

Access to High Quality Surgical Repair Services is a Fundamental Right of Patients with Obstetric Fistulas: A Study on Quality of Life Data in the Democratic Republic of the Congo

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Purpose: The aim of this study was to assess quality of life (QoL) using the WHOQOL-BREF questionnaire among obstetric fistula (OF) patients before and after surgical repair of OF (SROF).

Methods: A longitudinal cohort study was conducted between November 2022 and October 2023 in the Democratic Republic of the Congo (DRC) among OF patients to assess their QoL before and after SROF. A systematic sampling technique was used to recruit a total of 158 OF patients. The WHOQOL-BREF questionnaire assessed general health, life experience, as well as physical, social, psychological, and environmental domains.

Results: The mean age among the 158 respondents was 33.51 ± 9.63 years, and 77.85% of them lived in rural areas. In terms of surgical outcomes, 80.38% had closure of the OF with regained continence, 5.7% had closure of the OF with persistent incontinence, and 13.9% had a failed surgical repair. Overall mean QoL scores were higher after OF surgical repair (3.83, standard deviation [SD] = 0.89) in comparison to pre-operative (1.58, SD = 0.63) ($p < 0.001$). These QoL improvements included physical (mean score 66.32 post-surgery versus 28.37 before, $p < 0.001$), social (mean score 64.92 post-surgery versus 27.90 before, $p < 0.001$), psychological (mean score 68.09 post-surgery versus 21.28 before, $p < 0.001$), environmental (mean score 48.41 post-surgery versus 16.91 before $p < 0.001$), and general domains. Patients with a successful OF repair had a better QoL score than those with a closed fistula but ongoing incontinence or those for whom surgery failed to close the fistula.

Conclusion: The present study showed that among OF patients, all QoL domains were impaired before surgical repair and significantly improved after surgery. Successful OF closure alleviates the consequences of OF and helps to restore patients' wellbeing. Our findings call for improved access to high-quality surgical repair services as a fundamental right for OF patients.

Keywords: quality of life, obstetric fistula, surgical repair, questionnaire WHOQOL-BREF, DRC

Introduction

Obstetric fistula (OF), a devastating complication of childbirth, remains a tragic reality in many parts of the world, particularly in low-resource countries. OF is characterized by an abnormal communication between the genital tract and

the urinary or gastrointestinal tract, leading to persistent urinary or fecal incontinence. Research has documented the enormous physical and psychosocial consequences of living with OF,¹ including the impact that persistent incontinence has on one's quality of life (QoL). OF patients are often exposed to social stigma, isolation, and psychological distress,² which negatively impacts their QoL and wellbeing. Added to this is the emotional impact these women suffer following the deaths of their newborns, in most cases, and their abandonment by their husbands.

The World Health Organization (WHO) defines QoL as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. Women suffering from OF often experience a significant decline in their QoL, which has profound repercussions on their self-esteem, interpersonal relationships and social engagement. Additionally, the social stigma associated with OF contributes to patients' feelings of isolation and emotional distress.^{2,3} Surgical repair of obstetric fistula (SROF) is widely regarded as the standard treatment for restoring urinary and/or fecal continence in affected patients. High success rates of fistulas repair surgery have been recently shown worldwide, particularly in centres with experience.⁴

There have been a few previous studies examining the impact of surgical OF repair on QoL among women with OF. For example, Chimamise et al⁵ showed a significant improvement in QoL after surgical repair among OF patients in Zimbabwe. Similarly, Debela et al⁶ in Ethiopia reported that all areas of QoL showed significant improvement after successful SROF. SROF, which aims to restore anatomical integrity, offer a glimmer of hope for alleviating the physical and psychosocial sequelae of this debilitating condition. However, there remains a significant gap in the literature regarding a thorough evaluation of QoL changes among OF patients before and after surgical repair, particularly in the context of the DRC.⁷ Therefore, further studies are needed to better understand the impact of SROF on patients' QoL, using larger samples, standardized measurement tools, and in different settings.⁸

The objective of this study was to evaluate QoL among OF patients before and after surgical repair. To offer a comprehensive assessment, we examined various dimensions of QoL, including physical, psychological, social, and environmental aspects. We employed the World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire, a cross-cultural validated tool by the World Health Organization (WHO), to facilitate this evaluation.

