. Another participant, when asked about how she was treated by people from her community, responded: “They say this one smells (Patient 10, 19 years with fistula).”

Finally, one participant mentioned that her fistula had resulted in a loss of livelihood, not just because of her disability, but because of the enacted stigma against her. The participant reported that although the physical constraints of the fistula made running her business difficult, it was actually the knowledge of her fistula, along with the smell of urine, which had limited customers and encouraged gossip. She said: “I can no longer work efficiently because of this fistula problem. I cannot last long at my business because of the urine problem. If I stay long, I wet myself, and the urine smell is offensive to my customers, who will avoid me and start to backbite (gossip) about me (Patient 32, 3 years with fistula).”

### **3.2.3 Anticipated Stigma**

In addition to experiences of internalized and enacted stigma, participants reported that they anticipated stigma from others, which led to behavioral and emotional defenses. Participants talked about how they excluded themselves from society because they feared being rejected or taunted. These self-initiated exclusions included avoiding religious institutions [“I fear going to church because they will laugh at me for passing urine continuously; my clothes will be wet (Patient 16, < 1 month with fistula)”], as well as social gatherings [“Every time when I passed urine I could not go anywhere. I just stayed at home fearing that people would say I smell urine (Patient 20, < 1 month with

fistula)”. Fear of gossip was another reason for self-isolation. One participant reported being worried about visiting her neighbors, as she feared that “they will begin to backbite (gossip) about me (Patient 21, 4 months with fistula).”

The fear of being laughed at and gossiped about had also resulted in many participants refraining from disclosing their fistula. One participant explained: “I cannot tell them [community] because I feel ashamed, and some people will gossip about it (Patient 34, 17 years with fistula).” Moreover, this fear also served to increase their anxiety about their condition, as one participant reported: “I mean, you are full of anxiety that if you sit somewhere, when you rise you are already wet, and people will gossip about you, and you will feel ashamed (Patient 24, 12 years with fistula).” In some cases, family members encouraged women to keep their fistula a secret, so as to prevent stigmatizing experiences. One participant reported: “[My family] tells me there is no need to publicize my problem, because some people will stigmatize me (Patient 1, 10 years with fistula).”

### **3.2.4 Positive Experiences of Fistula**

A majority of women reported receiving social support for their fistula within the households they lived in. These households were varied: many women still lived with their husbands, others lived with their parents, and some lived with their siblings or neighbors. However, what many of these women had in common was positive support for dealing with the problems that arise because of their fistula. Participants reported experiences like: “As far as family and friends are concerned, nothing has changed, and

we have a harmonious relationship because they know I have a problem (Patient 24, 12 years with fistula),” and “My husband and I persevered with the problem (Patient 2, 13 years with fistula).” These participants received both emotional and physical help, and reported having someone to talk to about their experiences with fistula.

Women reported receiving support in various forms. Support included helping participants in their daily work (“with food, cooking, and washing or whenever I have a problem”), monetary support, and emotional support. Most participants expressed receiving support from their households, with participants reporting experiences like: “Whenever I have a problem, they [my relatives, brothers and sisters] help me (Patient 32, 3 years with fistula),” and “[My husband] consoles me and tells me not to despair, that there is a day I will be treated and I will recover (Patient 41, 2.2 years with fistula).”

One woman also described receiving support from her church community, indicating that there might be positive support available within the religious institutions. The participant said: “They are aware of my problem...They remember me. The church community and prayer groups are supportive. We pray together and I get aid whenever it is available. They even donate cash for my upkeep (Patient 11, 31 years with fistula).”

There were also a handful of participants who expressed that they had been accepted fully by their communities and experienced no stigma. Among them was a participant who had anticipated stigma but received none: “I thought people would laugh at me and say I smell of urine, [but] the situation was normal and they did not laugh at me (Patient 30, < 1 month with fistula).” There were other participants who felt confident that they would be accepted to begin with: “There are no changes. I go to church and can

stay there until the end of service without getting wet. I visit people and they visit me as well.... [Children and friends] take good care of me (Patient 11, 31 years with fistula).”

