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Evaluation of the Similarities and Differences in Response Patterns to the Pediatric Quality of Life Inventory and the Child Oral Health Impact Scores among Youth with Cleft

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Abstract

Purpose—To examine: 1) the pattern of responses to a generic health-related quality of life (HRQL) measure (Pediatric Quality of Life Inventory—PedsQL), and an oral health-related quality of life (OHRQoL) measure (Child Oral Health Impact Profile—COHIP), and 2) the associations of these scores with surgical recommendation status among youth with cleft.

Methods—Cross-sectional data (baseline) regarding clinicians' surgical recommendations and quality of life (QoL) measures were examined from an ongoing observational study on treatment outcomes. Approximately one-third of the racially and geographically diverse sample (N=1,200; x^- =11.6 years) received surgical recommendations to correct either visible (aesthetic) or invisible (functional) defects. Effect sizes were used to quantify differences in QoL based on surgical recommendation and to compare the sensitivity of the PedsQL and COHIP subscales. Using Pearson coefficients, the scores of those recommended for surgery were compared with those without a surgical recommendation.

Results—A moderate correlation (0.52) was found between the total scores on the PedsQL and COHIP (p<0.0001). Subscale correlations between the QoL measures ranged from 0.19 to 0.48 with the strongest correlation between the PedsQL Emotional (r=0.47) and COHIP Socioemotional Well-being subscale. The effect size for the COHIP Socioemotional Well-being (0.39) was larger than the PedsQL Social/Emotional (0.07/0.11) subscale (Z=5.30/Z=4.64, P<0.0001, respectively), and the total COHIP (0.31) was significantly greater than the total PedsQL scale (0.15, z=2.65, p=0.008).

Conclusions—A significant relationship was found between generic HRQL, OHRQoL, and surgical needs among youth with cleft with the COHIP having larger effect sizes than the PedsQL amongst surgical groups.

Keywords

quality of life; oral health-related quality of life; condition-specific scales; cleft/craniofacial; facial appearance; youth

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Quality of life (QoL) is a multidimensional construct that includes subjective evaluation of an individual's health, functional and socioemotional well-being, satisfaction with care, and sense of self [1–4]. Oral health-related quality of life (OHRQoL) allows for a shift from traditional clinical dental criteria such as caries or malocclusion to assessment and care that focus on a person's social, emotional, and physical experience. In the area of OHRQoL, youth with clefts are at risk for reduced QoL as they may have compromised functional well-being (e.g., impaired speech intelligibility and tooth development). Compromised functional well-being may reflect 'invisible' or functional defects while the facial appearance is a 'visible' or aesthetic defect. Further, coping with visible differences in facial appearance has been recognized as the most significant challenge impacting the well-being of youth with cleft [5–7].

OHRQoL in children with cleft is an important area of study since clefting is the second most common birth defect [8]. While the initial surgical repairs to the hard palate and lip are accomplished during the children's first year of life, habilitation often includes subsequent surgeries, and follow-up evaluations are typically completed every 12–24 months until early adulthood. In fact, cleft surgery may be recommended for youth to improve individuals' functional, social, and emotional well-being and thereby enhance their QoL as it relates to facial appearance, tooth and bone development, and speech.

Currently, health-related quality of life (HRQL) outcomes are being reported across health conditions from community-based epidemiological assessments to clinical trials, and over the past decade, the number of reports assessing HRQL and OHRQoL has increased. This growth has been most notable among pediatric populations [3]. Measuring OHRQoL in children can be problematic in longitudinal projects, however, that extend from one age grouping into another. The clear interpretation of explanatory factors and their association with OHRQoL and measured outcomes across different age groups can be challenging due to chronologically associated influences (i.e., specifically the transition into adolescence).

Regarding pediatric OHRQoL measures, the Child Oral Health Impact Profile (COHIP) [9] is the only scale developed and validated across a wide age span: 7–18 years using a cleft population. Further, the COHIP is congruent with current theoretical QoL perspectives that measure both negative as well as positive impacts [10–13]. To date, it has been used on pediatric community-based populations [14], treatment-seeking cleft, orthodontic and pediatric dental populations [9,15], and individuals with sickle cell [16] but has not been incorporated into treatment outcomes with patients having cleft conditions.