Materials and Methods

We conducted a longitudinal study from November 2022 to October 2023, using the standard WHOQOL-BREF tool to assess the QoL of study participants both before and after surgical repair. Data on the QoL before surgical repair were collected from each patient at the healthcare facility where they underwent surgery. The study sample consisted of women recruited and cared for during OF campaigns that were conducted free of charge in various provinces of the Democratic Republic of Congo (DRC). These campaigns were organized by the non-governmental organization HEAL Africa in collaboration with the DRC's National Ministry of Public Health. Surgical interventions in North Kivu province were performed at the HEAL Africa Hospital in Goma and the General Referral Hospital (GRH) in Beni. In five other provinces, the surgical procedures were conducted at the general referral hospitals (GRH) specific to each province, namely GRH Wamba (Haut-Uélé province), GRH Lukonga (Kasaï Central province), GRH Dr. Amu-Yasa-Bonga (Kwilu province), GRH Kipaka and GRH Kasongo (Maniema province), and GRH Karawa (Nord-Ubangi province).

The second phase of data collection occurred roughly six months after the SROF, primarily conducted through home visits to all patients. Study participants consisted of patients with OF, regardless of its type or anatomical localization or duration, who had sought care at the above-mentioned healthcare facilities. Inclusion in the study was contingent upon patients' willingness to participate and their provision of written informed consent for both the initial and follow-up interviews. Patients who declined to participate in the research were excluded. To ensure patients were adequately prepared for surgery, they were admitted to the center a few days before the surgical procedure. It was during this waiting period that participants were recruited for the study, and information assessing their QoL prior to surgical repair was collected. The research objectives and procedures were explained to patients at the time of surgical repair. The principal investigator, who also served as the lead surgeon, provided a comprehensive explanation of all aspects of the study to each participant. This included details about the procedures, potential advantages, and disadvantages, as well as the importance of collecting follow-up data. The need for a follow-up interview, scheduled for approximately six months

after the SROF, whether in clinical consultations or through home visits, was also clearly communicated. Informed written consent for participation in the study was formally obtained from all participants.

Data were collected using the WHOQOL-BREF questionnaire, a shortened version of the WHOQOL-100 designed by the WHO to assess the impact of illness and disability on daily activities and behavior. Questionnaires were administered twice: first before surgical repair and then at minimum 6 months post-SROF for all patients. Literate patients independently completed the questionnaire after receiving instructions, while illiterate patients underwent a face-to-face interview. The WHOQOL-BREF questionnaire is multidimensional and comprises 26 questions, with 24 of those divided into four domains: physical, psychological, social, and environmental. The remaining two questions independently assess QoL and health-related satisfaction. The physical health domain encompasses daily activities, medication and medical aid reliance, energy levels, mobility, pain, sleep, and work capacity. The psychological health domain evaluates body image, emotions, self-esteem, spirituality, beliefs, thinking, and memory. The social domain examines social relationships, encompassing personal relationships, social support, and sexual activity. Finally, the environmental domain assesses the personal environment, exploring financial resources, freedom, safety, health care, family environment, learning opportunities, participation, recreation, physical environment, and transportation. WHOQOL-BREF questions use a five-point Likert response scale to assess intensity, ability, frequency, and satisfaction within each of the four domains.

Raw WHOQOL-BREF scores were transformed into adjusted scores using SPSS syntax. This conversion directly scales the raw score into an adjusted score for each domain, ranging from 0 to 100, enabling comparisons between domains, even if they include a different number of items. The use of five-level scores is recommended for their ability to measure extremes and intermediate scores for accessibility.⁹ Continuous variables were summarized as means with standard deviations (SD) and categorical variables were summarized as frequencies with proportions. The mean score in each domain was obtained by calculating the mean of the transformed scores converted to a 0–100 scale for each domain. To compare the mean QoL scores across different domains before and after surgical repair, we employed Student's *t*-test or ANOVA. A *p*-value of less than 0.05 in the comparison tests indicated a statistically significant difference. All data analyses were conducted using STATA version 16 statistical software.

