

# **UCSF**

## **UC San Francisco Previously Published Works**

### **Title**

Validation of an adapted instrument to measure female genital fistula-related stigma

### **Permalink**

<https://escholarship.org/uc/item/0vc7625f>

### **Journal**

Global Public Health, 16(7)

### **ISSN**

1744-1692

### **Authors**

Ayadi, Alison M El  
Barageine, Justus K  
Neilands, Torsten B  
et al.

### **Publication Date**

2021-07-03

### **DOI**

10.1080/17441692.2020.1813786

Peer reviewed



# HHS Public Access

## Author manuscript

*Glob Public Health.* Author manuscript; available in PMC 2022 July 01.

Published in final edited form as:

*Glob Public Health.* 2021 July ; 16(7): 1057–1067. doi:10.1080/17441692.2020.1813786.

## Validation of an adapted instrument to measure female genital fistula-related stigma

**Alison M. El Ayadi<sup>1</sup>, Justus K. Barageine<sup>2,3,4</sup>, Torsten B. Neilands<sup>5</sup>, Nessa Ryan<sup>6</sup>, Hadija Nalubwama<sup>2</sup>, Abner Korn<sup>1</sup>, Janet M. Turan<sup>7</sup>**

<sup>1</sup>Department of Obstetrics, Gynecology and Reproductive Sciences, University of California, San Francisco; <sup>2</sup>Department of Obstetrics and Gynaecology, Makerere University College of Health Sciences, Kampala, Uganda; <sup>3</sup>Save the Mothers, Uganda Christian University, Mukono, Uganda;

<sup>4</sup>Urogynecology Division, Mulago National Referral and Teaching Hospital, Kampala, Uganda; <sup>5</sup>Center for AIDS Prevention Studies, Division of Prevention Sciences, Department of Medicine, University of California, San Francisco; <sup>6</sup>New York University College of Global Public Health, NYU-HHC Clinical and Translational Science Institute, New York University; <sup>7</sup>Department of Health Care Organization and Policy, School of Public Health, University of Alabama at Birmingham, Alabama

### Abstract

Female genital fistula results in severe physical, psychological, and social sequelae. Qualitative research confirms stigma pervasiveness; however, no quantitative instrument exists to measure fistula-related stigma. We adapted an existing HIV-related stigma instrument to fistula-related stigma, and assessed its reliability and validity. We recruited 60 Ugandan women seeking genital fistula surgery (December 2014-June 2015). We used exploratory factor analysis to explore the scale's latent structure and evaluated internal consistency reliability with Raykov's  $\rho$  statistic. We assessed construct validity through linear regression of stigma with quality of life, depressive symptoms and self-esteem. We retained 15 items across factors 'enacted stigma' and 'internalized stigma' ( $\rho=0.960$  and  $\rho=0.748$ , respectively). Stigma was inversely associated with all quality of life domains; effect sizes were largest for environmental (enacted stigma, 0.69-point reduction) and psychological (internalized stigma, 0.67-point reduction) domains. Both stigma domains were associated positively with depressive symptoms and inversely with self-esteem, with 0.75 and 1.05-point increases in depressive symptoms and 0.45 and 0.77-point decreases in self-esteem for enacted and internalized stigma, respectively. Results suggest the reliability and validity of the adapted fistula stigma instrument. This instrument may help us understand stigma levels, compare stigma across individuals and communities, prioritize stigma-reduction strategies, and assess intervention impact.

Corresponding author: Alison M. El Ayadi, ScD MPH, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California, San Francisco, 550 16<sup>th</sup> Street, 3<sup>rd</sup> Floor, San Francisco, CA 94158, 415.659.8367, alison.elayadi@ucsf.edu.

**Authors' participation in manuscript:** AE, JB, HN, and AK were responsible for project development, instrument review and adaptation process, and data collection. AE, TN, and JT analysed the data and developed the draft manuscript. AE, JB, TN, NR, HN, AK, and JT provided critical feedback on the interpretation of the findings. All authors approved the final draft of the manuscript.

**Declaration of interest statement:** All authors declare no conflict of interest

## Keywords

female genital fistula; obstetric fistula; stigma; quality of life; instrument development; Uganda

## Introduction

Female genital fistula is a debilitating injury with associated urinary and/or faecal incontinence that results from prolonged obstructed labour, iatrogenic, or traumatic aetiologies. Obstetric fistula is the most common form and causes severe physical, psychological and social sequelae.(Ahmed & Holtz, 2007; Roush, 2009) Women with fistula may also experience neurologic injury, gynaecologic morbidity, orthopaedic trauma, vaginal and genital ulcerations, difficulty walking without assistance, and secondary infertility. Estimates suggest up to two million women may be living with fistula globally, most in sub-Saharan Africa and Asia,(Adler et al., 2013) with as many as 100,000 annual incident cases. (de Bernis, 2007)

