

Oral Health and Quality of Life of Pediatric Patients with Complex Chronic Conditions

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ABSTRACT

The study means to analyze the correlation between clinical and subjective oral health indicators and quality of life in pediatric patients with Complex Chronic Conditions (CCC). A cross-sectional study was conducted with 63 pediatric patients with CCC. Data collection in a hospital setting involved oral clinical examinations using the Simplified Oral Hygiene Index, caries experience (DMFT/dmft), gingival bleeding, and Dental Aesthetic Index. Oral health-related quality of life (OHRQoL) was measured using the Parental-Caregivers Perceptions Questionnaire (P-CPQ), completed by caregivers. Correlations between indicators and quality of life scores were analyzed using Spearman's correlation coefficient (ρ), with a significance level of $p < 0.05$. Results: Poor oral hygiene was observed in 34.9% of participants (mean OHI = 2.03) and a dmft index of 1.67. Gingival bleeding was present in more than 30% of sites in 47.6% of children, and severe or very severe malocclusion was observed in 47.6%. Overall oral health-related quality of life (OHRQoL) had a mean score of 26.38, with the functional limitation domain being the most affected. There were no correlations between objective clinical indicators and quality of life domains. However, the subjective perception of "difficulty biting or chewing" showed a strong and significant correlation with the functional limitation domain ($\rho = 0.823$; $p < 0.001$) and with overall quality of life ($\rho = 0.812$; $p < 0.001$). Conclusion: Functional perception (chewing difficulty) proved to be a more sensitive indicator of the impact on OHRQoL in children with chronic heart disease (CHD) than traditional clinical indices. These findings underscore the importance of incorporating subjective and functional assessments into oral health care strategies for this vulnerable population.

Keywords: Oral Health, Quality of Life, Chronic Disease, Child, Pediatric Dentistry

Introduction

Advances in medical technologies and the consequent reduction in infant mortality have resulted in a significant increase in the number of children with critical and fragile conditions, including congenital malformations or with sequelae from extreme prematurity vulnerability. These patients are referred to as CCC (Complex Chronic Conditions) or children with special care needs, as they present greater clinical vulnerability and higher utilization of health services [1,2]. To be classified with this condition, the prerequisites include the involvement of two or more organs or systems requiring specialized care, and the disease must have been present continuously over the past 12 months [3,4]. The CCC encompasses various diagnoses, including congenital malformations and neurological, genetic, and metabolic disorders, which require continuous care and a

multidisciplinary approach to ensure well-being and quality of life [5,6].

Within this context, oral health emerges as a frequently neglected, yet essential, component of health [7]. Children with CCC or children with special health care needs (CHNS), have increased vulnerability to oral diseases such as caries, periodontal disease, and malocclusion [8,9]. Risk factors could include motor limitations that hinder hygiene, prolonged use of medications (often sugary), special diets, and barriers to accessing specialized dental services [10,11]. These conditions are not limited to the oral cavity, having a systemic impact that affects feeding, communication, social interaction, and, consequently, the child's quality of life and their family [12,13]. Especially in the family context, the various stressors involved in caring for a child with CCC have the potential to affect the entire family. Morbidities such as exhaustion, stress, anxiety, and depression have already been described among caregivers. In

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addition to this, social and economic vulnerability, well-known barriers to accessing healthcare services, and also poorer oral health conditions can worsen the patient's condition [11-13].

We can also observe in Dentistry that, oral health assessment has traditionally focused on objective clinical indicators, such as the prevalence and severity of caries and oral hygiene status [14]. Although essential, these parameters may not fully capture the patient's or their caregivers' perception of how oral conditions affect their daily lives [15]. In this sense, Oral Health-Related Quality of Life (OHRQoL) emerges as a complementary measure that assesses the functional, social, and emotional impact of oral problems, an outcome increasingly valued in research and clinical practice [16,17].

Considering the potential severity of oral health conditions in this group, as well as caregivers' perception of the oral health and quality of life of these children, the present study aimed to identify oral health conditions including objective indicators of dental caries, malocclusion, and oral hygiene, as well as subjective indicators of oral symptoms reported by parents, and correlate them with Oral Health-Related Quality of Life of pediatric patients with complex chronic conditions.