Results

A total of 158 OF patients were included in the study. Among the respondents, 71 (44.9%) fell within the 30–39 age group, with 38 (24.1%) belonging to the 40+ age category. On average, the respondents were 33.51 ± 9.63 years old. Of the participants, 123 (77.9%) resided in rural areas, while 35 (22.2%) lived in urban areas. In terms of marital status, 96 (60.8%) were married, while 27 (17.1%) were either divorced or separated from their husbands due to fistula. Nearly half (49.4%) of the respondents had no formal education (illiterate), 67 (42.41%) had completed primary education, and 11 (6.96%) had secondary education. The majority (79.8%) of the study participants were engaged in professional activities. Regarding religion, 38.6% of the respondents identified as Protestant/Pentecostal, while 45 (28.5%) were Catholic (Table 1).

At the time when fistula occurred, 68 (43%) of the respondents had given birth at a health center, 63 (39.9%) at a referral hospital, and 27 (17.1%) at home. Among the participants, 90 (57%) had had a vaginal delivery, while 68 (43%) had undergone a caesarean section. The average age at the onset of OF was 24.99 ± 7.81 years, with 46 (29.1%) experiencing OF before the age of 20. The average parity was 3.39 ± 2.57 , and 58 (36.7%) were first-time mothers. The average duration of fistula was 6.83 ± 6.01 years, and 96 (60.8%) participants had had their fistulas for less than 5 years. Among study participants, 137 (86.7%) reported that the fetus did not survive the labor during which the fistula developed. In terms of the type of fistula, 114 (72.2%) had a urogenital fistula, 37 (23.4%) had a recto-vaginal fistula, and 7 (4.4%) had a combination of both types. SROF was successful in 127 (80.4%) participants, 9 cases (5.7%) had fistula closure but with persistent incontinence, and 22 patients (13.9%) had non-closure of the fistula despite undergoing surgery (Table 2).

Table 3 shows the means, standard deviations and differential values for each WHOQOL-BREF item. Items 1 and 2 were general questions on QoL and overall health. Three items (numbers 3, 4 and 26) were reverse scored. Mean scores before surgical repair were lower than mean scores after surgical repair on all 26 questionnaire items and all differences were highly statistically significant ($p < 0.001$).

Table 1 Socio-Demographic Characteristics of the 158 Respondents

Variable	Frequency (N=158)	Percentage
Age		
15–19 years	11	7
20–29 years	38	24.1
30–39 years	71	44.9
≥40 years	38	24.1
Mean (±Standard Deviation)	33.51	(±9.63)
Residence		
Rural	123	77.9
Urban	35	22.2
Marital status		
Married	96	60.8
Divorced	27	17.1
Single	21	13.3
Widow	14	8.9
Level of Education		
No	78	49.4
Primary	67	42.4
Secondary	11	7
College/University	2	1.3
Profession		
Employed	126	79.8
Unemployed	32	20.3
Religion		
Protestant/Pentecostal	61	38.6
Catholic	45	28.5
Methodist	19	12
No religion	17	10.8
Muslim	16	10.1

Table 2 Obstetric Fistula Characteristics Among the 158 Respondents

Variable	Frequency (n=158)	Percentage
Place of delivery when OF developed		
Health Center	68	43
Referral Hospital	63	39.9
At home	27	17.1
Mode of delivery when OF developed		
Vaginal route	90	57
Caesarean section	68	43
Age when OF developed		
<20 years	46	29.1
20–29 years	72	45.6
≥30 years	40	25.3
Mean (±Standard Deviation)	24.99	(±7.81)

(Continued)

Table 2 (Continued).