The stigma surrounding female genital fistula is largely responsible for its devastating social and psychological consequences. Qualitative reports of women's experiences living with fistula describe overt discrimination, relationship dissolution, and social isolation causing poor mental health and economic consequences.(Ahmed & Holtz, 2007; Bangser, 2006; Changole et al., 2017) Stigma features heavily in Uganda, where women describe experiencing enacted, anticipated, and internalized stigma from various sources.(AM El Ayadi et al., 2020) Enacted stigma manifestations feature gossip and verbal abuse, interpersonal behaviours including distancing, exclusion, relationship dissolution, and social marginalization. Anticipated stigma reflect women's fears of experiencing enacted stigma. Internalized stigma manifestations include perceptions of low self-worth and shame. Stigma manifestations described by women with fistula across these three domains have important behavioural and psychological consequences, significantly reducing quality of life and delaying treatment.(Khisa et al., 2017; Ruder et al., 2018)

Despite broad acknowledgement of the pervasiveness of fistula-related stigma and the impact of fistula-related stigma in the lives of women, there have been few efforts to quantify stigma and its consequences within this population. Most of the literature on fistula-related stigma is limited to qualitative studies describing women's lived experiences. While women's accounts of their experiences represent a critical component of this field of inquiry, the development and validation of quantitative instruments targeting measurement of fistula-related stigma is largely missing from the literature. Only after the start of the current study were we able to identify one study which quantitatively assessed fistula-related stigma; (Wilson et al., 2016) however, item development and validation was not described. Quantitative characterization of the nature and nuances of fistula-related stigma is important for guiding and evaluating intervention work. The lack of a valid measurement instrument limits comparison across time, contexts, and characteristics, and hinders understanding of the role of fistula-related stigma in women's experiences living with fistula and in their outcomes after treatment.

Acknowledging the similarities and differences between fistula-related and other condition-specific stigmas,(Earnshaw et al., 2013; Holzemer, Uys, Makoa, et al., 2007) we sought to adapt a stigma instrument from the HIV literature to assess fistula-related stigma among Ugandan women, and to assess the reliability and validity of the adapted stigma instrument.

## Materials and methods

The current analysis is situated within the quantitative component of a sequential exploratory mixed-methods study on women's experiences of reintegration following female genital fistula in Uganda; study details are published elsewhere.(A El Ayadi et al., 2017) Briefly, we recruited a cohort of 60 women at the time of genital fistula repair surgery at Mulago National Teaching and Referral Hospital in Kampala, Uganda from December 2014 to June 2015. Sample size was based on feasibility for the original study aim. Women were eligible for participation at clearance for fistula surgery if they spoke Luganda or English, resided in a community with cellular telephone coverage, and were capable of providing informed consent for study participation. The research staff screened potential participants, and individuals who were eligible and interested were led through an informed consent process. At enrolment, we administered a questionnaire to participants to capture socio-demographic characteristics, obstetric and fistula-related history, current fistula-related symptoms, frequency of stigma,(Holzemer, Uys, Chirwa, et al., 2007) quality of life,(Martin et al., 2013; Webster et al., 2010) self-esteem,(Rosenberg, 1965) and depression.(Derogatis et al., 1974) Within the larger study we conducted follow-up surveys over mobile phone at 3, 6, 9, and 12 months following surgery; data for the current analyses were limited to baseline data, which represents pre-treatment status.

## Instrument adaptation process

We reviewed the literature for instruments assessing health condition-specific stigma that have been validated in East African settings among similar populations. No fistula-related stigma measurement instruments were found; however, we identified several validated instruments for the measurement of HIV-related stigma. We selected Holzemer et al's HIV/AIDS Stigma Instrument – People Living with HIV/AIDS (HASI-P) because it incorporated multiple relevant stigma domains and was validated among East African women of reproductive age. The HASI-P is an HIV-related stigma measure based on research conducted among 1,477 men and women living with HIV/AIDS in Lesotho, Malawi, South Africa, Swaziland, and Tanzania (~300 per country).(Holzemer, Uys, Chirwa, et al., 2007) The study sample had a mean age of 36 years and 74% were female. On average, time since HIV diagnosis was 3.4 years, and 46% were taking antiretroviral medication at time of study participation. The total scale comprised 33 items, with overall  $\alpha=0.940$  and 60.7% explained variance. Individuals were asked how frequently each of the items (Table 1) had occurred to them within the prior 3 months due to their HIV status (e.g., "I was called bad names", "People avoided me", "My employer denied me opportunities", etc.), with response options: never, once or twice, several times, or most of the time. Holzemer et al identified a six-factor solution including verbal abuse ( $\alpha=0.886$ ), negative self-perception ( $\alpha=0.906$ ), healthcare neglect ( $\alpha=0.832$ ), social isolation ( $\alpha=0.890$ ), fear of contagion ( $\alpha=0.795$ ), and workplace stigma ( $\alpha=0.758$ ).