Methodology

A cross-sectional study was conducted. The study population consisted of 63 pediatric patients diagnosed with complex chronic conditions who were treated at a university hospital of La Paz referral center from January to June 2023. The study included all patients seen at the hospital outpatient clinic during the period who were clinically able to undergo the examination, and whose parents completed the questionnaire and authorized the completion of all stages of the work. Patients who were hospitalized or whose parents refused to fill out the instrument or did not authorize the conduct of the study were excluded.

Data collection was carried out in two stages. The first consisted of applying the Parent-Caregivers Perceptions Questionnaire (P-CPQ) to caregivers to assess their perception of their children's oral health-related quality of life (OHRQoL). The P-CPQ comprises 33 items, distributed across four subscales: oral symptoms (OS), functional limitations (FL), emotional well-being (EWB), and social well-being (SWB). The questions refer only to the frequency of events that have occurred in the previous three months. The items have 5 Likert response options: 'never=0', 'once or twice=1', 'sometimes=2', 'often=3', 'every day or almost every day=4'. A 'don't know' response was also permitted and scored as 0. Global ratings of the child's oral health and the impact of the oral condition on their overall well-being were obtained from the parents/caregivers. The international ratings had a 5-point response format, ranging from 'excellent' (0) to 'poor' (4) for oral health and from 'not at all' (0) to 'very much' (4) for wellbeing [18,19].

The second stage involved a complete clinical dental examination, performed by a calibrated examiner (Kappa > 0.8 malocclusion and 0.92 dental caries), to determine the child's oral health conditions. The examiner was a PhD student in Dentistry at the Federal University of Bahia, a specialist in Pediatric Dentistry, and previously calibrated by his advisors to conduct the examinations. The following indices were used, as

recommended by the World Health Organization and relevant literature: Simplified Oral Hygiene Index (OHI), to measure the presence of bacterial plaque and calculus; The DMFT and dmft indices were used to assess caries experience in permanent and deciduous teeth, respectively; the Gingival Bleeding Index (GBI%) was used to evaluate the presence of gingival bleeding. All were performed in the hospital setting.

All were performed in the hospital setting. The data were tabulated and analyzed using SPSS software (Version 25.0). A descriptive analysis of sociodemographic variables and clinical indicators was performed. To test the study hypothesis, Spearman's correlation coefficient (ρ) was used to measure the association between the scores of the P-CPQ domains and clinical oral health indicators, as well as with specific questionnaire items. The significance level adopted was $p < 0.05$.

The ethics committee of La Paz Hospital authorized the study according to opinion no. 47/788313/23 and the ethics committee of the post-graduation Program of oral health of Federal University of Bahia reapproved the research protocol. It is worth noting that the children who participated in the study and were examined were those whose parents authorized the oral evaluation by signing the Informed Consent Form.

Results

The study population consisted of 63 individuals, of whom 57.1% were female. The mean age was 9.79 years (± 3.78). Regarding schooling, 68.4% attended special schools, and only 1.8% were in mainstream schools without adaptations. Among the chronic conditions presented, we have neuromuscular disorders (79.4%), genetic disorders (71.4%), respiratory disorders (66.7%), gastrointestinal disorders (58.7%), chronic kidney conditions (30.2%), among others. Overall, 49.2% of the patients had three or more conditions simultaneously.

The descriptive analysis of clinical indicators revealed a compromised oral health scenario in the studied sample (Table 1). Oral hygiene was classified as deficient in 34.9% of participants, with an average OHI score of 2.03. Although 60% of the individuals were caries-free in their permanent teeth, the deciduous dentition presented a dmft index of 1.67. Gingival health was also altered, with 47.6% of children presenting bleeding in more than 30% of the examined sites. Malocclusion was prevalent, with 31.7% classified as having severe malocclusion and 15.9% as having very severe malocclusion, according to the DAI index.

Table 1: Description of Oral Health Indices Observed in Children with Complex Clinical Conditions (n=63). Salvador- BA- Brazil, 2023

Clinical Indicator	Mean (SD)	Highlight Categories	Percentual (%)
OIHS	2.03 (0.85)	Poor Hygiene	34.9
DMFT	-	Caries free	60.0
dmft	1.67 (2.87)	-	-
Gingival Bleeding	-	>30% of sites with bleeding	47.6
DAI	42.09 (17.05)	Severe Malocclusion	31.7

		Very Severe Malocclusion	15.9
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SD: Standard Deviation;
IHOS: Simplified Oral Hygiene Index;
DMFT: Decayed, Missing, and Filled Permanent Teeth;
dmft: Decayed, Extracted, and Filled Deciduous Teeth; **DAI:** Dental Aesthetic Index.