#### **4. Discussion**

This mixed-methods study on women receiving surgical repair for obstetric fistula, documented the experience of stigma in this population and in part the burden of internalized stigma which helps to explain the high rate of psycho-social distress among these women (M. H. Watt et al., 2014). Internalized stigma was correlated with negative religious coping, impact of incontinence and lower social participation. Literature on stigma and obstetric fistula is extremely limited; however, a recent qualitative study in Uganda briefly highlighted the impact of stigma within the fistula population and the psychological stress that it causes, touching upon issues of fear, exclusion and isolation (Barageine et al., 2015). However, our data suggests that, the experiences of obstetric fistula are much nuanced, with a clear distinction between internalized and enacted stigma.

Although both internalized and enacted stigma were present in this sample of women with obstetric fistula, survey data and the qualitative interviews both revealed that feelings of internalized stigma were far more common than experiences of enacted stigma. Internalized stigma was characterized by participants' feelings of shame and embarrassment, mostly related to their incontinence. An incontinent woman, particularly as it pertains to fistula, is no longer able to control urine and/or feces. The constant smell of excrement combined with this loss of control, characteristic of untrained children, often leads to self-isolation and withdrawal. Perceptions of cleanliness lead to withdrawal from mosques and churches and embarrassment breeds a reduction in self-worth, as urine

control is considered to be an integral part of adulthood (Garcia, Crocker, & Wyman, 2005; Sheldon & Caldwell, 1994). Fear of humiliation due to this constant leaking and smell further exacerbate these negative emotions and leads to greater changes in lifestyles. Studies have shown that incontinence is attributed to increased sadness, depression and loneliness, and embarrassment about the condition may lead to delays in seeking health care (Fultz & Herzog, 2001; Norton, 1990). It is perhaps for this reason that higher internalized stigma scores were related to a high impact of incontinence on daily life. Since QoL explored behavioral changes made by participants because of a fear of leaking, such as withdrawal from society or voluntary isolation, the results reiterate that incontinence – more specifically the fear of discovered incontinence – translates into increased anxiety, shame and embarrassment, leading to increased internalized stigma.

Interestingly, the impact of incontinence on internalized stigma does not hold for the severity of incontinence. Although this may be a result of a measurement issue, the finding appears to be consistent with the literature, as certain studies suggest that the psychosocial impact of incontinence is disproportionately related to its severity. Moreover, in community-dwelling women, it appears to be that actual severity is not as much of a factor in the development of psychosocial stress as perceptions of incontinence and the subsequent changes they are forced to make (Norton, 1990; Wyman, Harkins, Choi, Taylor, & Fantl, 1987). These parallels can then be drawn with regards to the women with fistula as well – where not severity but the tangible changes made due to the incontinence serve to heighten the impact of the internalized stigma from their fistulas.



The impact of internalized stigma is also exacerbated due to increased negative religious cognitions and low social participation. Unsurprisingly, this phenomena of negative religious coping is also true for other stigmatizing conditions like HIV, where negative cognitions, such as thoughts of abandonment or punishment from God, are common (Roura et al., 2010; Melissa H Watt, Maman, Jacobson, Laiser, & John, 2009). These thoughts often result in behavioral changes pertaining to religion. Within the fistula population, participants reported that the development of their fistula has led to a change in their religious practices, resulting in an avoidance from churches and mosques. Although a certain amount of this change was a result of perceptions of cleanliness tying back to the problems associated with incontinence, a large number of experiences were related to feelings of unworthiness (negative cognition), along with a fear of discovery. Moreover, studies have shown that negative religious coping, although utilized less than positive religious coping, often results in spiritual discontent and cognitive appraisal of punishment from God. Specifically in the case of fistula patients, these cognitions have been shown to be symptoms of depression, and therefore understandably related to internalized stigma (Pargament et al., 1998; M. H. Watt et al., 2014).