Based on review by key stakeholders, including individuals working with women affected by genital fistula (i.e., clinical and social service providers) and the women themselves, we adapted the instrument following the WHO-recommended process for translation and adaptation of instruments,(World Health Organization, n.d.) ensuring content validity while limiting participant response burden. This resulted in removal of 17 items that were deemed to be less relevant for women with fistula, including items within the healthcare neglect and workplace stigma factors. These were excluded due to perceived differences in stigma manifestations among women with fistula compared to HIV due to differences in concealability (i.e., HIV being more concealable than fistula) and fear of contagion (i.e., fear of contagion less for fistula), and the chronic nature of HIV compared to fistula, where many women achieve anatomical fistula closure at surgery.(Stamatakos et al., 2014) For similar reasons and to reduce participant time burden with the survey, we reduced the fear of contagion domain by 5 items and the negative self-perception domain by 3 items. We added two items to the scale that were suggested by key stakeholders and our qualitative work with women affected by fistula: 'I avoided other people' which we placed under the social isolation domain to accommodate internalized stigma-driven social isolation, and 'Someone stopped eating food that I had prepared' which we placed under the fear of contagion domain and was based on women's typical household roles. The final adapted instrument included 18-items. Items included in the HIV-related Stigma Instrument-PLWA versus the adaptation for fistula-related stigma are presented in Table 1. The adapted fistula-related stigma scale maintained the time reference of the prior three months and the response categories of the HIV-related Stigma Instrument-PLWA (never, once or twice, several times, most of the time).

Given prior literature supporting significant impacts of stigma on quality of life and mental health,(Kane et al., 2019; Tsutsumi & Izutsu, 2010; Zeng et al., 2018) we assessed construct validity using three measures representing theoretically related constructs quality of life, depressive symptoms, and self-esteem, all previously validated in Ugandan populations. We used the WHO QOL BREF instrument, a 26-item instrument with 2 individually scored items on overall quality of life and general health, and 4 domains: physical health (7 items on pain, care needs, energy, and functional ability), psychological (6 items on enjoyment and meaning of life, concentration, self-image and esteem, and mood), social relationships (3 items on relationship satisfaction and support), and environmental (8 items on safety and security, financial and information access, and satisfaction with living space, health service access, and transport).(Martin et al., 2013; Webster et al., 2010) Response options followed a 5-point Likert-type scale adapted for each question text. In this sample, internal consistency reliability was acceptable ( $\alpha=0.73$ ). For assessment of depressive symptoms, we used the Hopkins Symptom Checklist, a 26-item instrument assessing the frequency of symptoms over the prior month.(Derogatis et al., 1974) A 4-point Likert-type scale was used for response options, ranging from not at all to extremely). Internal consistency reliability for our sample was good ( $\alpha=0.86$ ). Self-esteem was measured using the Rosenberg self-esteem scale, a 10-item unidimensional scale of global self-worth.(Rosenberg, 1965) Response options follow a 4-point Likert-type scale ranging from strongly agree to strongly disagree. (Rosenberg, 1965) Internal consistency reliability for our sample was good ( $\alpha=0.86$ ).

## Analysis

We described the socio-demographic characteristics of the sample using medians, means and standard deviations, and percentages. Exploratory factor analysis was conducted to explore the latent structure of the scale, specifying a promax oblique rotation to allow for correlation across factors, as was anticipated theoretically, and established a minimum factor loading criteria of 0.5. (DeVellis, 2016) We maintained factors based on scree plot patterning. (Auerswald & Moshagen, 2019) For each subscale extracted from factor analyses, internal consistency reliability was evaluated through Raykov's  $\rho$  statistic to accommodate unequal factor loadings,(T. Raykov, 1997; Tenko Raykov, 1998; Tenko Raykov & Shrout, 2002) and conventional thresholds were utilized for interpretation ( 0.7 acceptable, 0.8 good, 0.9 high).(DeVellis, 2016)

Finally, we assessed construct validity through estimating a series of linear regression models to explore the associations between the stigma scale and validated scales representing theoretically related constructs quality of life, depressive symptoms, and self-esteem. For comparability across the analyses, these measures were standardized to range 0–100. We hypothesized that both stigma measures would be negatively associated with measures of quality of life and self-esteem and positively associated with depressive symptoms. All statistical analysis was conducted within Stata v16 (StataCorp, College Station, TX), and differences were considered statistically significant at  $p<0.05$ .

## Ethical review

The Makerere University College of Health Sciences School of Medicine Research and Ethics Committee (Ref# 2014–052) and the University of California, San Francisco Human Subjects Research Protection Program, Committee on Human Research (IRB# 12–09573) approved the study protocol. All individuals eligible for the research underwent an informed consent process; individuals unable to provide written consent provided witness thumbprint confirmation.

