Function and disability status among women with fistula using WHODAS2.0: A descriptive study from Rwanda and Democratic Republic of Congo

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Abstract
Objective: To assess function and disability among women in Rwanda and Democratic Republic of Congo living with fistula and identify characteristics associated with higher disability scores.

Methods: Women presenting for fistula care were recruited. Eligible participants underwent a physical examination to classify fistula type and completed the WHO Disability Assessment Schedule 2.0 questionnaire to ascertain the impact of fistula on function across six domains: cognition, mobility, self-care, getting along, life activities, and participation. Disability scores were calculated (where 0 = no disability and 100 = complete disability). Participants were grouped according to no, low, or high disability status; results were examined to determine the domains most affected.

Results: Among 69 participants, fistula type included: vesicovaginal (59.4%), ureterovaginal (14.5%), total absence of proximal urethra (11.6%), and rectovaginal (14.5%). Median disability score was 43.0/100 (interquartile range 26.0–67.0); 83% exhibited high disability status. Life activities and participation in society domains were most affected. Women with rectovaginal fistula reported the lowest scores, and those with total absence of proximal urethra reported the highest scores.

Conclusion: WHO Disability Assessment Schedule 2.0 represents a simple, robust measure of global disability status, aligns with research efforts to estimate maternal disability, and may inform health needs and resource allocation for this population. In this study, disability was common, varied by fistula type, and affected physical, mental, and social domains.

KEYWORDS
disability, function, maternal morbidity, obstetrical fistula, pelvic fistula, prolonged obstructed labor

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1 | INTRODUCTION

As development efforts have achieved improvements in maternal mortality, healthcare providers and policy makers have increased their attention towards the significant, often silent, burden of maternal morbidities. Estimates indicate that for every maternal death, 20–30 women face acute or chronic morbidity with lasting effects on health and function. In 2012, WHO convened the Maternal Morbidity Working Group with the aim of standardizing measurement and building evidence to improve identification, prevention, and treatment of maternal health conditions and related disability. They define maternal morbidity as “any health condition attributed to and/or complicating pregnancy and childbirth that has a negative impact on the woman’s well-being and/or functioning.” The culmination of their efforts yielded a maternal morbidity framework and standardized assessment tool. One component of their assessment tool is the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) to evaluate and quantify disability with respect to maternal morbidity.

WHODAS 2.0 represents a standardized, cross-cultural measurement tool that quantifies aspects of function and disability in physical, mental, and social domains. It is rooted in the disability framework of the International Classification of Functioning, Disability, and Health (Figure 1) and offers a quantitative measure of the impact of injury or illness on daily life. It accounts for multi-dimensional influences on health and measures health through the lens of function and disability. According to this model, a person's body structures and functions, ability to perform daily activities, and social participation represent three distinct levels of function that are inter-related, and both influenced by and exert influence on contextual factors (i.e. physical environment). Identifying these factors and their relationships allows healthcare providers and researchers to understand differences in outcomes among individuals with the same health condition and can inform treatment planning and resource allocation. WHODAS 2.0 has been described for a variety of populations, including pregnant women and those with maternal health conditions of varying severity.

Pelvic fistula is among the most severe maternal morbidities. It is an atypical connection between the upper or lower genital tract and adjacent upper or lower urinary tract and/or lower gastrointestinal tract. It results in the uncontrolled passage of urine and/or feces and often leads to severe physical, psychological, and economic consequences. In low-resource settings, fistula is often associated with childbirth, following prolonged, obstructed labor; iatrogenic cases due to operative or instrumental delivery are also cited. Prevalence estimates indicate 1.57/1000 women of reproductive age in sub-Saharan Africa and South Asia experience this condition. Associated conditions include: bladder stones, kidney infection or dysfunction, fibrosis/stenosis, dyspareunia, pelvic inflammatory disease, amenorrhea, infertility, urea dermatitis, nerve damage, joint contractures, pain, and malnutrition. Psychosocial consequences include depression, anxiety, social isolation, abandonment, and loss of employment, income, and/or livelihood. Surgery is the primary treatment for most fistulae. However, multi-year delays in care are frequently cited as a result of resource limitations (i.e. lack of trained healthcare providers, equipment, and supplies) and financial barriers, including the cost of surgery and ancillary care. Postoperative health conditions often persist, including incontinence, pelvic and musculoskeletal pain, sexual dysfunction, weakness, and negative impacts on mental health.

WHO Disability Assessment Schedule 2.0 has not been described for this population with fistula. No known studies have quantified the level of disability for this population despite the well-documented negative impact of fistula on physical health, economic status, and psychosocial well-being. The objectives of this study are: (1) to assess function and disability among women in Rwanda and Democratic Republic of Congo (DRC) living with fistula and (2) to identify characteristics associated with higher disability scores. This will provide insight into the disability experienced by women with fistula and will inform future clinical program planning, research, and health policy initiatives.

