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RESEARCH ARTICLE

Impact of surgical repair on the patients' quality of life with cleft lip and palate in the DRC: A longitudinal study using the CLEFT-Q scale

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Abstract: Introduction: Cleft lip and/or palate (CLP) are congenital anomalies that can have profound impacts on individuals' lives, physically, emotionally and socially. In this context, patients' quality of life (QoL) is of paramount importance to evaluate the effectiveness of surgical interventions and improve patient-centered care. The objective of this study was to evaluate the QoL of patients with CLP in the Democratic Republic of the Congo (DRC) before and after surgical repair, using the CLEFT-Q scale as a standardized measurement tool. Methods: This longitudinal study was conducted between January and April 2024, involving 43 patients aged 8 to 29 years with CLP. The French version of the CLEFT-Q scale was utilized to evaluate various aspects of QoL both pre- and post-surgical intervention. Results: the study revealed a significant enhancement in all facets of QoL assessed by the CLEFT-Q following surgical repair. Mean scores exhibited a statistically notable increase across all scales post-intervention. Furthermore, noticeable variations were noted among facial cleft types, indicating varying effects on QoL based on the particular cleft type. Conclusion: This study underscores the significance of surgical repair in enhancing the QoL of individuals with CLP in the DRC. It also emphasizes the necessity of a personalized approach considering the distinct type of facial cleft to maximize treatment outcomes.

Keywords: cleft lip and palate, quality of life, reconstructive surgery, CLEFT-Q, DRC

1 Introduction

Cleft lip and/or palate (CLP) represent a group of birth defects that can have profound effects on individuals' physical, emotional, and social well-being. These conditions are characterized by openings or splits in the upper lip, palate, or both, and occur due to incomplete fusion during early fetal development. The global incidence of CLP varies, but it remains a significant concern due to the multifaceted challenges it presents for affected individuals [1].

CLPs are of significant importance, not only due to the inherent medical complexities linked with them but also because of the sociocultural implications that can result in patient stigma and isolation [2, 3]. In numerous regions worldwide, individuals with CLP encounter numerous obstacles in accessing timely and efficient treatment, which may involve surgical repair, dental care, speech therapy, and psychosocial support [4]. These challenges are further magnified in resource-constrained settings like the Democratic Republic of the Congo (DRC), where access to adequate healthcare services is frequently restricted and specialized services are scarce [5, 6].

The concept of quality of life (QoL) is particularly relevant in the context of CLP, as it encompasses a wide range of human experiences, including physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship with salient features of the environment. Patient-reported outcomes are essential for understanding QoL, as they provide a window into individuals' lived experiences, reflecting their subjective assessment of their well-being and satisfaction with the treatments received. The CLEFT-Q, an innovative

patient-reported outcome measure, was specifically designed to capture the unique concerns and experiences of people with CLP [7,8]. The CLEFT-Q is a rigorously developed instrument that is used internationally to collect and compare evidence-based data on outcomes of patients aged 8 to 29 years with CLP [8]. This instrument represents a significant advancement in the field of cleft care, providing a comprehensive and validated tool to assess a wide range of outcomes relevant to patients with CLP. Its development involved a significant international effort, encompassing psychometric analyses and the establishment of normative values based on a large sample of children and young adults from various countries [7,9]. This global perspective ensures the applicability of the CLEFT-Q in different cultural and healthcare contexts, making it an invaluable instrument for clinicians and researchers.

Despite the availability and proven effectiveness of the CLEFT-Q, its adoption has been limited in some regions, particularly sub-Saharan Africa, highlighting an important gap in current clinical practice and research. The underutilization of such a robust tool in these areas suggests a missed opportunity to improve the delivery of patient-centered care and fully understand the impact of CLP on individuals' lives [10].

To address this deficiency, our current study seeks to introduce the CLEFT-Q in the DRC to evaluate the QoL of individuals with CLP both pre- and post-surgical correction. This research endeavor will offer a comprehensive and informative evaluation of the QoL of those with CLP in the DRC utilizing the CLEFT-Q as a standardized assessment tool. The outcomes of this investigation are poised to make a substantial contribution to the understanding of the care provided to individuals with CLP, especially within developing countries.

2 Materials and methods

This longitudinal study was conducted between January 2023 and April 2024, utilizing the French version of the CLEFT-Q to assess the QoL before and after surgical repair in 43 patients aged 8 to 29 years with CLP. The CLEFT-Q comprises 12 scales that evaluate various aspects such as appearance (face, nose, nostrils, lip, cleft lip scar, teeth, and jaw), facial function (speech), and health-related QoL (psychological function, school function, social function, and speech-related distress). Additionally, a thirteenth scale focuses on "eating and drinking" [8].