## Results

### Participant characteristics

Characteristics of our study participants are presented in Table 2. Participants were of median age of 28 years (interquartile range (IQR) 21–36) years, with median age at fistula 23 (IQR 18–31) years. Forty percent lived with husbands and thirty two percent lived without another adult in the household, with or without young children (32%). Forty percent had attended some primary school, with 28% having completed primary school and 15% having attended some secondary school. Most participants had no occupation (58%) and 25% were farmers. Nearly half of women had lived with fistula for less than three months at enrolment (45%); however, 28% had lived with it for more than five years.

### Exploratory Factor Analysis

In exploratory factor analyses, two factors met our criteria for inclusion (Table 3). (Auerswald & Moshagen, 2019) Based on the patterning of items within each of these two factors, we termed these 'enacted stigma' and 'internalized stigma'. Enacted stigma refers to

verbal or behavioural discrimination directly experienced by individuals, and this factor included items such as name-calling, insults and other varieties of verbal abuse, physical avoidance and others ending a relationship with the affected individual. Internalized stigma refers to the effect of internalizing negative social attitudes about the condition or experiences of enacted stigma on an individual's sense of self-worth. This factor includes items addressing self-blame, shame, and self-isolation. Both factors evidenced high to acceptable internal consistency reliability, with Raykov's  $\rho=0.960$  and  $\rho=0.748$ , respectively, for enacted and internalized stigma. Internal consistency reliability for the full instrument was also high at  $\rho=0.941$ . Three items did not meet the minimum factor loading threshold (0.5) for either factor: 'I was blamed for my obstetric fistula', 'I stopped eating with other people' and 'I was told that God is punishing me'; these items were dropped from further analysis. Correlation between the two factors was 0.45.

### Construct Validity

The relationships between stigma, by domain, and quality of life, depressive symptoms, and self-esteem are presented in Table 4. Stigma was largely inversely associated with quality of life domains; however, some differences in magnitude were observed by stigma domain (enacted versus internalized). The full stigma scale was significantly and inversely associated with all quality of life (QOL) domains; each unit increase in overall stigma was associated with a 0.27-point reduction in physical health QOL, a 0.42-point reduction in psychological QOL, a 0.43-point reduction in social relationships QOL, and a 0.59-point reduction in environmental QOL. For each unit increase in enacted stigma score, individuals reported a statistically significant 0.28-point reduction in physical health QOL, a 0.43-point reduction in social relationships QOL and 0.69-point reduction in environmental QOL. For each unit increase in internalized stigma score, individuals reported a statistically significant 0.67-point reduction in psychological QOL and 0.45-point reduction in social relationships QOL.

Similarly, increases in stigma overall, and in enacted and internalized stigma, were significantly associated with increased depressive symptoms and decreased self-esteem (Table 4). Overall, each unit increase in stigma was associated with a statistically significant 0.81-point increase in depressive symptoms. For each unit increase in enacted and internalized stigma scores individuals reported a 0.75 and 1.05-point increase in depressive symptoms, respectively. Stigma was inversely associated with self-esteem; for each unit increase in overall stigma, the average decrease in self-esteem was 0.51-points. By stigma domain, each unit increase in enacted stigma was associated with a 0.45-point decrease in self-esteem whereas each unit increase in internalized stigma was associated with a 0.77-point decrease in self-esteem.

### Discussion

Overall the results of our study indicate that the adapted fistula-related stigma instrument was reliable and valid in a cohort of Ugandan women seeking repair for female genital fistula. Our exploratory factor analysis resulted in two factors that largely met the definitions of enacted stigma and internalized stigma, based on frameworks used to conceptualize

condition-specific stigma, including fistula-related stigma.(Earnshaw et al., 2013; AM El Ayadi et al., 2020; Holzemer, Uys, Makoa, et al., 2007) Reliability coefficients for the two factors and the overall scale surpassed commonly-used thresholds,(DeVellis, 2016) and stigma scores and domains behaved as theoretically expected when compared to quality of life, depressive symptoms, and self-esteem in construct validity analyses.

