Original Research

# Quality of life in patients with craniofacial anomalies: personal experience and review of literature

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## Abstract

**Background.** Craniofacial anomalies, particularly cleft lip and palate affecting 1 in 500 to 1 in 2,500 live births globally, exert profound influences on physical function, psychological well-being, and social integration throughout the entire life. While surgical advances have improved outcomes, the long-term impact on the quality of life remains incompletely understood, necessitating comprehensive evaluation of psychosocial outcomes following primary surgical repair.

**Methods.** We conducted a cross-sectional comparative study evaluating 85 pediatric patients aged 4-7 years with surgically repaired non-syndromic cleft lip and/or palate and their caregivers, compared to 90 age-matched healthy controls. All patients underwent standardized surgical repair with minimum 24-month postoperative follow-up. Quality of life was assessed using the validated KINDL questionnaire administered to both children and parents, measuring physical well-being, emotional well-being, self-esteem, family relationships, friendships, and school functioning. Statistical analysis employed independent-samples t-tests and chi-square tests with significance set at $p < 0.05$.

**Results.** Children with cleft conditions demonstrated overall quality of life scores comparable to healthy controls (82.15 ± 14.72 vs 83.78 ± 16.72, respectively; 1.9% difference, not statistically significant). However, self-esteem scores were significantly lower in the cleft group (78.17 ± 24.79 vs 83.49 ± 22.17, $p = 0.036$). Parental assessments yielded high overall scores (80.38 ± 12.41) but identified significant concerns in self-esteem (72.41 ± 16.82) and infirmity perception (72.15 ± 17.67) (both $p < 0.01$). Age-stratified analysis revealed that children requiring reinterventions and older children (6-7 years) demonstrated greater family-related quality of life concerns.

**Conclusions.** While children with surgically repaired cleft lip and/or palate achieve overall quality of life outcomes comparable to healthy peers, persistent self-esteem deficits indicate ongoing psychosocial challenges requiring comprehensive multidisciplinary intervention. These findings emphasize the need for holistic care approaches that integrate psychological support, targeted therapies, and family counseling to optimize both functional and psychosocial outcomes beyond primary surgical repair.

**Keywords:** craniofacial anomalies, cleft lip, cleft palate, quality of life, multidisciplinary care, questionnaire

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## Introduction

Craniofacial anomalies are a heterogeneous group of congenital malformations that disrupt the normal development of cranial and facial structures, ranging from relatively minor cosmetic variations to complex syndromic presentations involving multiple organ systems. The prevalence of craniofacial anomalies varies considerably by specific diagnosis, with orofacial clefts representing the most common manifestation, occurring in approximately 1 in 500 to 1 in 2,500 live births globally. This variability reflects both epidemiological differences across populations and inconsistencies in classification systems and diagnostic criteria across different healthcare systems [1-5].

The significance of craniofacial anomalies extends far beyond their immediate structural manifestations. These conditions create cascading effects that influence virtually every aspect of human development and experience, from fundamental physiological functions such as feeding, breathing, and hearing, to complex psychosocial phenomena including self-perception, social integration, and quality of life. The multifaceted nature of these impacts necessitates comprehensive, multidisciplinary approaches to care that extend across the entire lifespan, requiring coordination among diverse medical, dental, allied health, and psychosocial specialists [6-8].

Surgical treatment for cleft lip and palate involves multiple staged procedures spanning from infancy through adolescence, significantly improves anatomical and functional outcomes, yet quality-of-life (QoL) assessments reveal persistent challenges. While early repairs enhance speech intelligibility, facial aesthetics, and feeding capabilities, patients often report long-term deficits in psychosocial well-being (bullying, lower self-esteem, social anxiety) compared to peers.

Our study aimed to assess quality-of-life outcomes among Romanian pediatric patients who underwent surgical repair for cleft lip with or without cleft palate, as well as their caregivers.

## Methods

We performed a cross-sectional comparative study on 85 children aged 4-7 years who underwent surgical treatment for cleft lip and/or palate alongside their parents, compared to 90 age-matched healthy peers attending routine pediatric visits. All cleft repairs were performed at the St. Andrew Constanța County Emergency Clinical Hospital, using standard cheiloplasty (Millard – 68 cases, Tennison-Randall – 8 cases, other – 6 cases) and palatoplasty techniques (Von Langenbeck – 33 cases, Veau-Wardill-Kilner – 35 cases, other – 8 cases), with postoperative follow-up of at least 24 months.