Variable	Frequency (n=158)	Percentage
Parity when OF developed		
1	58	36.7
≥2	100	63.3
Mean (±Standard Deviation)	3.39	(±2.57)
Neonatal outcome when OF developed		
Alive Newborn	21	13.3
Neonatal death	137	86.7
Duration of OF		
<5 years	96	60.7
≥5 years	62	39.2
Mean (±Standard Deviation)	6.83	(±6.01)
Type of OF		
Uro-genital	114	72.2
Recto-vaginal	37	23.4
Both uro-genital and recto-vaginal	7	4.4
Result of SROF		
Closed, dry fistula	127	80.4
Closed fistula but persistent incontinence	9	5.7
Unclosed fistula	22	13.9

Table 3 WHOQOL-BREF Item Scores in 158 of Patients Before and After Surgical Repair

Items	Before Repair (N=158)	After Repair (N=158)	t-test	p-value	Mean Difference	95% Confidence Interval of the Difference	
	Mean (SD)	Mean (SD)				Lower	Upper
Overall Quality of Life (1)	1.58 (0.63)	3.83 (0.89)	-24.38	<0.0001	-2.25	-2.44	-2.07
Overall Health (2)	1.66 (0.70)	3.75 (0.85)	-22.58	<0.0001	-2.09	-2.28	-1.91
Physical Pain (3)	3.81 (0.71)	2.33 (0.52)	20.66	<0.0001	1.48	1.34	1.62
Medical Treatment Dependency (4)	3.25 (1.21)	2.28 (0.64)	7.47	<0.0001	0.97	0.71	1.22
Positive Feelings (5)	1.24 (0.43)	3.49 (1.16)	-23.57	<0.0001	-2.25	-2.44	-2.06
Personal Beliefs (6)	1.39 (0.51)	3.56 (1.20)	-19.86	<0.0001	-2.17	-2.39	-1.95
Concentration (7)	1.61 (0.66)	3.59 (0.98)	-20.18	<0.0001	-1.98	-2.17	-1.79
Security (8)	1.63 (0.68)	3.41 (1.02)	-17.61	<0.0001	-1.78	-1.98	-1.58
Personal Environment (9)	1.87 (0.79)	3.46 (0.87)	-17.09	<0.0001	-1.59	-1.77	-1.41
Energy (10)	1.67 (0.59)	3.56 (0.90)	-21.55	<0.0001	-1.89	-2.06	-1.71
Physical Appearance (11)	2.19 (0.55)	3.39 (0.98)	-15.98	<0.0001	-1.19	-1.34	-1.05
Financial Support (12)	1.33 (0.50)	2.09 (0.70)	-10.88	<0.0001	-0.76	-0.90	-0.62
Accessibility of Information (13)	1.39 (0.49)	2.29 (0.60)	-14.89	<0.0001	-0.90	-1.02	-0.78
Leisure activities (14)	1.00 (0.00)	2.57 (0.83)	-23.71	<0.0001	-1.57	-1.70	-1.44

(Continued)

Table 3 (Continued).

Items	Before Repair (N=158)	After Repair (N=158)	t-test	p-value	Mean Difference	95% Confidence Interval of the Difference	
	Mean (SD)	Mean (SD)				Lower	Upper
Mobility (15)	2.40 (0.55)	3.80 (0.75)	-21.61	<0.0001	-1.40	-1.53	-1.27
Sleep & Rest (16)	1.94 (0.65)	3.60 (0.84)	-21.75	<0.0001	-1.66	-1.81	-1.51
Daily Activities (17)	2.05 (0.39)	3.58 (0.74)	-25.24	<0.0001	-1.53	-1.65	-1.41
Ability to Work (18)	1.94 (0.57)	3.64 (0.80)	-22.00	<0.0001	-1.69	-1.85	-1.54
Self-Esteem (19)	2.26 (0.59)	3.59 (0.95)	-16.71	<0.0001	-1.33	-1.49	-1.17
Personal Relationships (20)	1.97 (0.44)	3.66 (0.77)	-22.39	<0.0001	-1.68	-1.83	-1.53
Sex Life (21)	1.93 (0.67)	3.50 (0.89)	-17.11	<0.0001	-1.57	-1.75	-1.39
Social Support (22)	2.44 (0.49)	3.63 (0.82)	-17.09	<0.0001	-1.19	-1.33	-1.05
Family Environment (23)	2.37 (0.53)	3.61 (0.88)	-15.91	<0.0001	-1.24	-1.39	-1.09
Access to Health Care (24)	1.77 (0.57)	3.45 (0.82)	-21.49	<0.0001	-1.68	-1.84	-1.53
Transportation (25)	2.04 (0.68)	2.92 (0.55)	-13.93	<0.0001	-0.87	-1.00	-0.75
Negative Feelings (26)	3.59 (0.69)	1.28 (0.55)	32.43	<0.0001	2.31	2.17	2.45

Abbreviation: SD, Standard Deviation.