Stigma has been identified as an important predictor of quality of life and mental health across multiple conditions.(Kane et al., 2019; Tsutsumi & Izutsu, 2010) Overall, fistula-related stigma was significantly and inversely associated with physical, psychological, social relationships, and environmental quality of life domains. The magnitude of effect for overall stigma varied, with stigma overall and both domains having the smallest average reduction in physical health quality of life, consistent with stigma and quality of life research.(Kane et al., 2019; Rueda et al., 2016) Unsurprisingly, enacted stigma had the largest impact on environmental quality of life, internalized stigma had the largest impact on psychological quality of life, and the two domains similarly impacted social relationships quality of life. The several comparisons in quality of life that did not meet statistical significance were in the anticipated direction. Depression and self-esteem were significantly correlated with both enacted and internalized stigma, with the magnitude of the correlation being higher for internalized stigma. This finding is consistent with HIV literature supporting a stronger relationship between internalized stigma and depression and self-esteem.(Kane et al., 2019; Zeng et al., 2018)

A valid and reliable measurement instrument for fistula-related stigma can be used in clinical and community settings to understand the level of stigma that women are experiencing, to compare stigma across individual and community characteristics, to prioritize strategies for reducing stigma, and to assess the impact of targeted interventions. The dual factor structure of the adapted fistula-related stigma instrument as enacted versus internalized provides important guidance for stigma reduction interventions, given the external versus internal orientation of these factors. Enacted stigma interventions typically focus on community and other interpersonal educational and behavioural strategies to improve an individual's environment whereas interventions targeting internalized stigma are heavily focused on psychological counselling.(Kemp et al., 2019; Rao et al., 2019) This tool could be applied to plan and evaluate multi-level interventions (e.g., intrapersonal, interpersonal, community) to address stigma. Furthermore, fistula-related stigma may persist in the post-repair period, particularly for women whose incontinence persists;(A. M. El Ayadi et al., 2018) therefore such an instrument could have value both before and after treatment.

Interestingly, our exploratory factor analysis of the adapted fistula-related stigma measure resulted in notably distinct factor patterns than are reported for the HASI-P. As described in the methods and presented in Table 1, Holzemer et al identified four distinct factors among shared items (i.e., excluding the two factors which were excluded from the adapted fistula-related stigma measure), representing verbal abuse, negative self-perception, social isolation, and fear of contagion.(Holzemer, Uys, Chirwa, et al., 2007) While our two-factor solution of enacted stigma and internalized stigma combined items from the four factors identified by Holzemer et al, it is consistent with current theoretical models of stigma.(Earnshaw et al.,

2013; AM El Ayadi et al., 2020; Holzemer, Uys, Makoe, et al., 2007) The differences in factor structure across the two instruments may be due to disparate stigma experiences based on condition-specific differences such as concealability, an important factor noted by Goffman.(Goffman, 1963) The primary presenting symptoms of genital fistula, uncontrollable urinary and/or faecal incontinence, are difficult to conceal and are unpleasant to the woman and those nearby. Common management strategies such as padding with fabric do not resolve the odour, which would make fistula less concealable.(Roush, 2009) Other differences between fistula and HIV may include greater community awareness and knowledge of HIV compared to fistula, which in part may be fuelled by differences in prevalence.

Strengths of this research include the fact that this is the first known report of a stigma instrument designed to assess fistula-related stigma using a robust methodology. Since our adaptation and implementation of this instrument, researchers involved in another study of 28 women seeking fistula repair in Tanzania also adapted the HASI-P for use regarding fistula-related stigma;(Wilson et al., 2016) however, neither explanation of the items nor validation of the instrument was included although reliability of the instrument was reported as high ( $\alpha=0.91$ ). Our analysis has several important limitations. First and foremost, we began with an already constructed measure developed to assess a different condition-specific stigma. Based on expert and key stakeholder input for content validity, we adapted these items following the WHO standards for instrument adaptations; however, we did not employ a grounded theory approach which could have been more comprehensive. Furthermore, we excluded some items from the initial instrument to reduce participant burden. While these items were not supported by experts and key stakeholders, it resulted in a loss of our ability to understand the importance of healthcare neglect and workplace stigma as potential structural components of fistula-related stigma. We did not assess temporal stability reliability in our measure adaptation process, which we plan to do in a subsequent study. Finally, while our results were robust, this analysis is limited by the small sample size and further assessment should be conducted among a larger sample with greater variability of characteristics that might impact enacted and/or internalized stigma (i.e. fistula duration, incontinence severity, etc.). Subsequent instrument modification would also benefit from attention to other stigma domains such as anticipated stigma and perceived community stigma.(AM El Ayadi et al., 2020) Finally, our assessment of an adapted fistula-related instrument does not comment on clinical significance, but this aspect should be included within subsequent research.

Stigma is a pervasive experience among women with fistula, and quantifying women's experiences and magnitude of fistula-related stigma is an important need for developing and evaluating stigma-reduction interventions to improve the health and quality of life of women living with fistula. Our study suggests the adapted fistula-related stigma instrument is a valid and reliable assessment instrument for enacted and internalized stigma among women affected by female genital fistula.

## Acknowledgements

This work was supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development of the United States National Institutes of Health (grants R21HD075008 and R00HD086232), the Fistula Foundation, and the United States Agency for International Development (USAID) via the Fistula Care *Plus* Project, administered by EngenderHealth under cooperative agreement AID-OAA-A14-00013. The opinions expressed are those of the authors and do not necessarily reflect the views of USAID, the National Institutes of Health, or the United States Government.