Inclusion criteria for patients with cleft lip ± cleft palate included: non-syndromic cleft lip, cleft palate, or cleft lip and palate (unilateral or bilateral); complete medical documentation; completed primary and secondary surgical treatment; and written informed consent from parents or legal guardians for study participation.

Exclusion criteria for patients with cleft lip ± cleft palate included: genetic syndromes or intellectual disabilities, patients who failed to attend postoperative follow-up appointments, cases with incomplete medical records, patients treated outside the designated study period, and patients with postoperative follow-up shorter than 24 months.

The control group consisted of healthy children aged 4-7 years who presented for routine pediatric examinations but had no diagnosed medical conditions or craniofacial anomalies.

Data were systematically collected from medical records and through structured quality of life questionnaire administration to both children and their parents. Sociodemographic variables included age, gender, origin (urban/rural), and family history of clefts in first- or second-degree relatives. Clinical variables included cleft type classification (cleft lip and palate, isolated cleft lip, isolated cleft palate), laterality (unilateral right/left, bilateral), degree of involvement (incomplete/complete), gestational age at birth, birth weight, maternal toxic substance exposure during pregnancy (alcohol, tobacco, benzodiazepines, anticonvulsants), and presence of associated malformations.

Surgical variables included type of surgical intervention (cheiloplasty, palatoplasty, other procedures), surgical technique employed, patient age and weight at intervention, operative time, hospitalization length, intensive care unit hospitalization length, operative complications, and long-term surgical sequelae.

Operative complications were systematically documented, with particular attention to oronasal fistula requiring secondary surgical repair and velopharyngeal insufficiency necessitating pharyngoplasty procedures. Aesthetic and functional sequelae were comprehensively evaluated, including lip contour irregularities (oversize, discontinuity, asymmetry), labial deformities, nasal region distortions, persistent velopharyngeal insufficiency, and dento-facial anomalies. The assessment protocol incorporated both objective clinical measurements and subjective quality of life impact evaluations to provide comprehensive understanding of treatment outcomes from multiple perspectives.

Each child completed the Revised KINDL questionnaire—covering physical well-being, emotional well-being, self-esteem, family relationships, friendships, and school life—using a three-point scale. Parents filled out the Parental KINDL, which assesses the same domains with a five-point scale.

Statistical analyses were performed using SPSS v.26.0 (IBM Corp.). Descriptive statistics (means, standard deviations, medians, ranges, and proportions) were employed to characterize patient demographics, clinical

variables, and questionnaire scores. We verified internal consistency using Cronbach's alpha, then compared cleft and control groups via independent-samples t-tests or Mann–Whitney U tests for non-normal data. Categorical variables were analyzed with chi-square or Fisher's exact tests. Parent–child score agreement was assessed by Wilcoxon signed-rank tests. Significance was set at $p < 0.05$.

Written informed consent was obtained in all cases.

## Results

We evaluated 85 pediatric patients with various cleft conditions and their primary caregivers and compared results to those obtained from 90 healthy children and their caregivers. The patient population demonstrated a mean age of 5.9 ± 1.4 years with a slight male predominance of 46 males versus 39 females, yielding a male-to-female ratio of 1.16:1. The control group had a mean age of 5.6 ± 1.7 years with an equal male-to-female distribution.

The distribution of cleft types included cleft lip and palate (CLP) in 32 patients, isolated cleft lip (CL) in 28 patients, and isolated cleft palate (CP) in 25 patients. Notably, 14 patients required surgical reinterventions, with this need being predominantly observed in patients with palatal involvement (CP and CLP groups).

Post-surgical outcomes revealed generally improved quality of life compared to pre-treatment conditions, though specific functional and aesthetic sequelae persisted in measurable proportions of patients requiring additional interventions: orthodontic and orthognathic treatments for maxillary growth limitations, speech therapy for phonetic disorders, prosthetic reconstruction for dental growth anomalies, management of surgical scar-related discomfort, and otolaryngological interventions for breathing, phonation, and hearing complications.

