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Original Article

Impact of Cleft Lip and Palate on Oral Health-Related Quality of Life (OHRQOL) in Brazilian Patients

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Abstract

Objective: To evaluate self-esteem, satisfaction with facial aesthetics and the impact of oral health on the quality of life of patients with cleft lip and palate aged from 12 years treated at the Hospital for Rehabilitation of Craniofacial Anomalies (HRAC), Brazil. **Material and Methods:** A cross-sectional study was conducted with patients (n=94) with cleft lip and palate, aged 12 years and older, treated at the Hospital for Rehabilitation of Craniofacial Anomalies, University of São Paulo, Brazil. The instruments used in this study were: Rosenberg's Self-Esteem Scale, the Oral Health Impact Profile-14 (OHIP), and a visual analogue scale of self-perceived facial aesthetics were applied, and socioeconomic and contextual data were collected from all patients. The statistical analysis included Poisson regression with robust variance (RR – rate ratio) and it was performed to evaluate the association between predictors and the outcome oral health related-quality of life. **Results:** Worse OHRQoL was reported by female patients (RR 1.21; 95%CI: 1.09-1.35) and older individuals (RR 1.25; 95%CI:1.13-1.39). **Conclusion:** The presence of cleft lip and palate has a negative impact on OHRQoL. Females and older individuals reported worse quality of life.

Keywords: Quality of Life; Cleft Lip; Cleft Palate.

Introduction

Nonsyndromic oral clefts (NSOC) are the most frequent craniofacial malformation, affecting approximately 1 in 650 live births in Brazil [1]. NSOCs are generally divided into two groups: isolated cleft palate and cleft lip with or without cleft palate [2]. Individuals with cleft lip and/or palate may suffer from impaired functions and facial appearance, often requiring multiple treatments for reconstruction or improvement [3]. Although rehabilitation is possible with high-quality care, orofacial clefts inevitably pose individual, family, and societal burdens, including substantial expenditures on health care and related services [3].

Individuals with NSOC commonly have facial disfigurement due to craniofacial diseases and conditions, treatment of which can have significant consequences for these patients' lives [4]. Moreover, patients may experience anxiety, depression [4], low self-esteem, dissatisfaction with their appearance [5], difficulties in pronouncing some phonemes [4], reduced cognitive function, limited academic achievement, and parental stress [6,7].

The Rosenberg Self-Esteem Scale (RSES) is one of the self-esteem measures most widely used in research. It is a 10-item instrument in which participants rate their agreement with statements on a 4-point scale, ranging from "Strongly agree" to "Strongly disagree," with items expressing positive and negative self-esteem (e.g., "I feel that I have a number of good qualities"). Low scores indicate high self-esteem (range: 10 to 40). This scale has been used in adults with disfigurement [8].

Visual analogue scales (VAS) are also used to score facial aesthetics. The VAS employs a 100 mm scale with a broad range of distinctive possibilities, whereas the RSES and similar Likert-type scales use ratings from 1 to 5 or from 1 to 10 [9]. Oral health-related quality of life (OHRQoL) is the result of an interaction between oral health conditions and social and contextual factors [10]. The Oral Health Impact Questionnaire (OHIP) has been tested and validated to measure OHRQoL, using reports on quality of life from healthy children and children recruited from pediatric, orthodontic, and craniofacial centers.

This study aimed to assess the influence of NSOC on self-esteem, satisfaction with facial aesthetics, and OHRQoL in patients treated at the Hospital for Rehabilitation of Craniofacial Anomalies, São Paulo, Brazil. The hypothesis was that patients with NSOC are affected differently depending on gender and age.

Material and Methods

Subjects and Ethical Aspects

The present study included a sample of 94 patients aged >12 years who had been treated since birth at the Hospital for Rehabilitation of Craniofacial Anomalies, São Paulo, Brazil. This study was conducted in accordance with relevant international statutes and national legislation on ethics in research involving human beings. All patients agreed to participate and provided written consent.

The study protocol was approved by the Hospital for Rehabilitation of Craniofacial Anomalies Research Ethics Committee.

Data Collection

Three questionnaires were administered to each patient, by three examiners, who were also responsible for impartially clarifying any doubts that might arise during the procedure. Patients completed a general questionnaire about sex, age, type of cleft, skin color, and educational attainment (maternal and their own), among other items.

The 14-item version of the OHIP was used for OHRQoL assessment. This questionnaire has seven domains, each containing two items: (1) functional limitation, (2) physical pain, (3) psychological discomfort, (4) physical disability, (5) psychological disability, (6) social disability, and (7) handicaps. Responses for each item were obtained on a Likert-type scale and ordinal values were coded for each question, ranging from 0 for a response of “never” to 4 for a response of “very often”. The overall OHIP-14 score can range from 0 to 56 points, with 0 indicating no impact and 56 points indicating the worst impact of oral health on a person’s quality of life. Individual domain scores can be calculated by adding the values of the answers to the items of each domain, and can range from 0 to 8 points [10].