## References

- Derogatis LR, Lipman RS, Rickels K, Uhlenhuth EH, & Covi L (1974). The Hopkins Symptom Checklist (HSCL): A self-report symptom inventory. *Behavioral Science*, 19(1), 1–15. 10.1002/bs.3830190102 [PubMed: 4808738]
- DeVellis RF (2016). *Scale Development: Theory and Applications*. SAGE Publications, Inc.
- Earnshaw VA, Smith LR, Chaudoir SR, Amico KR, & Copenhaver MM (2013). HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS Behav*, 17(5), 1785–1795. 10.1007/s10461-013-0437-9 [PubMed: 23456594]
- El Ayadi A, Barageine JK, Miller S, Byamugisha J, Nalubwama H, Obore S, Korn A, Sukumar S, Kakaire O, Mwanje H, Lester F, & Turan JM (2020). Women's experiences of fistula-related stigma in Uganda: a conceptual framework to inform stigma-reduction interventions. *Culture Health & Sexuality*, 22(3), 352–367. 10.1080/13691058.2019.1600721
- El Ayadi A, Byamugisha J, Obore S, Mwanje H, Kakaire O, Barageine J, Nalubwama H, Lester F, Knight S, Korn A, & Miller S (2017). Development and preliminary validation of a post-fistula repair reintegration instrument among Ugandan women. *Reproductive Health Journal*, 14(1), 109. 10.1186/s12978-017-0372-8.
- El Ayadi AM, Barageine J, Korn A, Kakaire O, Turan J, Obore S, Byamugisha J, Lester F, Nalubwama H, Mwanje H, Tripathi V, & Miller S (2018). Trajectories of Women's Physical and Psychosocial Health Following Obstetric Fistula Repair in Uganda: A Longitudinal Study. *Trop Med Int Health*. 10.1111/tmi.13178
- Goffman E (1963). *Stigma: Notes on the Management of Spoiled Identity*. Prentice-Hall.
- Holzemer WL, Uys L, Makoa L, Stewart A, Phetlhu R, Dlamini PS, Greeff M, Kohi TW, Chirwa M, Cuca Y, & Naidoo J (2007). A conceptual model of HIV/AIDS stigma from five African countries. *J Adv Nurs*, 58(6), 541–551. 10.1111/j.1365-2648.2007.04244.x [PubMed: 17484748]
- Holzemer WL, Uys LR, Chirwa ML, Greeff M, Makoa LN, Kohi TW, Dlamini PS, Stewart AL, Mullan J, Phetlhu RD, Wantland D, & Durrheim K (2007). Validation of the HIV/AIDS Stigma Instrument - PLWA (HASI-P). *AIDS Care*, 19(8), 1002–1012. 10.1080/09540120701245999 [PubMed: 17851997]
- Kane JC, Elafros MA, Murray SM, Mitchell EMH, Augustinavicius JL, Causevic S, & Baral SD (2019). A scoping review of health-related stigma outcomes for high-burden diseases in low- and middle-income countries. *BMC Med*, 17(1), 17. 10.1186/s12916-019-1250-8 [PubMed: 30764819]
- Kemp CG, Jarrett BA, Kwon CS, Song L, Jette N, Sapag JC, Bass J, Murray L, Rao D, & Baral S (2019). Implementation science and stigma reduction interventions in low- and middle-income countries: a systematic review. *BMC Med*, 17(1), 6. 10.1186/s12916-018-1237-x [PubMed: 30764820]
- Khisa AM, Omoni GM, Nyamongo IK, & Spitzer RF (2017). 'I stayed with my illness': a grounded theory study of health seeking behaviour and treatment pathways of patients with obstetric fistula in Kenya. *BMC Womens Health*, 17(1), 92. 10.1186/s12905-017-0451-6 [PubMed: 28962566]
- Martin F, Russell S, & Seeley J (2013). The WHOQOL BREF questionnaire in Uganda: Validation with a sample including people living with HIV in Uganda. Working Paper 46 (<https://www.uea.ac.uk/documents/439774/542576/wp46+final.pdf/ad7405dd-2dc6-4f20-bbd6-bba96574912c>
- Rao D, Elshafei A, Nguyen M, Hatzenbuehler ML, Frey S, & Go VF (2019). A systematic review of multi-level stigma interventions: state of the science and future directions. *BMC Med*, 17(1), 41. 10.1186/s12916-018-1244-y [PubMed: 30770756]
- Raykov T (1997). Scale Reliability, Cronbach's Coefficient Alpha, and Violations of Essential Tau-Equivalence with Fixed Congeneric Components. *Multivariate Behav Res*, 32(4), 329–353. 10.1207/s15327906mbr3204\_2 [PubMed: 26777071]
- Raykov T (1998). A Method for Obtaining Standard Errors and Confidence Intervals of Composite Reliability for Congeneric Items. *Applied Psychological Measurement*, 22(4), 369–374. 10.1177/014662169802200406
- Raykov T, & Shrout PE (2002). Reliability of Scales With General Structure: Point and Interval Estimation Using a Structural Equation Modeling Approach. *Structural Equation Modeling: A Multidisciplinary Journal*, 9(2), 195–212. 10.1207/S15328007SEM0902\_3