The KINDL questionnaire was completed by all 85 children with cleft conditions and 90 healthy controls and demonstrated excellent overall internal validity with a global Cronbach's alpha coefficient of 0.827. Children with cleft conditions reported high overall quality of life scores with a mean of 82.15 ± 14.72, compared to healthy controls who scored 83.78 ± 165.72, representing only a 1.6-point difference (1.9% lower) that was not statistically significant.

However, the only statistically significant difference between groups was observed in self-esteem scores, cleft patients scored 78.17 ± 24.79 compared to healthy children's 83.49 ± 22.17, representing a 5.4-point difference (6.5% lower, $p = 0.036$). Age-stratified analysis revealed that in the CLP subgroup, children requiring reinterventions scored significantly lower on family perception (64.5 vs. 79.7 points, 19.2% reduction), and older children (6-7 years) scored lower than younger ones (4-5 years) on the same domain (68.5 vs. 83.1 points, 17.5% reduction).

Parents KINDL questionnaire demonstrated superior internal consistency with a global Cronbach's alpha of 0.892. Parental assessment yielded high quality of life scores with a mean of 80.38 ± 12.41, but identified specific areas of concern, self-esteem received the lowest rating at 72.41 ± 16.82 ($p < 0.01$) and infirmity perception at 72.15 ± 17.67 ($p < 0.01$), both scoring approximately 9.7% and respectively 10.3% lower than the overall mean (Figure 1).

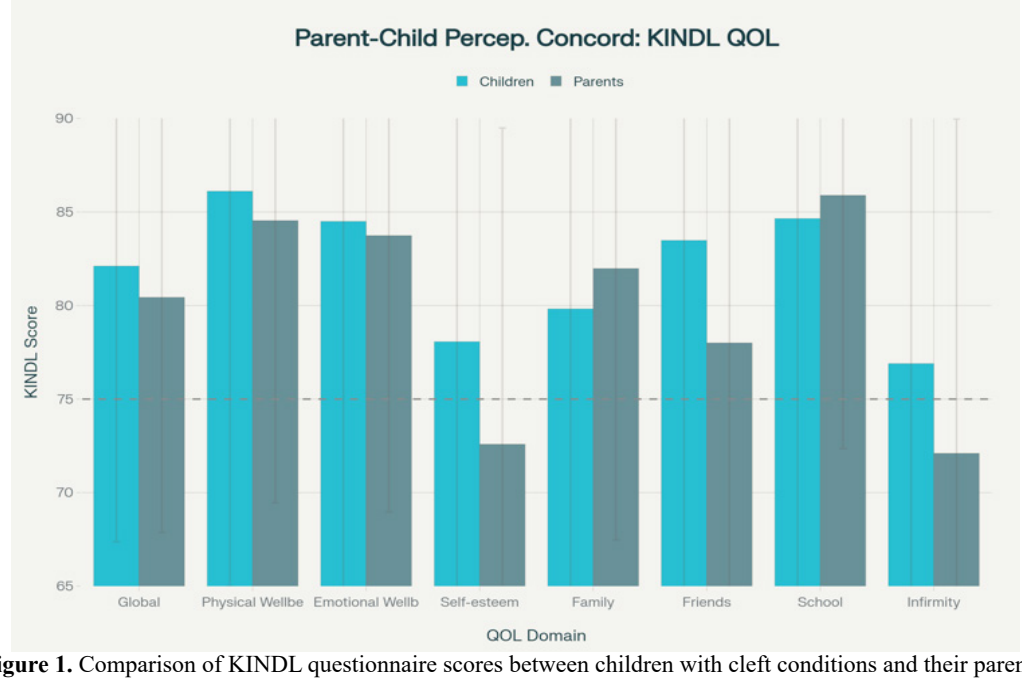


**Figure 1.** Comparison of KINDL questionnaire scores between children with cleft conditions and their parents.

Cleft type significantly influenced parental perceptions; parents of children with CL rated emotional wellbeing lower than those with isolated CP: 82.49 versus 86.82 (p = 0.03). A similar result was reported for friendship relationships: CL 76.92 versus CP 81.32 (p = 0.030).