Regarding quality of life, the overall mean P-CPQ score was 26.38. The most affected domain was functional limitation (mean = 12.18), followed by oral symptoms, emotional well-being, and social well-being. There was a high prevalence of oral impacts in all domains. (Table 2)

Table 2: Prevalence and Impact Scores of Each Item by Domain of the Parent-Caregivers Perceptions Questionnaire (P-CPQ). Salvador-BA, Brazil, 2023. (n=63).

During the last 3 months, how often did your child (have/was)	Prevalence (%)	Mean	Standard Deviation (SD)
ORAL SYMPTOMS			
Pain in teeth, lips, jaw, or mouth?	40.90	3.48	1.90
Bleeding gums?	47.70	2.72	1.45
Mouth sores?	54.50	2.17	1.11
Bad breath?	36.40	3.00	1.18
Has food ever been stuck in the palate?	51.10	2.67	1.35
Has food ever been stuck between the teeth?	52.30	2.81	1.40
Difficulty biting or chewing foods like a fresh apple, corn, or meat?	38.60	3.10	1.56
FUNCTIONAL LIMITATIONS			
Have you been breathing through your mouth?	27.30	3.21	1.55
Have you been having trouble sleeping?	43.21	2.83	1.48
Have you been having difficulty pronouncing some words?	34.10	2.90	1.60
Have you been having difficulty drinking or eating hot or cold foods?	43.20	2.80	1.42
Have you been having difficulty eating what you always liked?	45.50	2.95	1.53
Have you been on a diet restricted to certain foods (e.g., a pureed diet)?	27.05	3.05	1.62
EMOTIONAL WELL-BEING			
Uncomfortable?	38.60	3.15	1.54
Irritated or unhappy?	36.40	3.12	1.52
Anxious or scared?	45.50	2.95	1.49

Missed school due to pain, medical appointments, or surgery?	68.20	2.40	1.35
Had difficulty paying attention in class?	50.00	2.60	1.41
Refused to speak or read aloud in class?	61.40	2.55	1.32
Refused to talk to other children?	61.40	2.62	1.36
Avoided speaking or smiling when with other children?	70.50	2.50	1.30
SOCIAL WELL-BEING			
Worried about not being as healthy as other children?	56.80	2.70	1.40
Worried about being different from others?	61.40	2.65	1.38
Were you worried about not being as good-looking as the others?	72.70	2.75	1.42
Did you behave shyly or feel embarrassed?	65.90	2.80	1.44
Were you the target of teasing or name-calling by other children?	68.20	2.60	1.36
Were you excluded from the group by other children?	68.20	2.55	1.33
DURING THE LAST 3 MONTHS, HOW OFTEN DID YOUR CHILD (HAVE/WAS)			
Feel unenthusiastic or unable to interact with other children?	61.40	2.68	1.39
Did you not want to or lack the energy to participate in activities such as sports, theater, music, or school trips?	61.40	2.72	1.41
Were you worried about having few friends?	70.50	2.66	1.37
Were you worried about what other people think about your teeth, lips, mouth, or jaw?	72.70	2.78	1.43
Did you receive questions from other children about your teeth, lips, mouth, or jaw?	59.10	2.70	1.40

The correlation analysis between objective clinical indicators and quality of life domains showed weak associations without statistical significance (Table 3). For example, the correlation between gingival bleeding and overall quality of life was $\rho = 0.268$ ($p = 0.076$), and between DAI clas-sification and overall quality of life was $\rho = 0.103$ ($p = 0.458$).

Table 3: Spearman Correlation Between Oral Health Indicators and Quality of Life do-mains of the Parental-Caregivers Perceptions Questionnaire (P-CPQ). Salvador-BA, 2023 (n=63).