In general, HRQL instruments are categorized as either generic or condition-specific. Established generic HRQL instruments are advantageous over condition-specific measures as they often report normative data across a range of health conditions to facilitate comparisons across study populations. Generic instruments are commonly developed for descriptive epidemiological research applications for either adults or children/adolescents. The most widely utilized generic pediatric instruments are the Child Health Questionnaire (CHQ) [17], a 98-item self-report measure, and the Pediatric Quality of Life Inventory (PedsQL) [18], a 23-item measure. The advantage of both of these scales is that they can be used for children through 18 years of age.

Condition-specific instruments, on the other hand, are generally designed for application in clinical populations and are thought to be sensitive to change following treatment [19]. In the medical arena, numerous condition-specific (e.g., cancer, asthma) measures have been developed. From a theoretical perspective, the advantage of such measures may be that they are more sensitive to the specific symptoms and/or manifestations of the condition. Therefore, these instruments can be used for baseline assessments to identify impact of the

condition or clinical issues using subjective patient evaluations as well as for longitudinal evaluations to measure impact of treatment on the well-being of patient groups.

Limited data are available, however, that compare the scores and sensitivity between generic and condition-specific assessments of OHRQoL. Further, in developing theoretical models examining OHRQoL and longitudinal outcomes, it may be critical to understand the relationship between HRQL and OHRQoL [3].

The aims of this study are to understand the association between responses to the PedsQL, a generic measure, and the COHIP, an OHRQoL measure. We hypothesize that the two instruments will be correlated, yet the OHRQoL measure, the COHIP, will be more sensitive in measuring treatment needs of school-aged youth with cleft. Our second hypothesis is that youth with current surgical needs will have lower QoL and OHRQoL scores than youth with no surgical needs.

Methods

Procedure

School-aged treatment-seeking youth between 7-18 years old with cleft were recruited into the longitudinal, observational study examining QoL and related outcomes. The overall aim of the five-year multi-center is to improve our understanding of patient-oriented outcomes in school-aged children with cleft. The large study will be the first to examine clinically meaningful change among treatment-seeking children who undergo surgical intervention and a comparison group who do not undergo surgical intervention. The current analysis includes only baseline, cross-sectional data. Baseline enrollment began in March 2010 through August 2012; the project is currently evaluating participants and their caregivers for their two and three year follow-up visits. Inclusion criteria are: (a) children ages 8–17 years old with cleft lip/palate (CLP) and cleft palate only (CPO) and their caregivers seeking care at the study sites; and (b) children who speak English or Spanish at least at the second grade level. Exclusion criteria for cross-sectional and longitudinal studies are: (a) children with an incomplete cleft lip without cleft of the alveolus; and (b) children with a classified craniofacial syndrome or other complex medical condition. As per the IRB-approved protocol, dyads (youth with cleft and their caregivers) being evaluated at one of six prominent, geographically diverse cleft centers were asked to participate in the study. Consent and assent forms were signed by all participants with an average recruitment rate of over 90%. The patient participants completed baseline questionnaire packets and then had their scheduled clinical evaluations from the centers' multidisciplinary team of specialists (e.g., plastic surgeons, dentists, speech and language pathologists). They received a \$40 gift card for their time and effort.

Measures

The Pediatric Quality of Life Inventory (PedsQL Version 4.0) is a 23-item self-report generic QoL questionnaire that is widely used in health, school, and community populations as well as in pediatric populations with acute and chronic health conditions [20]. This instrument is appropriate for children ages five to eighteen years and has good test/retest reliability (*r* range, .75–.90) [21]. The discrete domains include: Health and Activities; Emotional Well-being; Social Well-being, and School. The domains identify problems or deficits in these areas. It uses a five-point scale from 'Never' to 'Almost Always.' The PedsQL has strong psychometric properties (e.g., Cronbach alphas ~.90) [20].

The Child Oral Health Impact Profile (COHIP) is a 34-item self-report OHRQoL measure with five discrete domains [9]. Oral Health includes varied/specific oral symptoms (e.g.,

tooth pain, bleeding gums); Functional Well-being reveals ability to carry out daily functions (e.g., eating, speaking clearly); Socioemotional Well-being addresses peer interactions and mood states; School/Environment involves tasks associated with school; and Self-esteem incorporates positive feelings about oneself. The COHIP has been shown to discriminate within and between diagnostic groups based on the extent of the condition (e.g., orthodontic needs, caries status, and treatment needs) [9,22]. Reports yield excellent psychometric properties (e.g., internal consistency and strong test-retest reliability). The COHIP uses a five-point scale ranging from 'never' to 'almost always.'

As part of the standard of care, clinical evaluations by the teams' plastic surgeons were completed independently to determine whether the participants had surgical needs warranting surgical intervention within one year. The research packet also includes demographic data.