## Discussion

The current findings demonstrate that pediatric patients with surgically repaired cleft lip ± palate exhibit QoL scores comparable to healthy controls on the KINDL questionnaire, with only self-esteem showing a statistically significant deficit (6.5% lower, p=0.036), aligning with prior research such as the study by Ruiz-Guillén et al. which reported minimal overall QoL differences post-surgery but persistent self-esteem challenges in 40% of CLP children aged 4-16 [9]. Similarly, parental KINDL assessments identified self-esteem and infirmity as key concerns (9.7-10.3% below mean), consistent with meta-analyses by Gkantidis et al. across European cohorts, where parents perceived greater emotional burdens in CL groups versus CP, particularly in friendship [10]. Age and reintervention effects, notably lower family perception in older CLP children needing revisions (17.5-19.2% reduction), mirror longitudinal data from the Americleft Project, emphasizing that multiple surgeries exacerbate perceived family strain [11].

These results carry clear clinical implications for multidisciplinary care protocols. Routine integration of self-esteem-focused psychological interventions, such as cognitive-behavioral therapy starting at age 4-5, could mitigate the isolated but impactful deficit observed, potentially reducing long-term social withdrawal risks reported in 20-30% of cleft patients per IPDTOC guidelines [12]. For high-risk subgroups (e.g., CLP with reinterventions), proactive family counseling and early orthodontic planning are warranted to address family perception gaps, optimizing QoL trajectories; this supports shifting from reactive surgical models to holistic, patient-reported outcome-driven pathways, ultimately decreasing secondary morbidities like anxiety.

The development of normal craniofacial structures represents one of the most complex orchestrated processes in embryogenesis, involving precise spatial and temporal coordination of neural crest cell migration, tissue proliferation, apoptosis, and fusion events. During the critical period between the fourth and twelfth weeks of gestation, failure of these fundamental developmental processes results in the spectrum of malformations collectively termed craniofacial anomalies [3,5,13,14].

Cleft lip results from the failure of fusion between the maxillary processes and the medial nasal prominences, typically occurring around the seventh week of gestation. This disruption may be unilateral or bilateral and can range from a minor notching of the lip to a complete separation extending through the nostril. Cleft palate, conversely, arises from the failure of the lateral palatine processes to meet and fuse with each other and with the nasal septum, occurring slightly later in development, around the ninth to twelfth weeks of gestation [3,5,13,15].

The classification of cleft lip and palate has evolved considerably, with numerous systems developed to address different clinical, research, and epidemiological needs. The most commonly employed classification systems include the International Classification of Diseases (ICD-10), the LAHSHAL system (Lip, Alveolus, Hard palate, Soft palate, Hard palate, Alveolus, Lip), and the Veau classification. Recent international surveys indicate significant variation in classification system usage across different centers and countries, with the LAHSHAL system gaining increasing acceptance due to its comprehensive nature and ability to describe laterality, completeness, and specific anatomical involvement [1].

The epidemiology of craniofacial anomalies demonstrates significant variation across ethnic groups, geographical regions, and socioeconomic strata. Orofacial clefts show higher prevalence rates among Asian and Indigenous populations, with lower rates typically observed in African populations. These disparities reflect complex interactions between genetic susceptibility factors, environmental exposures, and access to prenatal care and nutrition [3,4,14,16,17].

Genetic factors contribute substantially to cleft lip and palate risk, with both syndromic and non-syndromic forms demonstrating familial clustering patterns. Recent advances in genomic research have identified numerous candidate genes involved in craniofacial development, including IRF6, MSX1, GRHL3, and TBX22, among others. However, the majority of non-syndromic cases appear to follow complex, multifactorial inheritance patterns involving multiple genes of small effect interacting with environmental factors [3,14].

Environmental risk factors include maternal smoking, alcohol consumption, certain medications, nutritional deficiencies (particularly folic acid), and viral infections during critical developmental periods. The recognition of these modifiable risk factors has informed prevention strategies, including periconceptional folic acid supplementation and smoking cessation programs, which have contributed to reduced prevalence in some populations [3,13].