Patients also evaluated their facial aesthetics through a VAS, on which they were asked to score, on a 10-cm scale (from 0 to 10), their satisfaction with facial aesthetics, with 0 being the worst perception (completely dissatisfied) and 10 cm the best self-perception (completely satisfied with facial aesthetics) [9].

The other instrument employed was the Portuguese version of the RSES, which previously showed good rates of reproducibility and validity in our setting. The instrument comprises 10 items graded on a 4-point Likert scale from SA to SD, i.e., answers corresponding to strongly agree (SA), agree (A), disagree (D), and strongly disagree (SD). Numeric values are assigned to each answer as follows: for items 1, 2, 4, 6, and 7, SA = 3, A = 2, D = 1, and SD = 0; for items 3, 5, 8, 9, and 10, SA = 0, A = 1, D = 2, and SD = 3. The sum of the points represents the individual’s classification. Results range from 0 to 30 points, with higher scores indicating higher self-esteem (values between 15 and 25 points are within normal range, and values below 15 points suggest low self-esteem) [8].

Data Analysis

Statistical analysis was carried out in SPSS Version 16.0 (SPSS Inc, Chicago, IL). First, histograms were used to assess the normality of distribution of the variables satisfaction with facial aesthetics, OHRQoL (OHIP-14), and self-esteem (RSES). Once the assumption of normality had been confirmed, we assessed outcomes across the different categories of independent variables. Analysis of variance (ANOVA) was used to test differences for statistical significance ($p < 0.05$).

To assess the relationship between independent variables and the OHRQoL outcome measure (OHIP-14), we used a Poisson regression model with robust variance, rate ratio (RR) with 95% confidence intervals.

Results

The study sample comprised 94 patients with CLP, 54 male (57.4%) and 40 female (42.6%). Age ranged from 12 to 50 years (mean [SD], 21.7 [8.4] years; median [IQR], 19.5 [15.7-26.0] years). Of the 94 subjects, 82 (87.2%) had complete CLP, and 12 (12.8%) had incomplete CLP. Age at treatment onset ranged from 0 to 120 months, with a mean (SD) of 11.3 (21.1) months and a median (IQR) of 6 (3-9) months.

On bivariate analysis, female patients had a significantly higher OHRQoL impact compared to male subjects ($p < 0.001$). Subjects aged ≥ 20 years had significantly more negative perceptions than younger participants ($p = 0.001$), and those with higher educational attainment also reported worse OHRQoL ($p = 0.008$) (Table 3). Regarding satisfaction with facial aesthetics, there were no significant differences between the complete and incomplete CLP groups. Similar results were obtained for self-esteem (Table 3).

After adjusting for confounders, the impact on OHRQoL was 21% greater in females than in males (RR 1.21, 95%CI 1.09-1.35). Older subjects experienced a 25% greater impact on OHRQoL than younger patients (RR 1.25, 95%CI 1.13-1.39) (Table 4).

Table 1. Sample characteristics of patients assisted at Hospital for Rehabilitation of Craniofacial Anomalies (HRAC), Brazil.

| Variables | n | % |
|----------------------------|----|------|
| Sex | | |
| Male | 54 | 57.4 |
| Female | 40 | 42.6 |
| Age (years) | | |
| < 20 | 47 | 50.0 |
| ≥ 20 | 47 | 50.0 |
| Skin Color | | |
| White | 63 | 67.0 |
| Nonwhite | 31 | 33.0 |
| Maternal Education (years) | | |
| < 8 | 42 | 44.7 |
| ≥ 8 | 52 | 55.3 |
| Patient Education (years) | | |
| < 11 | 46 | 48.9 |
| ≥ 11 | 48 | 51.1 |
| Age at Treatment | | |
| > 6 months | 31 | 33.0 |
| ≤ 6 months | 63 | 67.0 |
| Type of Cleft | | |
| Incomplete | 12 | 12.8 |
| Complete | 82 | 87.2 |

Table 2. Descriptive analysis of outcomes involving patients (n=94) assisted at Hospital for Rehabilitation of Craniofacial Anomalies, Brazil.

| Variable | Min | Max | Median | Q25-Q75 | Mean | SD* |
|---------------------------------------|------|------|--------|-----------|------|-----|
| Perception of facial aesthetics (VAS) | 4.0 | 10.0 | 8.0 | 7.0-9.0 | 8.0 | 1.4 |
| Self-esteem | 16.0 | 26.0 | 19.0 | 21.0-23.0 | 21.2 | 2.4 |
| OHIP-14 | 14.0 | 49.0 | 25.0 | 19.0-30.0 | 25.6 | 7.7 |

*SD: standard deviation.