Variables	Functional Limitations	Oral Symptoms	Emotional Well-Being	Social Well-Being	Quality of life (All)
Objective Clinical Indicators					
Gingival Bleeding (%)	$\rho=0.25$ ($p=0.10$)	$\rho=0.20$ ($p=0.20$)	$\rho=0.20$ ($p=0.20$)	$\rho=0.15$ ($p=0.30$)	$\rho=0.27$ ($p=0.08$)
DAI Classification	$\rho=0.01$ ($p=0.48$)	$\rho=0.12$ ($p=0.41$)	$\rho=0.052$ ($p=0.71$)	$\rho=0.03$ ($p=0.82$)	$\rho=0.10$ ($p=0.46$)
Subjective Indicator					
Difficulty biting/chewing	$\rho=0.82$ ($p<0.001$)*	$\rho=0.49$ ($p=0.001$)*	$\rho=0.48$ ($p=0.001$)*	$\rho=0.33$ ($p=0.028$)*	$\rho=0.81$ ($p<0.001$)*

Statistically significant correlation ($p < 0.05$). Values in bold highlight the most substantial cor-relations in the study.

Conversely, the analysis of subjective items from the questionnaire revealed substantial and statistically significant correlations. The self-reported variable “difficulty biting or chewing food” showed a robust correlation with the functional limitation domain ($\rho = 0.823$; $p < 0.001$) and with overall quality of life ($\rho = 0.812$; $p < 0.001$). Moderate and significant correlations were also observed between this item and the oral symptoms domain ($\rho = 0.490$; $p = 0.001$) and the emo-tional well-being domain ($\rho = 0.481$; $p = 0.001$) (Table 3).

Discussion

The results of this study reveal a dissociation between clinical indicators of oral health and the perceived impact on the quality of life of children with complex chronic conditions. Although the population presented a high prevalence of poor oral hygiene, gingival bleeding, and severe malocclusion—findings consistent with the literature on pediatric populations with special needs [9,21,22]—these objective findings did not correlate significantly with the QOL-R scores re-ported by caregivers. This finding is of extreme clinical relevance and suggests that, for this population, clinical signs of disease may not be the primary determinant of well-being.

One possible explanation for the initial underreporting of minor oral problems is the phenomenon of response shift or adaptive response change, proposed by Sprangers and Schwartz. This model suggests that individuals facing chronic health conditions (CCC) may recalibrate their internal standards of severity and impact. Children with CCC and their caregivers deal with more sig-nificant health challenges daily, which may lead to a reassessment of what constitutes a “prob-lem.” Clinically relevant conditions, such as plaque or gingival bleeding, may be seen as sec-ondary or less urgent compared to the manifestations of the underlying chronic condition [23,24, 25].

The impact on quality of life would only be perceived when the oral condition reaches a threshold that directly interferes with an essential function, such as eating. The most critical finding of our study is the strong correlation between “difficulty biting or chewing” and the deterioration of quality of life in multiple domains. The masticatory function is a fundamental daily activity, linked to nutrition, the pleasure of eating, and socialization [25]. When this function is compromised, the impact is immediate and easily noticeable, affecting the child’s ability to feed themselves properly (a functional limitation), generating discomfort (oral symptoms), and possibly causing frustration or embarrassment (affecting emotional well-being) [26].

This result is consistent with a robust body of evidence demonstrating the association between impaired masticatory function and worsened quality of life in general pediatric populations and adults [27,28]. Yeung et al. (2024) emphasize that chewing is essential for breaking down food and absorbing nutrients, which is crucial for child development [29]. Our finding is corroborated by studies that used the Early Childhood Oral Health Impact Scale (B-ECOHIS), where it was found that the Function domain in the Child Impact Section (CIS) had the highest average value. Additionally, untreated dental caries and its severity were consistently associated with the CIS domains, except for the self-image/social interaction domain [30, 31, 32]. Although chewing difficulties were the main functional indicator found, parents/caregivers also reported other sig-nificant impacts on OHRQoL (affected in 68.75% of participants). The item with the highest average corresponding to some type of impact on the CIS was “pain in teeth, mouth or jaws” (28.1%). In the Family Impact Section (FIS), the most reported item was “being upset” (29.1%). Severe caries was associated with a worse quality of life, with a significant correlation between untreated dental caries and the overall B-ECOHIS score ($r = 0.333$, $p = <0.001$) in other Studies [31,33,34].