2 | MATERIALS AND METHODS

Women with fistula presenting for medico-surgical care were recruited at Kibagabaga District Hospital (Kigali, Rwanda) in October 2017 and Panzi General Reference Hospital (Bukavu, DRC) in May 2019. Kibagabaga District Hospital hosts international surgical teams approximately three times a year, who work alongside local staff, providing fistula care in a camp setting. Medical teams complete up to 50 surgeries during a single visit. Panzi Hospital is a tertiary care facility specializing in gynecologic surgery. Fistula repairs are scheduled regularly, 25–30/month on average.

Due to investments by the Rwandan Ministry of Health, emergency obstetrical services are widely available. Quality of care varies depending on hospital type (i.e. district hospital, academic referral center) and healthcare provider (i.e. intern, general practitioner, obstetrician). Similarly, DRC’s Ministry of Health supports a national
strategy for obstetrical service provision; however, this has not yielded significant improvements in maternal health outcomes because of infrastructure, financial and human resource limitations.

All women underwent a medical examination by a gynecologist to classify fistula type and completed intake documentation regarding demographics and health history. Fistulae were classified as vesicovaginal (VVF), ureterovaginal (UVF), total absence of proximal urethra (TAPU), and rectovaginal (RVF). All women provided verbal informed consent before completing the questionnaire. WHODAS 2.0 was verbally administered to all participants by local research assistants with fluency in the native languages in each country, which included Kinyarwandan (Rwanda), Swahili, Lingala, or Mashi (DRC). Ethical approval was obtained from the Johns Hopkins School of Medicine National Health Research Committee, the Rwandan National Ethics Committee, and the South Kivu Province Ethics Committee (DRC).

The WHODAS 2.0 questionnaire captures the impact of health conditions on functional status by providing a measure of an individual’s level of function over the previous 30 days across six domains: cognition, mobility, self-care, getting along, life activities, and participation.\(^5\) Surveys may be self-, interviewer-, or proxy-administered. Respondents rate level of difficulty performing tasks related to these domains on a five-point Likert scale (from 0 to 4) from “none” to “extreme or cannot do.” Both 12- and 36-item surveys are available. The 12-item version (0–48 points) includes two questions related to each domain and explains 81% of the variance in scores on the 36-item version.\(^5\) Population-level data suggests that 12-item scores of 10–48 points represent the top 10% of the population distribution, and are probably indicative of clinically significant disability.\(^19\) Although there is no consensus, proposed cut-points based on 12-item scores are: 0 points, no disability; 1–9 out of 48 points, low disability; and 10–48 out of 48 points, high disability.\(^19\)

We used the 36-item interviewer-administered questionnaire, and computed disability scores for both 12- and 36-item versions to enable comparison. Scoring methods include a simple sum score and a complex, weighted score based on item-response theory.\(^5\) The complex scoring method yields scores ranging 0 to 100; where 0 is no disability and 100 is complete disability. WHODAS 2.0 has been validated in a variety of populations, including in the context of reproductive health, and has good psychometrical properties.\(^5\)

Data were analyzed using Stata 15 (StataCorp LLC., College Station, TX, USA). Demographic data were summarized using frequency distributions, medians, and interquartile ranges (IQR). Fisher exact test (for categorical variables) and Kruskal–Wallis test (for continuous variables) were used to test strength of association between fistula type and disability scores.

### RESULTS

Of the 77 women who presented for care and completed WHODAS 2.0, 47 (61%) were from Rwanda and 30 (39%) from DRC. Seven participants presented with incontinence but on examination were found not to have fistula and were excluded from further analysis. An additional participant was excluded for a missing diagnosis, leaving 69 participants for analysis. Table 1 presents participant demographic information. The most common fistula type was VVF \((n = 41, 59.4\%)\), followed by UVF \((n = 10, 14.5\%)\) and RVF \((n = 10, 14.5\%)\), then TAPU \((n = 8, 11.6\%)\). There were no significant differences in age \((P = 0.310)\), years in school \((P = 0.331)\), marital status \((P = 0.499)\), or occupational status \((P = 0.311)\) by fistula classification. The median 12-item disability score was 43.0/100 (IQR 26.0–67.0), indicating high disability in this sample. Disability assessed by the 12-item questionnaire differed by fistula type \((P = 0.002)\) with highest disability among women with TAPU and lowest among women with RVF. When grouped according to degree of disability,\(^19\) most women with fistula experienced high disability (83%). The remainder reported low (12%) or no disability (4.5%). There were significant differences based on fistula type \((P = 0.000)\); women with RVF had lower disability scores than women with other fistula types (Table 2).