The questionnaires were administered to patients or their parents/guardians during hospitalization for primary or secondary surgical repair of the CLP. They were instructed to complete the questionnaires together at least one week before and three months after surgery. For patients who were not fluent in French, a non-study health professional assisted them in completing the questionnaire. All patients underwent surgical treatment based on the specific type of CLP they had. The recruitment and surgeries took place at the HEAL Africa hospital in Goma, located in the North Kivu province of the DRC. A clinical form, filled out by a research team member, was used to identify the type of cleft present, which included cleft lip isolated (CL), cleft lip and alveolar (CLA), and cleft lip and palate (CLP).

Data was collected using the CLEFT-Q questionnaire. Once the CLEFT-Q scales were finalized, CLEFT-Q scores for each participant were calculated by converting logits to scores on a scale of 0 to 100 using the Rasch transformation strategy [8]. The type of cleft was determined from the clinical form. A higher score on each scale indicates a better or more satisfactory result. Twelve of the 13 scales have conversion tables, while the eating/drinking scale is used as an independent scale without the Rasch transformation strategy.

Continuous variables were summarized as mean with standard deviation (SD), and categorical variables were summarized using frequencies and percentages. The mean scores of the different scales before and after surgical repair were compared using a Student t test or ANOVA. The differences between the mean scores before and after surgical repair, along with their 95% confidence intervals (95% CI), were also calculated. A p-value < 0.05 from the comparison tests indicated a statistically significant difference. Data analysis was conducted using STATA version 16 statistical software.

The research protocol was authorized by the Medical Ethics Committee of the University of Goma (Approval number: UNIGOM/CEM/013/2022). Throughout the study, we rigorously respected the ethical principles outlined in the Declaration of Helsinki. This ensured the informed consent of the participants, the confidentiality of their data, and respect for their well-being. Prior to any interview, we obtained informed consent from each participant, without providing any financial incentive. We provided detailed information about the study to each patient or their parent/guardian for those under 18 years of age. Participants had the opportunity to ask questions and seek clarification before giving consent. We scrupulously preserved the

confidentiality of the participants and reminded them of their right to withdraw from the study at any time, without the need for justification, and without facing any risk of reprisals or consequences on their treatment.

3 Results

Table 1 presents the demographic characteristics of patients who participated in the study; a total of 43 patients with CLP were included. The mean age of the respondents was 19.07 ± 0.94 years. Twenty-four (55.8%) of the respondents were female and 19 (44.2%) were male. Thirty (69.8%) of the respondents were single while 13 (30.2%) of the participants were married. More than half (53.5%) of the respondents were at primary level, 18 (41.9%) were at secondary level and 2 (4.6%) were at university level. A total of 24 (55.8%) patients had CLA, 15 (34.9%) patients had CL and 4 (9.3%) patients had CLP.

Table 1 Demographic characteristics of patients who participated in the study (Age (years) = 19.07 ± 0.94)

Variable	Number (n = 43)	Percentage (%)
Sex		
Feminine	24	55.8
Male	19	44.2
Marital status		
Single	30	69.8
Married	13	30.2
Educational level		
Primary	23	53.5
Secondary	18	41.9
University	2	4.6
Type of cleft		
CLA	24	55.8
CL	15	34.9
CLP	4	9.3

Table 2 presents the comparison of mean scores of the CLEFT-Q scales before and after surgical repair. We found that all scales were statistically lower before surgical repair than after surgical repair ($p < 0.01$). The mean differences in scores were as follows: face scale -62.42; jaws scale -40.46; lips scale -73.37; nose scale -45.35; nostril scale -45.09; teeth scale -26.88; psychological function scale -47.60; social function scale -23.30; school function scale -20.05; speech distress scale -22.18; speech function scale -17.79; and eating/drinking scale -3.37.