Table 3. Mean (\pm standard deviation) scores for perception of facial aesthetics (visual analogue scale), quality of life (OHIP-14), and self-esteem (Rosenberg scale) in relation to the independent variables.

| Variable | VAS (mean \pm SD) | Rosenberg (mean \pm SD) | OHIP (mean \pm SD) |
|----------------------------|------------------------|---------------------------|-------------------------|
| Sex | | | |
| Male | 8.05 (\pm 1.44) | 20.87 (\pm 2.45) | 23.70 (\pm 6.19) |
| Female | 7.97 (\pm 1.37) | 21.57 (\pm 2.28) | 28.25 (\pm 8.71) |
| | p = 0.803 | p = 0.160 | p = 0.004* |
| Age (years) | | | |
| < 20 | 8.06 (\pm 1.37) | 21.06 (\pm 2.53) | 23.00 (\pm 5.67) |
| \geq 20 | 7.97 (\pm 1.45) | 21.27 (\pm 2.28) | 28.27 (\pm 8.51) |
| | p = 0.738 | p = 0.670 | p = 0.001* |
| Skin color | | | |
| White | 7.98 (\pm 1.42) | 21.09 (\pm 2.36) | 25.87 (\pm 7.67) |
| Nonwhite | 8.08 (\pm 1.40) | 21.32 (\pm 2.49) | 25.16 (\pm 7.76) |
| | p = 0.753 | p = 0.668 | p = 0.675 |
| Maternal education (years) | | | |
| < 8 | 7.95 (\pm 1.36) | 20.90 (\pm 2.47) | 24.50 (\pm 7.53) |
| \geq 8 | 8.07 (\pm 1.45) | 21.38 (\pm 2.33) | 26.55 (\pm 7.72) |
| | p = 0.690 | p = 0.338 | p = 0.198 |
| Patient education (years) | | | |
| < 11 | 8.22 (\pm 1.34) | 21.04 (\pm 2.64) | 23.52 (\pm 6.57) |
| \geq 11 | 7.82 (\pm 1.45) | 21.29 (\pm 2.15) | 27.66 (\pm 8.15) |
| | p = 0.174 | p = 0.619 | p = 0.008 |
| Family history | | | |
| Positive | 8.18 (\pm 1.91) | 21.35 (\pm 2.69) | 24.58 (\pm 6.48) |
| Negative | 7.98 (\pm 1.30) | 21.06 (\pm 2.30) | 25.82 (\pm 8.02) |
| | p = 0.608 | p = 0.656 | p = 0.554 |
| Type of cleft | | | |
| Incomplete | 7.83 (\pm 1.74) | 21.50 (\pm 1.31) | 24.50 (\pm 8.75) |
| Complete | 8.04 (\pm 1.36) | 21.12 (\pm 2.52) | 25.80 (\pm 7.54) |
| | p = 0.635 | p = 0.613 | p = 0.585 |
| Age at treatment | | | |
| \leq 6 months | 7.92 (\pm 1.36) | 21.41 (\pm 2.50) | 26.03 (\pm 7.15) |
| > 6 months | 8.21 (\pm 1.50) | 20.67 (\pm 2.11) | 24.83 (\pm 8.70) |
| | p = 0.358 | p = 0.164 | p = 0.481 |

Table 4. Unadjusted and adjusted analysis of oral health-related quality of life in patients assisted at Hospital for Rehabilitation of Craniofacial Anomalies, Brazil.

| Variables | Unadjusted | | | Adjusted | | |
|-------------|------------|-----------|--------|----------|-----------|--------|
| | RR | (95% CI) | p | RR | (95% CI) | p |
| Sex | | | 0.003 | | | <0.001 |
| Male | 1.00 | | | 1.00 | | |
| Female | 1.19 | 1.06-1.34 | | 1.21 | 1.09-1.35 | |
| Age (years) | | | <0.001 | | | <0.001 |
| < 20 | 1.00 | | | | | |
| \geq 20 | 1.23 | 1.10-1.37 | | 1.25 | 1.13-1.39 | |
| Skin color | | | 0.672 | | # | |

| | | | | |
|----------------------------|------|-----------|-------|---|
| White | 1.03 | 0.90-1.17 | | |
| Nonwhite | 1.00 | | | |
| Maternal education (years) | | | 0.191 | # |
| < 8 | 0.92 | 0.82-1.04 | | |
| ≥ 8 | 1.00 | | | |
| Patient education (years) | | | 0.006 | # |
| < 11 | 0.85 | 0.76-0.95 | | |
| ≥ 11 | 1.00 | | | |
| Family history | | | 0.492 | # |
| Positive | 0.95 | 0.83-1.09 | | |
| Negative | 1.00 | | | |
| Type of cleft | | | 0.617 | # |
| Incomplete | 1.00 | | | |
| Complete | 1.05 | 0.86-1.29 | | |
| Age at treatment | | | 0.508 | # |
| ≤ 6 months | 1.00 | | | |
| > 6 months | 0.95 | 0.83-1.10 | | |

#: Variable not carried forward into multivariate model / RR rate ratio.