Table 4 presents a comparison of mean QoL scores across the four different domains among the 158 patients before and after SROF. In the physical QoL domain, the mean score was 28.37 ± 8.72 before SROF, which significantly increased to 66.32 ± 14.38 after surgical repair ($p < 0.0001$). For the psychological domain, the mean score was 21.28 ± 7.58 before surgical repair, and it notably improved to 68.09 ± 21.27 after surgical repair, which was a statistically significant difference ($p < 0.0001$). In the social domain, the mean score was 27.90 ± 8.67 before surgical repair and increased to 64.92 ± 18.48 after surgical repair, with a significant difference between the two ($p < 0.0001$). Regarding the environmental domain, the mean score was 16.91 ± 7.22 before surgical repair, and it showed a significant increase to 49.41 ± 14.82 after surgical repair ($p < 0.0001$).

Table 5 shows participants' mean QoL scores in all four domains as a function of SROF outcome. There were highly statistically significant differences in QoL between mean scores ($p < 0.0001$) reflecting better QoL in patients with closed fistula and continence compared to those with closed fistula but incontinent or those with non-closed fistula.

Table 4 Mean QoL Scores Across Four Domains Before and After SROF

Domain	Mean Score Before Repair (n=158)	Mean Score After Repair (n=158)	t-test	p-value	Mean Difference	95% Confidence Interval of the Difference	
						Lower	Upper
Physical Domain	28.37 (8.72)	66.32 (14.38)	-25.45	<0.0001	-37.95	-40.90	-35.01
Psychological Domain	21.28 (7.58)	68.09 (21.27)	-26.76	<0.0001	-46.81	-50.26	-43.35
Social Domain	27.90 (8.67)	64.92 (18.48)	-22.41	<0.0001	-37.02	-40.29	-33.76
Environmental Domain	16.91 (7.22)	49.41 (14.82)	-26.77	<0.0001	-32.50	-34.89	-30.10

Table 5 Mean QoL Scores Across Four Domains Before and After SROF Based on Surgical Outcome

Domain	Closed and Dry Fistula (n=127)	Closed Fistula but Incontinence (n=9)	Unclosed Fistula (n=22)	F-test	p-value (ANOVA)
Physical Domain	72.69 (5.97)	41.27 (5.39)	39.77 (8.27)	330.40	<0.0001
Psychological Domain	78.08 (6.13)	31.02 (7.25)	25.57 (7.19)	805.62	<0.0001
Social Domain	73.03 (8.62)	33.33 (5.89)	31.06 (8.21)	298.19	<0.0001
Environmental Domain	56.15 (5.28)	21.53 (6.34)	21.87 (7.59)	452.25	<0.0001

Discussion

According to the WHO, QoL is the subjective perception of one's own life situation, assessed within the cultural context and value systems in which one lives, and in relation to one's own goals, expectations, norms and concerns.¹⁰ The WHOQOL-BREF questionnaire developed by the WHO is a cross-cultural instrument, focusing broadly on all domains of QoL (physical, psychological, social and environmental). It is considered the most useful instrument for assessing QoL.

The aim of this study was to assess the impact of OF and reconstructive surgery on patients' QoL across physical, psychological, social, and environmental domains using the WHOQOL-BREF assessment tool. Our findings demonstrate a significant improvement in QoL scores after OF surgical repair across all domains among 158 patients. Overall, the study highlights that corrective surgery is useful for improving physical, psychological, social, and environmental health and wellbeing among patients with OF.