This result is also consistent with studies that suggest functional and subjective indicators are often more sensitive to capturing the actual impact of oral diseases than traditional clinical indices [15,30]. The perception of parents or caregivers is a crucial factor, but it can also be influenced by their own oral health literacy and experiences [31,32]. However, functional difficulty is a con-crete event and difficult to ignore. Severe malocclusion, prevalent in the study population, is a direct cause of chewing difficulties, and although the DAI index itself did not correlate with OHRQoL, the symptom it causes (chewing difficulties) was present. This suggests that it is not the presence of malocclusion per se that impacts quality of life, but rather its functional conse-quence [12].

The clinical implications of these findings are clear. The assessment of oral health in children with CCC should transcend the mere clinical inspection of signs and symptoms. It is crucial that healthcare professionals, especially pediatric dentists, include direct questions about masticatory function and other functional difficulties in their anamneses. I a hospital in South Africa, most CCC with caries were treated through extractions (96.5%), and there was a lack of restorative care. Although extractions may alleviate pain, early tooth loss leads to functional, psychological, aesthetic, and orthodontic problems, resulting in a further decline in quality of life [35,36]. Therefore, restorative treatment and prevention strategies are critical to improving quality of life. In contrast, a study in Rio de Janeiro,

Brazil, showed that the most common treatments performed were dental restorations (63%) and extractions (47%) [37].

The American Academy of Pediatric Dentistry (AAPD) already recommends a patient- and family-centered approach for children with special needs, which includes consideration of functional and quality-of-life aspects [33]. Managing children with CCC often requires specialized approaches due to anxiety or lack of cooperation. The use of techniques such as Tell, Show, Do (TSD) can be effective. However, in cases of severe behavioral problems, sedation or general anesthesia (GA) may be the only option for dental treatment [33-37].

This study has limitations, including its cross-sectional design, which does not permit the establishment of causality. The small size of the study population, and therefore the variability in age among patients and their clinical conditions, may have introduced biases into the results obtained. Future studies suggest longer follow-up periods, given the limited nature of this population. Also, a case-control study may be more appropriate, which, in this work, was not possible due to operational issues at the hospital. In addition, caregivers collected perceptions, which may not perfectly reflect the child's experience could happen; however, this is a widely validated method for pediatric populations [18,34]. Despite that, the strength of the correlations provides robust evidence for formulating new hypotheses and, more importantly, for reorienting clinical practice to align with a more holistic and functional approach centered on what matters to the patient and their family [35].

Conclusion

The population presented a scenario of compromised oral health, with poor oral hygiene in 34.9% of participants and severe or very severe malocclusion observed in 47.6% of children. The functional limitation domain was the most affected in the OHRQoL, which had an average score of 26.38%. Traditional objective clinical indicators, such as gingival bleeding and the Dental Aesthetic Index (DAI) classification, did not show statistically significant correlations with the OHRQoL domains. In contrast, the subjective perception of functional difficulty, namely "difficulty biting or chewing," demonstrated a strong and significant correlation with the functional limitation domain ($\rho=0.823$; $p<0.001$) and with overall quality of life ($\rho=0.812$; $p<0.001$). It is concluded that the perception of chewing difficulty is a more sensitive indicator of the impact on the OHRQoL than traditional clinical indices in children with CCC. The findings reinforce the importance of incorporating functional and subjective assessments into oral care strategies for a comprehensive diagnosis.

Conceptualization

Figueiredo A; Methodology: Lopes L, Figueiredo A, Sampaio W; Forma analysis: Lopes L, Figueiredo A, Sampaio W, Cangussu MCT; Investigation: Lopes L, Figueiredo A; Project Administration: Figueiredo A, Cangussu MCT. Writing and reviewing: Figueiredo A, Cangussu MCT, Duarte AR. All authors have read and agreed to the published version of the manuscript.

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Institutional Review Board Statement

The study was conducted in accordance with the Declaration of Helsinki, and approved by Ethics Committee) of La Paz Hospital (protocol code 47/788313.9/23 in April 21, 2023) The Ethics Committee of Federal University of Bahia, that the authors were part also approved the study.

Informed Consent Statement

Informed consent was obtained from all subjects involved in the study.

Data Availability Statement

Data is unavailable due to privacy or ethical restrictions. La Paz did not authorize the publication of patients' individual data

Conflicts of Interest

The authors declare no conflict of interest.

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