While isolated cleft lip and palate represent the most common presentation, these anomalies frequently occur as components of broader syndromic conditions. Van der Woude syndrome, the most common syndromic form of cleft lip and palate, accounts for approximately 2% of all cases and is characterized by the additional presence of lower lip pits. Other significant syndromic associations include 22q11.2 deletion syndrome, Stickler

syndrome, and various ectodermal dysplasias [2-4,16].

The therapeutic management of craniofacial anomalies begins immediately following birth, with initial priorities focused on ensuring adequate airway patency, establishing effective feeding, and addressing any associated medical complications. Infants with cleft lip and palate face immediate challenges in establishing effective feeding patterns due to disrupted oral anatomy that interferes with the generation of intraoral suction pressure necessary for efficient milk extraction [17-22].

Feeding management strategies encompass a comprehensive range of interventions tailored to the specific anatomical presentation and severity of the cleft [18-20,22].

Surgical management follows established protocols that balance the benefits of early repair with considerations of infant growth, anesthetic risk, and optimal timing for tissue healing. Primary lip repair is typically performed between 3 to 6 months of age, when the infant has achieved adequate weight gain and can safely tolerate general anesthesia. Palatal repair generally follows between 9 to 18 months of age, timed to optimize speech development while minimizing interference with maxillary growth [18-20].

The role of presurgical orthopedics, including nasoalveolar molding techniques, has gained increasing acceptance in many centers as a means of improving surgical outcomes and reducing the complexity of primary repairs. These techniques involve the use of custom-fabricated appliances worn by the infant in the months preceding surgery to guide the growth and positioning of cleft segments, potentially improving final aesthetic and functional outcomes [23].

The management of craniofacial anomalies during adolescence requires careful consideration of ongoing growth and development, particularly the complex interactions between surgical interventions and normal craniofacial growth patterns. This period is characterized by significant pubertal growth spurts that may necessitate revision surgeries or additional interventions to address residual functional or aesthetic concerns [23-25].

Orthodontic management plays a crucial role during this stage, often involving comprehensive treatment planning that coordinates with surgical interventions. The typical sequence includes early interceptive orthodontics to guide dental development, alveolar bone grafting procedures around 8 to 10 years of age to provide bony continuity across cleft segments, and comprehensive orthodontic treatment in preparation for any necessary orthognathic surgery [23-25].

Secondary surgical procedures commonly performed during adolescence address residual functional and aesthetic concerns. Velopharyngeal insufficiency, affecting speech resonance and intelligibility, may require pharyngeal flap surgery or sphincter pharyngoplasty. Rhinoplasty procedures address nasal deformities associated with cleft lip repair, while orthognathic surgery corrects skeletal discrepancies that may affect both function and appearance [23,24].

The psychosocial aspects of care during adolescence require particular attention, as this developmental stage is characterized by heightened awareness of peer acceptance and physical appearance. The timing of surgical interventions must consider not only technical and growth-related factors but also the psychological readiness of the adolescent and the potential impact on social and academic functioning [8,26-28].

The management of craniofacial anomalies extends well into adulthood, with many individuals requiring ongoing care to address both residual concerns from childhood treatment and new issues that emerge with aging. The transition from pediatric to adult care represents a critical juncture that requires careful planning and coordination to ensure continuity of care and ongoing access to specialized services [6,29-31].

Adult management often focuses on refinement procedures designed to optimize both functional and aesthetic outcomes. These may include revision surgeries to address scarring, asymmetry, or functional concerns that were not fully resolved during childhood treatment [23,29,31,32].

Psychosocial support remains crucial during the adult years, as individuals navigate challenges related to employment, relationships, and family planning. Many adults with craniofacial anomalies report ongoing concerns about appearance, social acceptance, and the potential for passing on their condition to offspring. Access to genetic counseling and psychological support services is essential for addressing these concerns and promoting optimal adjustment [26,29].

The impact of craniofacial anomalies on quality of life begins immediately following birth, affecting not only the infant but also extending to the family. During infancy, the primary quality of life concerns center on fundamental physiological functions essential for survival and healthy development, including feeding efficiency, growth velocity, respiratory function, and sleep patterns [18,19,22,26,33].