- Rosenberg M (1965). Society and the adolescent self-image. Princeton University Press.
- Roush KM (2009). Social implications of obstetric fistula: an integrative review. *J Midwifery Womens Health*, 54(2), e21–33. <https://www.sciencedirect.com/science/article/abs/pii/S1526952308003371?via%3Dihub> [PubMed: 19249652]
- Ruder B, Cheyney M, & Emasu AA (2018). Too Long to Wait: Obstetric Fistula and the Sociopolitical Dynamics of the Fourth Delay in Soroti, Uganda. *Qual Health Res*, 28(5), 721–732. 10.1177/1049732317754084 [PubMed: 29415634]
- Rueda S, Mitra S, Chen S, Gogolishvili D, Globerman J, Chambers L, Wilson M, Logie CH, Shi Q, Morassaei S, & Rourke SB (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ Open*, 6(7), e011453. 10.1136/bmjopen-2016-011453
- Stamatakos M, Sargedji C, Stasinou T, & Kontzoglou K (2014). Vesicovaginal fistula: diagnosis and management. *Indian J Surg*, 76(2), 131–136. 10.1007/s12262-012-0787-y [PubMed: 24891778]
- Tsutsumi A, & Izutsu T (Eds.). (2010). Quality of Life and Stigma. Springer.
- Webster J, Nicholas C, Velacott C, Cridland N, & Fawcett L (2010). Validation of the WHOQOL-BREF among women following childbirth. *Aust N Z J Obstet Gynaecol*, 50(2), 132–137. <https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/j.1479-828X.2009.01131.x> [PubMed: 20522068]
- Wilson SM, Sikkema KJ, Watt MH, Masenga GG, & Mosha MV (2016). Psychological Symptoms and Social Functioning Following Repair of Obstetric Fistula in a Low-Income Setting. *Matern Child Health J*, 20(5), 941–945. 10.1007/s10995-016-1950-z [PubMed: 27010550]
- World Health Organization. (n.d.). Process of translation and adaptation of instruments [http://www.who.int/substance\\_abuse/research\\_tools/translation/en/](http://www.who.int/substance_abuse/research_tools/translation/en/)
- Zeng C, Li L, Hong YA, Zhang H, Babbitt AW, Liu C, Li L, Qiao J, Guo Y, & Cai W (2018). A structural equation model of perceived and internalized stigma, depression, and suicidal status among people living with HIV/AIDS. *BMC Public Health*, 18(1), 138. 10.1186/s12889-018-5053-1 [PubMed: 29334959]

**Table 1.**

Comparison between the HIV/AIDS Stigma Instrument-PLWA and Adapted Fistula-Related Stigma Instrument

Holzemer HIV-related Stigma Instrument (33 items)	Adapted Fistula-related Stigma Instrument (18 items)
<b>Verbal abuse (<math>\alpha=0.886</math>)</b>	
Someone scolded me.	Someone scolded me.
Someone insulted me.	Someone insulted me.
I was blamed for my HIV status.	I was blamed for my obstetric fistula.
I was told that I have no future.	I was told that I have no future.
I was told that God is punishing me.	I was told that God is punishing me.
I was called bad names.	I was called bad names.
Someone mocked me when I passed by.	Someone mocked me when I passed by.
People sang offensive songs when I passed by.	People sang offensive songs when I passed by
<b>Negative self-perception (<math>\alpha=0.906</math>)</b>	
I felt completely worthless.	
I felt ashamed of having this disease.	I was ashamed of having this condition.
I felt that I am no longer a person.	
I felt that I brought a lot of trouble to my family.	I felt that I brought a lot of trouble to my family.
I felt that I did not deserve to live.	
<b>Healthcare neglect (<math>\alpha=0.832</math>)</b>	
I was discharged from the hospital while still needing care.	
I was shuttled around instead of being helped by a nurse.	
In the hospital or clinic, my pain was ignored.	
I was refused treatment because I was told I was going to die anyway.	
At the hospital, I was left in a soiled bed.	
I was denied health care.	
At the hospital/clinic, I was made to wait until last.	
<b>Social isolation (<math>\alpha=0.8906</math>)</b>	
People cut down visiting me.	People cut down visiting me.
People ended their relationships with me.	People ended their relationships with me.
A friend would not chat with me.	A friend would not chat with me.
Someone stopped being my friend.	Someone stopped being my friend.
People avoided me.	People avoided me.
	I avoided other people.
<b>Fear of contagion (<math>\alpha=0.795</math>)</b>	
I was told to use my own eating utensils.	
I was made to drink last from the cup.	
I stopped eating with other people.	I stopped eating with other people.
I was asked to leave because I was coughing.	
I was made to eat alone.	
I was asked not to touch someone's child.	
	Someone stopped eating food that I had prepared

Holzemer HIV-related Stigma Instrument (33 items)	Adapted Fistula-related Stigma Instrument (18 items)
<b>Workplace stigma (<math>\alpha=0.758</math>)</b>	
Someone tried to get me fired from my job.	
My employer denied me opportunities.	