However, it also appears that religious institutions can also serve to be a positive force in the lives of these women, as some participants described the religious community as an important source of support. This, combined with the handful of experiences of complete community acceptance after disclosure of the fistula, provides hope that disclosure, especially through religious institutions, can help normalize the stigma

associated with fistula (Obermeyer, Baijal, & Pegurri, 2011; Melissa H Watt et al., 2009; M. H. Watt et al., 2014)

Social participation on the other hand seems to reversibly govern the impact and intensity of internalized stigma, where higher levels of SP appear to be associated with lower internalized stigma. Social inclusion and participation have been recognized as key elements in global mental health and stigma, and have been extensively used to examine stigma in mental health disorders like schizophrenia (Baumgartner & Burns, 2014; Brohan, Slade, Clement, & Thornicroft, 2010; Carter, Satcher, & Coelho, 2013). Recently, social participation has also been used to evaluate the impact of stigma in other disorders like HIV and leprosy, where low social participation has been shown to be indicative of higher stigma (Stevenson, van Brakel, & Augustine, 2011). This also seems to be true in the case of fistula, where low social participation appears to be characteristic of increased internalized stigma. Additionally, low social participation could also be a result of either enacted or anticipated stigma, as either negative experiences of participation or the fear of these experiences might result in decreased social participation.

Internalized stigma within the fistula population appear to not be related to either the number of living children or the social support provided to the women. Although initially surprising, as childlessness and infertility are stigmatizing and generate psychological distress, while social support, especially emotional support, should help ease anxiety, the findings appear to be consistent with the literature and the fistula population (McQuillan, Greil, White, & Jacob, 2003; Miall, 1986).

A study conducted in northern Tanzania revealed that in that setting, it is not the number of children that mattered, but whether a woman had any children at all; if a woman had no children, she was classified as “useless,” and stigmatized and disrespected (Hollos & Larsen, 2008). This indicates that the question needs to be reframed by asking whether a woman has any or no children, rather than asking about the number of children. Unfortunately, the limited sample size and the sample’s distribution proved this investigation to be beyond the scope of this study

Similarly for social support, even though there were a multitude of experiences of positive social support, both tangible and emotional, given the high rates of internalized stigma within the population, combined with experiences of anticipated stigma, this might result in a smaller effect that could become more pronounced in a larger sample size. On the other hand, it is also possible that the amount of social support itself might be limited and laced with underlying familial tensions, thereby negating any positive effects on internalized stigma (Murphy, 1981).

Lastly, enacted and anticipated stigma are two phenomena that appear to be inter-related within the fistula context. Enacted stigma is common among the fistula population in experiences of getting blamed for their fistula (punishment from God) and being mocked for their condition. In many cases, these experiences result in divorce or separation. Much of this appears to stem from misunderstandings about the origin and treatment of the fistula. Some studies have shown that patients attribute their fistulas to a curse from God and do not completely understand the cause for, their fistula (Emma-Echiegu, Okoye, & Odey, 2014; Hassan & Ekele, 2009). Therefore a significant step

forwards towards reducing enacted stigma seems to be increasing awareness in order to reduce, if not eliminate, these experiences.

High enacted stigma was highly correlated with internalized stigma. Various studies have shown that stigmatizing experiences often lead to depression and anxiety, which, when considered with our definition of internalized stigma, helps explain the association (Markowitz, 1998; Quinn & Chaudoir, 2009). Therefore even though internalized stigma is more prevalent compared to enacted stigma, the importance of enacted stigma to holistically understand the stigma associated with fistula populations therefore cannot be denied.