Feeding difficulties represent one of the most immediate and pressing concerns affecting quality of life during infancy. These challenges create stress for both infants and caregivers, potentially interfering with the establishment of secure attachment relationships and maternal confidence in caregiving abilities [18,19,22,26].

The impact on family quality of life during this period is substantial, with parents reporting elevated levels of stress, anxiety, and uncertainty about their child's future. The need for frequent medical appointments, specialized feeding techniques, and preparation for surgical procedures creates additional burdens on family functioning and may

strain financial and social resources. However, research also demonstrates remarkable resilience among families, with many adapting successfully to these challenges and developing effective coping strategies [26,34].

Adolescence represents a particularly vulnerable period for individuals with craniofacial anomalies, as the normal developmental tasks of identity formation and peer acceptance intersect with the visible differences and functional limitations associated with these conditions. Research consistently demonstrates increased risks for psychological distress, social difficulties, and reduced quality of life during this developmental stage [26-28].

Body image and appearance satisfaction emerge as central concerns during adolescence, with studies indicating that up to 68% of adolescents with cleft lip and palate express dissatisfaction with at least one aspect of their facial appearance. This dissatisfaction appears particularly pronounced among females and is associated with increased investment in appearance-related concerns. However, it is important to note that many adolescents with craniofacial anomalies demonstrate remarkable resilience and maintain positive self-concepts despite these challenges [27,28].

Social functioning during adolescence is significantly influenced by peer reactions and the broader social environment. Experiences of teasing, bullying, and social exclusion are unfortunately common among adolescents with visible facial differences. These negative social experiences can have profound effects on self-esteem, social confidence, and willingness to engage in typical adolescent activities [26-28].

The quality of life impacts of craniofacial anomalies persist well into adulthood, although the specific nature of these effects evolves as individuals transition through different life stages and developmental tasks. Adult outcomes demonstrate considerable heterogeneity, with some individuals achieving excellent functional and psychosocial outcomes while others continue to experience significant challenges [29,35,36].

Mental health outcomes in adulthood show mixed patterns, with some studies indicating elevated risks for anxiety and depression while others demonstrate resilience and positive adjustment. The factors associated with better mental health outcomes include strong social support networks, successful treatment outcomes, effective coping strategies, and access to psychological services when needed [26,29,35].

Quality of life assessment is a crucial step in the therapeutic management of craniofacial anomalies. Generic quality of life instruments provide standardized measures that allow for comparisons between individuals with craniofacial anomalies and general population norms, as well as between different medical conditions. These instruments typically assess broad domains of functioning including physical health, mental health, social functioning, and role limitations [37-39].

Condition-specific quality of life instruments have been developed to capture the unique experiences and concerns of individuals with craniofacial anomalies that may not be adequately assessed by generic measures. These instruments typically focus on domains particularly relevant to craniofacial conditions, including oral health, speech, hearing, appearance satisfaction, and social functioning [37-39].

The Child Oral Health Impact Profile (COHIP) represents one of the most comprehensively validated condition-specific instruments for pediatric populations. This instrument assesses oral health, functional well-being, social-emotional well-being, school environment, and self-image domains. Research has demonstrated that the COHIP effectively discriminates between children with craniofacial anomalies and controls and shows good responsiveness to treatment interventions [38-40].

The Youth Quality of Life Instrument-Facial Differences (YQOL-FD) was specifically developed to assess quality of life in adolescents and young adults with visible facial differences. This instrument includes domains assessing negative self-image, positive consequences, stigma, and social isolation. While showing promise in initial validation studies, the YQOL-FD has been less widely adopted than some other condition-specific instruments [37,38].

The Orthognathic Quality of Life Questionnaire (OQLQ) was developed specifically for individuals with dentofacial deformities and has been widely used in orthognathic surgery research. This instrument assesses social aspects of deformity, facial esthetics, oral function, and awareness of facial deformity. Studies have demonstrated good reliability and validity for the OQLQ, and the instrument has been translated into multiple languages for international use [32].

The Pediatric Quality of Life Inventory (PedsQL) represents one of the most widely used generic instruments in pediatric craniofacial research. This instrument assesses physical, emotional, social, and school functioning across different age groups and includes both child and parent report versions. Research utilizing the PedsQL in craniofacial populations has generally demonstrated good reliability and validity, with the instrument effectively discriminating between children with craniofacial anomalies and healthy controls [37-39].