Discussion

The present study confirms the hypothesis that the presence of cleft lip and palate has a negative impact on oral health-related quality of life. In addition, this study indicates that patients are affected differently by the malformation depending on gender and age. Planning for rehabilitative interventions and public policies focusing on oral health should take these findings into account.

Individuals born with cleft lip and/or palate may be affected by a combination of facial difference, swallowing and speech disorders, and various disturbances of dentition and growth [11]. Generally, treatment is long – beginning immediately after birth and extending into adolescence, if not longer – and affects many aspects of the individual's life [12]. Patients with CLP who are dissatisfied with their facial appearance may be at increased risk of developing social problems and withdrawal [12,13]. It is well known that the quality of the reconstructive and supportive procedures that an individual with a chronic health condition receives can have an impact on their health-related quality of life [14]. A recent systematic review and meta-analysis on overall and oral health-related quality of life in individuals with CLP showed the impact of these conditions on quality of life, especially in the psychosocial domain [15].

Oral diseases are known to have a major negative effect on quality of life. Furthermore, these conditions are often damaging to society due to their impact on academic performance and workplace productivity, as well as to high treatment costs. Pain, suffering, psychological issues, and social withdrawal are additional factors that can have negative impacts both individually and collectively [16]. Clinical assessment of the subjective impact of health and disease on the physical and psychosocial activities of the individual [16] is essential to any comprehensive approach to rehabilitation. Within this context, the use of OHRQoL instruments has many applications, including to support policy-building, research, public health interventions, and clinical management [17].

In the present study, female patients experienced a greater impact on OHRQoL. Overall, females appear to be more sensitive to perception of different levels of overall and oral health than males [17-19]. This finding is consistent with the literature, as women tend to be more dissatisfied with their facial appearance; furthermore, females with CLP tend to experience worse quality of life than males with the same condition [20]. Women are also more concerned with health overall, tend to ascribe greater value to medical attention, and better understand the concept that quality of life is associated with health and diseases [18].

Another notable finding of the present study is that older participants (aged ≥ 20 years) reported worse quality of life than their younger counterparts. Older subjects were 25% more likely to have high OHRQoL scores, indicating a negative impact of cleft lip and/or palate. A study showed that younger individuals experienced worse quality of life [21]. However, the association between age and quality of life remains controversial in the literature. A review of more than 60 studies found that age could influence the level of concern and psychosocial problems. Additional studies are warranted to assess this and evaluate how these issues could be addressed from a clinical standpoint [22].

On the VAS scale, patients reported satisfaction with dental appearance, which contributed positively to the impact on OHRQoL. This result may be explained by the comprehensive, multidisciplinary care that is provided since birth to all patients at the study facility, which is a referral hospital for patients with CLP from all across Latin America. In addition, our treatment protocols, which combine correction of dentition, tooth replacement, plastic surgery, and complete orthodontic and clinical follow-up, enable achievement of dental aesthetics consistent with normality.

One particularly noteworthy aspect concerns the main instrument we used to measure OHRQoL. The OHIP is considered a validated instrument to assess the main outcome of this study. However, authors conducted a review of measures used in patients with CLP and found 44 different instruments. The authors also mention there is a lack of comprehensive, valid, and reliable questionnaires for cleft lip and/or palate [22]. Unquestionably, quality of life should be evaluated in patients with CLP, while taking into account possible confounders, such as age. The fact that our sample was recruited from a referral hospital and that all patients had been followed at the study facility since birth mitigates other factors that could have interfered with our analyses. It has been suggested that other studies are necessary to confirm these findings.

Research into quality of life in patients with CLP is important, as it can help identify specific needs while taking subjective aspects into account. Furthermore, such research can support the development of public policies to reduce the economic and psychosocial burden of cleft lip and palate at the individual, family, and societal levels [9]. Moreover, the presence of this condition requires strategies for the reestablishment of aesthetics, function and psychological support for such individuals [23].

Conclusion

In general terms, OHRQoL in individuals with cleft lip/palate was worse than in their healthy counterparts without CLP. Gender differences were also found; females were affected more negatively than males. In addition, older individuals reported worse quality of life than younger ones. Further studies are needed to explore possible associations between CLP and OHRQoL.

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