Table 2 Comparison of mean scores of the CLEFT-Q scales before and after surgical repair

Measured scale	Mean score±SD before repair	Mean score±SD after repair	t-test	p-value	Mean difference	Lower	Upper
Appearance scales							
Face	23.98±23.17	86.40±16.63	-14.35	< 0.0001	-62.42	-71.07	-53.77
Jaws	50.39±27.08	90.86±15.16	-8.55	< 0.0001	-40.46	-49.88	-31.05
Lips	10.09±22.04	83.47±18.17	-16.84	< 0.0001	-73.37	-82.03	-64.71
Nose	43.86±24.81	89.21±17.56	-9.78	< 0.0001	-45.35	-54.57	-36.13
Nostrils	42.44±27.63	87.53±18.26	-8.93	< 0.0001	-45.09	-55.14	-35.05
Teeth	18.70±28.00	45.58±27.40	-4.50	< 0.0001	-26.88	-38.77	-15.00
Cleft lip scar	-	79.09±2.93	-	-	-	-	-
Health-related quality of life scales							
Psychological function	34.07±19.99	81.67±17.52	-11.74	< 0.0001	-47.60	-55.67	-39.54
School function	35.67±30.58	55.72±37.22	-2.73	0.0077	-20.05	-34.66	-5.44
Social function	43.60±18.89	66.91±13.88	-6.52	< 0.0001	-23.30	-30.41	-16.19
Speech-related distress	61.05±23.88	83.23±21.58	-4.52	< 0.0001	-22.18	-31.94	-12.43
Facial function scales							
Eat/drink	27.02±5.09	30.39±2.08	-4.02	0.0001	-3.37	-5.04	-1.70
Speech	68.70±28.11	86.49±25.54	-3.42	0.0009	-17.79	-28.11	-7.47

Table 3 presents the comparison of mean scores of the CLEFT-Q scales between the different types of CLP before surgical repair. Compared to CL and CLP, we found that CLA presented significantly higher mean scores for the scales of teeth ($p = 0.0027$), psychological function ($p =$

0.0431), social function (p = 0.0225), speech-related distress (p = 0.0151), and speech function (p = 0.0225). Furthermore, the mean lip scale score was statistically higher in patients with CLP than in patients with CL or CLA (p = 0.0235).

Table 3 Mean CLEFT-Q scale scores by cleft type before surgical repair

Measured scale	CLA (n = 24)	CL (n = 15)	CLP (n = 4)	F-test	p-value
Appearance scales					
Face	17.47±24.29	24.67±20.19	44.25±29.57	2.26	0.1173
Jaws	56.00±29.32	44.62±25.23	64.00±26.58	1.40	0.2593
Lips	11.80±25.84	4.67±10.81	36.25±40.31	4.12	0.0235
Nose	44.27±27.29	40.45±23.21	62.75±21.06	1.41	0.2551
Nostrils	35.73±31.29	42.71±24.13	66.00±26.23	1.98	0.1504
Teeth	36.60±33.95	6.63±16.19	24.00±28.01	6.86	0.0027
Health-related quality of life scales					
Psychological function	43.40±26.39	27.46±12.99	38.75±15.37	3.41	0.0431
School function	49.07±34.30	26.00±22.96	43.50±42.84	3.04	0.0591
Social function	76.07±31.78	69.92±23.17	33.75±18.04	4.18	0.0225
Speech-related distress	71.13±25.58	59.25±20.34	34.00±15.68	4.66	0.0151
Facial function scales					
Eat/drink	28.60±5.42	26.29±5.13	25.50±1.91	1.16	0.3249
Speech	76.07±31.78	69.92±23.17	33.75±18.04	4.18	0.0225

Table 4 presents the comparison of mean scores of the CLEFT-Q scales between the different types of CLP after surgical repair. In comparison to CL and CLP, it was found that CLA exhibited significantly higher mean scores for the scales of teeth (p = 0.0481), psychological function (p = 0.0131), school function (p = 0.0041), social function (p = 0.0015), and speech function (p = 0.0041).

Table 4 Mean CLEFT-Q scale scores by cleft type after surgical repair

Measured scale	CLA (n = 24)	CL (n = 15)	CLP (n = 4)	F-test	p-value
Appearance scales					
Face	92.53±13.82	82.29±17.37	88.00±18.49	1.84	0.1718
Jaws	96.20±10.65	87.92±16.72	88.50±18.06	1.46	0.2438
Lips	87.60±17.34	79.92±18.81	89.25±16.60	1.05	0.3590
Nose	93.40±14.41	87.21±19.46	85.50±17.52	0.66	0.5219
Nostrils	92.80±14.90	85.17±19.70	82.00±20.78	1.01	0.3736
Teeth	58.87±31.13	39.96±21.77	29.50±29.58	3.28	0.0481
Cleft lip scar	84.60±16.41	76.50±20.95	74.00±17.64	0.97	0.3868
Health-related quality of life scales					
Psychological function	90.13±15.16	74.87±16.34	90.75±18.50	4.84	0.0131
School function	89.73±22.63	89.29±13.53	57.50±10.85	6.32	0.0041
Social function	76.67±16.96	62.21±8.67	58.50±5.74	7.65	0.0015
Speech-related distress	87.93±26.54	84.17±17.55	60.00±5.67	2.95	0.0639
Facial function scales					
Eat/drink	31.33±1.63	30.00±2.21	29.25±1.89	2.77	0.0745
Speech	89.73±22.63	89.29±13.52	57.50±10.85	6.32	0.0041