The Short Form-36 (SF-36) represent the most commonly used generic quality of life measures in adult populations. These instruments assess eight domains of health-related quality of life including physical functioning, role limitations, bodily pain, general health, vitality, social functioning, role emotional, and mental health. Studies utilizing the SF-36 in adults with craniofacial anomalies have provided important insights into the long-term impact of these conditions on health-

related quality of life [32,37].

More recently developed generic instruments, such as the Patient-Reported Outcomes Measurement Information System (PROMIS), offer computerized adaptive testing approaches that may provide more efficient and precise measurement of quality of life domains. These instruments utilize item response theory and computer algorithms to tailor questionnaires to individual respondents, potentially reducing assessment burden while maintaining measurement precision [37,40].

The Derriford Appearance Scale (DAS) represents one of the most widely used appearance-related measures in craniofacial research. The DAS-24, a shortened version of the original instrument, assesses general self-consciousness of appearance, negative self-concept, and social self-consciousness. Research has demonstrated good psychometric properties for the DAS across diverse craniofacial populations [27,28].

The Fear of Negative Evaluation scale specifically assesses anxiety about being judged negatively by others, a concern that is particularly relevant for individuals with visible facial differences. This instrument has been widely used in craniofacial research and has demonstrated good reliability and validity in this population [27,28].

Body image measures, such as the Body Esteem Scale for Adolescents and Adults, assess satisfaction with physical appearance and body image disturbance. These measures have been adapted for use in craniofacial populations and provide important insights into appearance-related concerns and their impact on psychological well-being [28,29].

In our research, we applied the KINDL questionnaire to both children and caregivers and demonstrated that, following primary surgical repair of non-syndromic cleft lip and/or palate, children aged 4–7 years achieve overall quality of life scores comparable to their healthy peers, with mean global KINDL scores of 82.15 versus 83.78, respectively, a nonsignificant 1.9% difference. Despite this equivalence in global quality of life, the cleft cohort exhibited a statistically significant reduction in self-esteem (78.17 vs. 83.49, $p = 0.036$), suggesting that aesthetic and functional sequelae—such as lip contour irregularities, nasal distortion, velopharyngeal insufficiency, and dento-facial anomalies—continue to impact children's psychosocial perceptions. Moreover, our age-stratified and reintervention analyses indicate that palatal involvement and secondary surgeries exacerbate family-related quality-of-life deficits, particularly in older children (6–7 years), highlighting the cumulative psychosocial burden of multiple interventions over time.

Parental assessments corroborate these child-reported findings, yielding high overall scores (mean 80.38 ± 12.41) yet pinpointing self-esteem (72.41 ± 16.82) and infirmity perception (72.15 ± 17.67) as domains of greatest concern (both $p < 0.01$). Notably, parents of children with isolated CL perceived lower emotional wellbeing (82.49 vs. 86.82, $p = 0.03$) and friendship quality (76.92 vs. 81.32, $p = 0.03$) compared to those of children with isolated cleft palate, suggesting that visible scarring and lip asymmetry may pose greater social and emotional challenges than palatal defects alone. These insights emphasize the need for comprehensive, multidisciplinary follow-up that integrates psychological support and targeted interventions—such as speech therapy, orthodontics, and counselling—to address persistent self-esteem concerns and optimize both functional and psychosocial outcomes for children and their families.

Generally, research examining quality of life in craniofacial anomalies is characterized by several significant methodological limitations that affect the interpretation and generalizability of findings. These limitations reflect both the inherent challenges of conducting research in rare condition populations and the historical evolution of research methodologies in this field [30].

Sample size limitations represent one of the most pervasive challenges in craniofacial research. The relative rarity of many craniofacial conditions makes it difficult to recruit large, representative samples for research studies. This limitation is compounded by the heterogeneity of craniofacial conditions, which often necessitates combining different diagnostic groups or conducting analyses with insufficient statistical power. The result is a literature characterized by numerous small-scale studies with limited generalizability [30,31,41].