The median disability score on the 36-item questionnaire was 40.0/100 (IQR 28.0–55.0). Disability assessed by the 36-item survey differed by fistula type \((P = 0.005)\) with highest among women

### Table 1 Demographics and patient characteristics\(^a\)

| Variable               | Rwanda \((n = 44)\) | DRC \((n = 25)\) | Total \((n = 69)\) |
|------------------------|---------------------|-----------------|-------------------|
| Age, year              | 36 (29–41)          | 28 (24–25)      | 34 (27–40)        |
| Years in school        | 5 (1.5–6)           | 3 (0–6)         | 5 (0–6)           |
| Marital status         |                     |                 |                   |
| Married                | 29 (65.9)           | 18 (72.0)       | 47 (68.1)         |
| Separated              | 11 (25.0)           | 6 (24.0)        | 17 (24.6)         |
| Divorced               | 1 (2.3)             | 0               | 1 (1.5)           |
| Widowed                | 2 (4.5)             | 1 (4.0)         | 3 (4.4)           |
| Never married          | 1 (2.3)             | 0               | 1 (1.5)           |
| Occupational status    |                     |                 |                   |
| Paid work              | 5 (11.4)            | 0               | 5 (7.3)           |
| Self-employed          | 29 (65.9)           | 0               | 29 (42.0)         |
| Unemployed (health reasons) | 8 (18.2)  | 0               | 8 (11.6)          |
| Unemployed (other reasons) | 2 (4.5)   | 5 (20.0)        | 7 (10.1)          |
| Other                  | 0                   | 20 (80.0)       | 20 (29.0)         |
| Fistula type           |                     |                 |                   |
| VVF                    | 26 (59.0)           | 15 (60.0)       | 41 (59.4)         |
| UVF                    | 7 (15.9)            | 3 (12.0)        | 10 (14.5)         |
| RVF                    | 8 (18.2)            | 2 (8.0)         | 10 (14.5)         |
| TAPU                   | 3 (6.8)             | 5 (20.2)        | 8 (11.6)          |

Abbreviations: DRC, Democratic Republic of Congo; RVF, rectovaginal fistula; TAPU, total absence of proximal urethra; UVF, ureterovaginal fistula; VVF, vesicovaginal fistula.

\(^a\)Values are given as median (interquartile range) or as number (percentage).
with TAPU and lowest among women with RVF. When considering the impact of fistula on disability scores by domain, the highest scores for all groups included participation in society and life activities. There were significant differences between fistula type in all domains, except participation in society. Women with RVF had the lowest scores and those with TAPU had the highest scores (Table 3).

### 4 | DISCUSSION

Women with fistula in Rwanda and DRC experience a high level of disability. In our study, women with RVF scored significantly lower than women with any urinary tract involvement on 12- and 36-item questionnaires. Domain-specific scores reflected high levels of difficulty with participation in society for all groups (score range 53.1–79.7 out of 100). On the 36-item questionnaire, women with urinary tract involvement reported varying degrees of disability in all other domains, indicating that all aspects of life were affected by their experience of fistula. Of note, women with TAPU scored highest on 12- and 36-item surveys and reported a high degree of difficulty with mobility (70.0/100), work/school-related activities (73.4/100), and community participation (64.1/100). Women with UVF scored lowest on cognition (18.8/100), mobility (25.0/100), self-care (12.5/100), and getting along (20.0/100) domains, when compared with women with VVF or TAPU. Differences in pathophysiology between fistula types may contribute to the observed variation in disability.

In comparison to WHODAS 2.0 scores from other studies, the severity of disability reported by women with fistula is greater than that reported by a cohort of Brazilian women with severe maternal morbidity and in another group of premenopausal women with urinary incontinence. Regional WHODAS 2.0 data are limited. One study from Uganda describes 12-item scores for individuals with physical disabilities affiliated with a community-based rehabilitation program; the reported mean was 12.68 points (26.4/100) with 47% categorized as low disability and 53% as high disability. Another report from South Africa used the 36-item questionnaire to ascertain domain-specific disability in community-dwelling stroke survivors, indicating severe to complete disability in mobility, self-care, life activities, and participation in society. Although women with fistula represent a different population from those described in these studies, comparable or higher scores in our study suggest that women with fistula experience a significant burden of disability akin to levels experienced by those with conditions that may result in overt, physical disabilities requiring rehabilitation services.