4 Discussion

Our research aimed to explore the application of the CLEFT-Q as a patient-reported tool to assess the QoL of individuals with CLP in the DRC. This was achieved by capturing patients' perspectives before and after surgical interventions. The CLEFT-Q, with its established psychometric properties validated by Klassen et al. [8], provided a robust foundation for our study. Previous utilization of this tool in international research with varied populations, as documented by Wong Riff et al. [7], added to its credibility and applicability in our specific study context.

Our results were in line with the intended purpose of the instrument, demonstrating significant enhancement in all the measured scales of the CLEFT-Q after surgical interventions. This observation aligns with the documented substantial improvements in post-operative QoL for CLP patients, consistent with the experiences of individuals from various cultural and geographical contexts, as highlighted by Klassen et al. [8] and supported by Wong Riff et al. [7].

When we examined the CLEFT-Q scale scores, we observed statistically significant improvements across all dimensions following surgical repair, with p-values below the 0.01 threshold. Specifically, the face and lips scales demonstrated notable enhancements, with mean score differences of -62.42 and -73.37, respectively. These findings align with the findings of Michael and Olusanya [10], emphasizing the efficacy of the CLEFT-Q in capturing the beneficial impacts of palatoplasty on patients' well-being.

An intriguing aspect of our study was the examination of mean CLEFT-Q scores across various CLP types, both pre- and post-surgery. The data indicated that patients with CLA consistently exhibited higher scores on scales related to teeth, psychological function, social function, and speech distress before surgery in comparison to those with CL and CLP. Following surgical intervention, a similar trend was observed, suggesting that the specific type of facial cleft plays a crucial role in influencing the QoL dimensions affected. This finding is in line with the conclusions drawn by Wong Riff et al. [7], who also noted disparities in outcomes based on the type of cleft, underscoring the nuanced impact of clefts on individual patients.

Evidence from our study in the DRC presents a compelling narrative that surgical interventions lead to substantial enhancements in the QoL for individuals with CLP, quantitatively assessed through the CLEFT-Q. Additionally, our findings underscore the significance of cleft type in influencing the extent and nature of effects on various QoL domains. This insight holds valuable implications for healthcare practitioners, particularly in settings with limited resources, in recognizing the holistic advantages that surgical interventions can provide for CLP patients.

The strengths of this study include its rigorous longitudinal approach in the DRC, as well as the use of the CLEFT-Q scale as a standardized measurement tool. This enabled in-depth analysis of patients' QoL and provided valuable data to improve patient-centered care in this setting. However, some limitations should be noted, including the limited sample size, which could limit the generalizability of the results. Additionally, the study did not take into account other potential factors that could influence patients' QoL, such as socioeconomic conditions or levels of access to healthcare. Finally, as the study was conducted in a single hospital center in the DRC, there could be regional variations in the results that were not explored.

5 Conclusion

Our study effectively utilized the CLEFT-Q in the DRC, showcasing its efficacy as a standardized tool for evaluating the QoL of CLP patients. The substantial enhancements across all CLEFT-Q scales post-surgery underscore the pivotal role of surgical access for individuals with CLP, especially in resource-limited settings. Furthermore, the distinct outcomes based on cleft morphology underscore the necessity for tailored patient care approaches and thorough postoperative monitoring. This research adds valuable insights to the current literature on patient-centered CLP care and acts as a compelling advocacy tool for enhancing healthcare systems in developing countries.

Abbreviations

95% CI:	95% confidence interval
CL:	cleft lip
CLA:	cleft lip and alveolar
CLP:	cleft lip and/or palate
DRC:	Democratic Republic of the Congo
QoL:	quality of life
SD:	Standard deviation
UNIGOM:	University of Goma.

Conflicts of interest

The authors declare that they have no conflict of interest.

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