Longitudinal follow-up represents another significant challenge in craniofacial research. Many studies rely on cross-sectional designs or short-term follow-up periods that provide limited insights into long-term outcomes and developmental trajectories. The extended treatment timelines characteristic of craniofacial conditions, often spanning from infancy through adulthood, require longitudinal study designs that are expensive and logistically challenging to maintain [30,31,42].

Measurement standardization represents an additional methodological challenge, with different studies utilizing different outcome measures and assessment approaches. This heterogeneity in measurement approaches makes it difficult to compare results across studies and synthesize findings through meta-analytic approaches. The lack of consensus regarding core outcome measures for craniofacial research limits the ability to build cumulative knowledge in this field [41,42].

Significant disparities in access to specialized craniofacial care represent a major challenge affecting quality of life outcomes for individuals with these conditions. These disparities operate at multiple levels, including geographic, socioeconomic, and cultural factors that can significantly impact treatment accessibility and

outcomes [16,17].

Despite significant advances in surgical techniques and technology, important limitations remain in the treatment of craniofacial anomalies that affect long-term outcomes and quality of life. Understanding these limitations is crucial for setting appropriate expectations and guiding future research and development efforts [42-44].

Surgical limitations include the inherent challenges of reconstructing complex three-dimensional anatomy, particularly in cases involving significant tissue deficiency or distortion. While modern surgical techniques have dramatically improved outcomes, complete restoration of normal anatomy and function is not always achievable. The risk of complications, including infection, poor healing, and need for revision surgery, remains a significant concern that can affect patient outcomes and satisfaction [43,44].

Growth-related complications represent another important limitation in craniofacial surgery, particularly for procedures performed during childhood. Surgical interventions may interfere with normal growth patterns, potentially necessitating additional procedures as the child develops. Balancing the benefits of early intervention with the potential for growth-related complications remains a significant challenge in treatment planning [43,44].

Future research priorities in craniofacial anomaly outcomes research should focus on addressing the identified evidence gaps while incorporating methodological innovations that can improve the quality and applicability of research findings. These priorities include both specific research questions and broader methodological approaches [30,41,42].

Registry-based research represents an important methodological innovation that can address sample size limitations and facilitate long-term follow-up. National and international registry systems that collect standardized data on treatment approaches and outcomes could provide the foundation for large-scale comparative effectiveness research. The development of these registry systems requires coordination among healthcare providers, researchers, and funding agencies [30,41,42].

Patient-reported outcome measure development and validation represents another important research priority. While several condition-specific instruments have been developed for craniofacial populations, additional work is needed to develop measures that are sensitive to change, culturally appropriate, and suitable for use across different age groups and diagnostic categories. The incorporation of modern psychometric approaches, including item response theory and computer adaptive testing, could improve the efficiency and precision of outcome measurement [33,37,38].

Implementation science research examining strategies for translating research findings into clinical practice represents an emerging priority. Understanding how to effectively implement evidence-based practices in diverse healthcare settings is crucial for improving outcomes at the population level. This research should examine barriers and facilitators to implementation, develop strategies for overcoming implementation challenges, and evaluate the effectiveness of different implementation approaches [41,42].

## Conclusions

This comprehensive study demonstrates that children with surgically repaired cleft lip and/or palate achieve overall quality of life outcomes comparable to their healthy peers, with no statistically significant differences in global KINDL scores. However, persistent deficits in self-esteem emerge as a critical concern, affecting both child and parental assessments, indicating that aesthetic and functional sequelae continue to impact psychosocial well-being despite successful primary surgical repair. The findings underscore that while surgical advances have significantly improved functional outcomes, residual challenges in appearance satisfaction and social confidence require ongoing attention throughout the developmental trajectory.

The research highlights the importance of comprehensive, multidisciplinary follow-up that extends beyond surgical intervention to address persistent psychosocial concerns. Future therapeutic approaches should integrate targeted psychological support, speech therapy, orthodontic care, and family counseling to optimize both functional and psychosocial outcomes. The evidence suggests that successful management of craniofacial anomalies requires a holistic approach that addresses not only the physical reconstruction but also the complex interplay of psychological, social, and family factors that influence long-term quality of life and adjustment.

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