Note: reference period was the prior 3 months. Response options for both scales: never, once or twice, several times, most of the time.

**Table 2.**

Sociodemographic characteristics of study population (n=60)

Characteristic	n	%
Current age in years <sup>a</sup>	28 (21–36)	
Age at First Birth in years <sup>a</sup>	18 (17–20)	
Age at Fistula in years <sup>a</sup>	23 (18–31)	
Living Situation, with or without young children		
Husband	24	40
Alone	13	22
Other	15	25
Parents	8	13
Educational Attainment		
None	10	17
Some Primary	24	40
Completed Primary	17	28
Any Secondary	9	15
Occupation		
None	35	58
Farmer	15	25
Other <sup>c</sup>	10	17
Primary Source of Financial Support		
Self	18	28
Husband	21	40
Other	21	32
Household characteristics and assets		
Piped Water	9	15
Flush/pour flush toilet	4	7
Electricity	26	43
Radio	35	58
Mobile phone	39	65
Duration living with fistula		
< 3 Mo	27	45
3–12 Mo	9	13
1–5 Years	8	13
>5 Years	17	28
Likely fistula aetiology		
Obstetric	41	68
Iatrogenic	19	32
Any Living Children	39	65

Notes.

<sup>a</sup>: iqr =interquartile range.

<sup>c</sup> vendor/shopkeeper (n=5), skilled service (n=3), housemaid (n=5).

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

**Table 3.**

Factor Loadings of Adapted Fistula-related Stigma Instrument

Factor	Factor Loading	Item
<b>Factor 1. Enacted Stigma, 12 items (<math>\rho=0.960</math>)</b>	0.96	People sang offensive songs when I passed by
<b>Eigenvalue 9.59, 65.6% explained variance</b>	0.95	I was called bad names
	0.95	People avoided me
	0.93	Someone mocked me when I passed by
	0.79	Someone scolded me
	0.78	Someone insulted me
	0.77	I was told that I have no future
	0.72	A friend would not chat with me
	0.64	Someone stopped being my friend
	0.63	People ended their relationships with me
	0.60	Someone stopped eating food that I had prepared
	0.54	People cut down visiting me
<b>Factor 2. Internalized stigma, 3 items (<math>\rho=0.748</math>)</b>	0.74	I felt that I brought a lot of trouble to my family
<b>Eigenvalue 1.42, 33.0% explained variance</b>	0.59	I was ashamed of having this condition
	0.55	I avoided other people
<b>Total scale 15 items (<math>\rho=0.941</math>)</b>		

Participant instructions: In the past 3 months, how often did the following events occur because of your obstetric fistula? Response categories: 0=never, 1=once or twice, 2=several times, 3=most of the time. Sample size 60.  $\rho$ = Raykov's reliability coefficient.

**Table 4.**

Construct Validity Assessment: Relationship between Stigma Domains and Quality of Life, Depressive Symptoms, and Self-esteem

	Stigma Overall		Enacted Stigma (Factor 1)		Internalized Stigma (Factor 2)	
	$\beta$	95% CI	$\beta$	95% CI	$\beta$	95% CI
Quality of life						
Physical health	-0.27	(-0.52, -0.01)*	-0.28	(-0.56, -0.01)*	-0.21	(-0.54, 0.11)
Psychological	-0.42	(-0.83, -0.02)*	-0.36	(-0.80, 0.08)	-0.67	(-1.16, -0.17)**
Social relationships	-0.43	(-0.70, -0.17)**	-0.43	(-0.72, -0.14)**	-0.45	(-0.78, -0.11)*
Environmental	-0.59	(-0.99, -0.20)**	-0.69	(-1.11, -0.27)**	-0.21	(-0.73, 0.31)
Depressive symptoms	0.81	(0.49, 1.12)***	0.75	(0.39, 1.10)***	1.05	(0.67, 1.42)***
Self-esteem	-0.51	(-0.91, -0.12)*	-0.45	(-0.88, -0.01)*	-0.77	(-1.24, -0.29)**

Sample size 60

\*  
p<0.05,

\*\*  
p<0.01,

\*\*\*  
p<0.001.