Malembaka et al. surveyed a community-based sample from rural and semi-urban regions of eastern DRC, stratifying individuals into three clusters according to WHODAS 2.0 scores. In their study, cluster 3 represents individuals with the poorest functional status with a median WHODAS 2.0 score of 62.1/100 (IQR 53.2–75.7); this comprised 9.2% of their total study population. Those in cluster 2 represent 21.1% of the study population with a median WHODAS 2.0 score of 31.7/100 (IQR 24.7–39.7). According to this stratification, most women in our study stratify to cluster 3, indicating high resource needs beyond a single hospital visit. The authors suggest applying this stratification to inform provision of cost-effective solutions to manage disability. Broadly, individuals in cluster 3 may benefit from targeted interventions, including multidisciplinary care,
case management, and home visits, whereas those in cluster 2 may gain from self-management solutions, such as health coaching and education, in addition to primary prevention and treatment of acute and chronic health conditions.

To date, the majority of resources for fistula programs have been allocated to surgical care, whether to finance international missions or to support local skills training efforts. Although surgical capacity is much needed, a narrowly focused biomedical approach does not account for the multidimensional aspects of health and function of women with fistula and its associated morbidities. Malembaka et al. cite the problem of “donors-dictated disease-based indicators” in low- and middle-income countries, which often undermine efforts to strengthen health systems through multidisciplinary, comprehensive approaches to healthcare delivery. Despite growing recognition of the significant burden of maternal morbidities in low- and middle-income countries, broad investment in health services, including physical and psychosocial rehabilitation, remains limited. Our results may alert health policy-makers in this region to the ongoing needs of women with fistula, to improve health services for this population. Women in our study experienced significant disability, yet variability in general and domain-specific scores indicates individual differences in severity and type of disability. Employing WHODAS 2.0 in the context of fistula care may improve our understanding of the functional impact of this condition, inform resource allocation, and may be useful in monitoring response to policy-level changes over time.

A recent publication indicates a significant and previously underestimated global burden of disease related to prolonged, obstructed labor, including fistula and its sequelae, calling for quantitative and patient-reported measures to improve assessments of disease burden. WHODAS 2.0 represents one such measure that may fill this need. Although surgical needs of women with fistula are well-documented, understanding of women’s experiences and their ability to participate in home and community life is limited, informed predominantly by important, yet small, qualitative studies. Understanding the impact of fistula, both pre- and post-operatively, will guide evidence-based interventions to meet a broad set of needs. This includes women with successful surgical closure, those who have experienced medical trauma due to prolonged, obstructed labor and/or failed or repeat procedures, and those deemed incurable. Apart from surgical intervention, there exist myriad treatment options to address related health conditions. This includes psychosocial and physical rehabilitative care aimed at minimizing the burden of disability, as well as family/community sensitization and public health education to promote understanding and acceptance of fistula and its consequences and to reduce the widespread stigma associated with disability.

Our study has several limitations. First, this was a small sample of women seeking care at two regional hospitals and may not represent all women with fistula. Second, WHODAS 2.0 scores were captured at a single time-point, pre-operatively. Though this was the goal of the study, post-operative measures may be captured at or beyond the 30-day mark to ascertain the functional impact of surgery, as well as any related co-morbidities that may persist. Third, WHODAS 2.0 has not been previously validated in the native languages spoken in Rwanda and DRC or in a population with fistula. Although the survey provides a measure of global function, it may not capture important, condition-specific information. Lastly, available patient data were limited in this study. We were unable to examine associations between disability scores and certain patient characteristics, such as parity or length of time living with fistula, which may be important factors in understanding disability status in this population.

To conclude, disability was common in this study population. Women reported functional limitations in physical, mental, and social domains related to their fistula status. Use of WHODAS 2.0 represents a simple, robust measure of global disability status and is aligned with Maternal Morbidity Working Group research efforts to estimate maternal disability. WHODAS 2.0 may also be used to track outcomes to determine the impact of medico-surgical, rehabilitative and reintegration interventions, to appropriately direct resources, to strengthen fistula programs and to alleviate the significant burden of this condition.

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CONFLICTS OF INTEREST
The authors have read the journal’s policy and have the following conflicts: LK and JM are co-founders of Mama LLC, a consulting firm providing expertise in women’s health, physiotherapy and rehabilitation, and public health. Mama LLC has partnered with Panzi Hospital and Foundations since 2016, collaborating on program development and research initiatives. All services provided are completely pro bono. No funding was provided to Mama LLC or from Mama LLC to Panzi Hospital or any of the authors for this work. JM is also the Vice President of Medical Affairs for Renovia, Inc., a digital health company focused on innovation for female pelvic floor disorders. This work is unrelated to the current paper; no funds were received for this research.

AUTHOR CONTRIBUTIONS
LK and JM designed the study; LK, JM, DM and CCGC planned it and LK, RM, DM, CCGC conducted it. ENBM analyzed the data. All authors contributed to writing and editing the manuscript.

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