More specifically, our results indicate that surgical repair of OF has a substantial positive impact on the physical aspects of QoL. These findings align with prior research emphasizing the effectiveness of OF reconstructive surgery in enhancing the physical well-being of patients.^{5,6,11–13} OF-related symptoms, such as urinary and/or fecal incontinence, recurrent infections, and pelvic pain, can severely limit mobility and daily autonomy, leading to a deteriorating cycle where each symptom exacerbates physical decline. Successful surgical repair addresses these physical symptoms of incontinence, pain, recurrent infections, and limited mobility, thereby improving QoL.

Psychologically, our study demonstrates a substantial improvement in QoL, with a significant increase from pre-operative to post-operative scores. This aligns with previous research by Chimamise et al⁵ and emphasizes the psychological benefits of successful OF surgery. The relief from urinary/fecal incontinence, malodors, and other OF-related symptoms allows patients to regain concentration, self-confidence, self-esteem, positive emotions, and a healthier self-image, all contributing to improved psychological health.

Similarly, our study reveals a notable enhancement in the social domain of QoL following surgical repair. These findings are consistent with previous research demonstrating the positive relationship between OF reconstructive surgery and QoL from a social perspective.^{5,6,11,13,14} OF patients often experience discrimination, stigmatization, and rejection within their families and communities,^{2,15} compromising their social well-being. Successful surgical repair enables these patients to reintegrate socially, participate in familial and community activities, and regain self-confidence.⁵

In the environmental domain, the overall QoL score significantly improved following surgery. Specifically, participants reported higher scores on aspects such as leisure activities, personal finances, daily living activities, and mobility after surgery. This improvement can be attributed to patients' ability to resume daily activities without the burden of OF-related symptoms, enabling them to work, engage in leisure activities, and perform daily tasks freely.

In summary, our study demonstrates that QoL scores across all domains significantly improved in OF patients after successful reconstructive surgery. Given that OF patients often face debilitating consequences such as urinary and/or fecal incontinence, associated unpleasant odours, psychological distress, and social stigma, it is critical to improve the accessibility of SROF to improve QoL and overall wellbeing among affected women.

The questionnaire used in the present study is a WHO-validated questionnaire, which is general and not specific to OF patients. To our knowledge, there is currently no validated questionnaire specifically designed to assess the quality of life of women with OF. Thus, some aspects specific to OF patients have not been considered, such as the emotional impact on these

patients of losing their newborns and being abandoned by their husbands. The same applies to the analysis of the impact on quality of life of the post-traumatic stress these patients experience as a result of the tragedy caused by the fistula in their lives and bodies. In future research, the analysis of such an impact should be considered.

Conclusions

This study demonstrated significant impairments across all domains of QoL among OF patients before surgical repair, with substantial improvements observed after the surgery. Successful OF reconstructive surgery not only provides relief from the physical burdens of OF but also empowers patients to reintegrate into their familial and societal roles, contributes to the mitigation of social disparities, and ultimately fosters improved QoL. These results underscore the importance of improving access to high-quality surgical repair services as a fundamental right for OF patients and incorporating these SROF services into comprehensive reproductive health programs. The profoundly positive impact of successful surgical repair on patients' QoL emphasizes the need for sustained efforts in raising awareness, preventing and treating OF, and offering a brighter future for patients, their families, and their communities. Preventive strategies and strategies to increase the request of medical attention have to be taught to all young women before marriage, pregnancy and delivery: the most important preventive strategies, like education, family counselling, care during pregnancy, instructions to traditional care centers to encourage them to refer women to health care official centers, should be mentioned.

Abbreviations

DRC, Democratic Republic of Congo; OF, Obstetrical fistula; QoL, Quality of life; SROF, Surgical repair of obstetrical fistula; WHO, World Health Organization; WHOQOL-BREF, World Health Organization Quality of Life-BREF.

Data Sharing Statement

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Ethics Approval and Informed Consent

The study obtained the approval of the Medical Ethics Committee of the University of Goma (Approval No.: UNIGOM/CEM/011/2022). Informed consent was obtained from all the participants in the current study. All methods adhered to the guidelines for the ethical review of research involving human subjects in the Democratic Republic of the Congo as well as the 1964 Declaration of Helsinki. Participants under the age of 18 gave their assent after obtaining informed consent from their parents/guardians.

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Disclosure

The authors declare no conflicts of interest in the course of conducting this study.

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