Experiences of anticipated stigma are also widespread within the fistula population and seem to be a major factor in voluntary isolation and nondisclosure of the condition. It is most commonly observed within dynamics of interpersonal relationships and employment, impacting both of them negatively (Cechnicki, Angermeyer, & Bielańska, 2011; Golub & Gamarel, 2013) Anticipated stigma has been shown to generate high levels of psychological stress in concealable and possibly stigmatizing conditions (Cechnicki et al., 2011; Pachankis, 2007; Quinn & Chaudoir, 2009), and to be a significant predictor of negative health seeking behaviors (Gilbert & Walker, 2010; Golub & Gamarel, 2013; Turan et al., 2011). All of this, combined with the fact that anticipated stigma is negatively related to the quality of life of patients suffering from chronic illnesses and mediated through social support and stress, the examination of anticipated stigma becomes all the more necessary when considering the impact of internalized stigma within the fistula population (Earnshaw, Quinn, & Park, 2011).

Given the pervasive accounts of anticipated stigma and the resulting isolation and non-disclosure, the phenomena also helps elucidate the lower reports of enacted stigma. As so many practice behavior modifications to prevent stigma experiences, it is only natural to expect that a lesser number of participants expose themselves to possibility of being stigmatized. Although the study observed a single participant who experienced no enacted stigma even though she anticipated it, more research needs to be conducted in order to better understand the relationship between anticipated and enacted stigma.

## **5. Limitations**

A major limitation of this study was the small quantitative sample size. This, combined with the fact that the collected data was not normally distributed, limited the use of parametric tests. Moreover, it should be noted that the study cannot discern the directionality of the associations observed between internalized stigma and other measures listed above and only predict unique associations.

Another limitation of the study is that the two study samples, although similar, came from two distinct group of women. This then limits the generalizations made between the groups and may result in some biases when combining the two sets of results.

It is also worth noting that since all participants had reached care at a tertiary hospital, it is very possible that those had not reached care had higher levels of stigma. Furthermore, as the qualitative instruments were not originally designed to investigate stigma, it is possible that the data lacks in major stigma experiences that might have remain untouched.

## 6. Conclusion

As discussed earlier, stigma is defined as the convergence of the components of labeling, stereotyping, status loss and discrimination that occur concurrently with existing power dynamics (Link & Phelan, 2001). For the study population, it is apparent that their incontinence not only labels them as unfit individuals, but combined with the negative stereotypes about why a fistula develops and the discrimination they feel from the community and family, results in a status loss both internally and externally. Moreover, all of this occurs in an environment where patriarchy is rampant and women are often relegated to roles of farm-keeping, childbearing and housekeeping, roles a fistula has a significant impact on, creating power dynamics that enable stigmatization (Mbilinyi, 1972).

In conclusion, stigma is a pressing problem within the fistula population. It not only generates psychological stress, but also promotes self-isolation and may serve as a barrier for accessing health care. There were high levels of internalized stigma within this sample, mostly related to women's incontinence. There was also some enacted stigma with experiences of divorce, mockery and exclusion. The intensity of internalized stigma was significantly greater than that of enacted stigma, with the former significantly being associated with negative religious cognitions, low social participation, and compromised quality of life due to incontinence. There is a need for an in-depth examination of these associations, along with the experiences for both enacted and internalized stigma, in order to tailor interventions that would help alleviate the suffering of this population.

There is a need for interventions that not only focus on connecting these women to care, but also those that would raise awareness within communities regarding obstetric fistula. Women with fistula practice isolation and non-disclosure because of intense shame and to avoid embarrassment because of their incontinence. By raising community awareness, not only the shame can be lessened due to clarifications as to the origins of the fistula, but communities would be able to be supportive without attaching negative labels to the patients. Lastly, this study has provided some evidence of communities and churches welcoming and supporting women with fistula even after high levels of anticipated stigma on the parts of the patient. This really highlights the opportunities to begin interventions at the local level and the use of religious institutions to provide mental support as well guidance towards care for fistula patients. Future studies should not only involve confirmation of the results above, but should also focus on developing such interventions and testing them within the Tanzanian context.



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