Data Analysis

All variables were summarized using means and standard deviations for continuous measures or frequencies and percentages for categorical variables. Relationships between categorical variables were assessed using Pearson's Chi Square test, and differences in QoL scales between the surgery recommended and non-surgery recommended groups were assessed using independent sample T tests. Relationships between QoL scales were assessed using Pearson's Correlation coefficients. Like subscales between the two QoL measures were matched to establish paired subscales. The group means and standard deviations from the T tests for surgical groups were converted to Cohen's d statistics [23] to enable comparison of the effect sizes for the subscale pairs. Using a normal theory test described by Lambert [24], the effect sizes between scale pairs of the PedsQL and COHIP were compared to measure the sensitivity of the two measures. Finally, in order to compare impact scores by surgical recommendation group, a post-hoc Severity Prevalence Score was calculated by combining the items, 'sometimes,' 'fairly often,' and 'almost all of the time' in the two subscales with the highest correlation—the COHIP Socioemotional Well-being and PedsQL Emotional Well-being subscales [25].

Results

Descriptives

The study sample includes 1200 patients (x =11.6 years, s.d. = 3.1) evaluated at six prominent and geographically diverse U.S. cleft centers. Of the sample, 76.1% (N=913) had cleft lip and palate, with the remainder (N=287) being cleft palate only. Forty-four percent (N=526) was female. Self-reported racial identification included: 68% White (N=813), 11% Asian (N=128), 10% Black (N=117), 12% other (N=142); self-reported ethnicity revealed that 16% (N=193) identified as Hispanic. Approximately one-third (N=433) of the participants received a surgical recommendation (current surgical need) which involved either visible (aesthetic) defects like lip/nose appearance (n=208, 48%, includes subjects with both) or invisible (functional) defects like speech (n=225, 52%). As expected, surgery was recommended more often in subjects with cleft lip and palate (CLP) (40.9%, n=491) than in those with cleft palate only (20.9%, n=251) (χ^2 =37.8, df=1, p<0.0001), as the individuals with CLP have visible and functional defects.

Table 1 shows comparisons of the PedsQL subscales between the surgery recommended (current surgical need) and non-surgical recommendation groups. All PedsQL scores, with the exception of the Emotional and Social Functioning Scales, were significantly lower in those subjects with a surgical recommendation than those without such a recommendation; the differences, however, were small in magnitude. It is important to note that total scores

among youth with CLP were lower than reported scores for normative samples both for the COHIP (102 with a standard deviation of 3.0) [9] and the PedsQL (79.62 with a standard deviation of 15.26) [20]. The Cronbach's Alpha values were: Physical Functioning Scale = 0.77, Emotional Functioning Scale = 0.77, Social Functioning Scale = 0.61, School Functioning Scale = 0.70, Psychosocial Health Summary = 0.86 and Total QoL = 0.89.

Table 2 reveals the results of the COHIP subscales for the surgical and non-surgical recommendation groups. All COHIP scores except for Self-Esteem differed between the two groups with QoL scores lower in those recommended for surgery, although most differences were small. The number of subjects differs among the domains of the COHIP and PedsQL due to some missing item data across domains. The Cronbach's Alpha values for the subscales and total were: Oral Symptoms = 0.70, Functional Well-Being = 0.70, Socioemotional Well-Being = 0.87, School/Environmental = 0.61, Self Esteem = 0.71, and Total COHIP QoL = 0.89.

All subscales of the PedsQL were then correlated to all subscales of the COHIP (Table 3). Correlations were small to moderate in all cases, though all were highly statistically significant due to the sample size. They ranged from 0.19 to 0.48 with the strongest correlations between the COHIP Socioemotional Well-being subscale and the PedsQL Emotional (r=0.47) and Social subscales (r=0.43). In addition, the total scores of each instrument were moderately correlated (r=0.52, n=1120, p<0.0001). For each subscale of the PedsQL, the subscale of the COHIP with the highest correlation was identified to form pairs of subscales.

The effects sizes of these paired subscales were then calculated and compared statistically (Table 4). In four pairs of scales, the COHIP subscale effect size was significantly larger than the paired PedsQL subscale. Additionally, there was a significant difference between the total COHIP score and the total PedsQL score (z=2.65, p=0.008). Finally, the effect size for the COHIP Socioemotional Well-being (0.39) subscale is larger than the effect size for the PedsQL Social/Emotional (0.07/0.11) subscales (Z=5.30/Z=4.64, P<0.0001, respectively). In both of these cases, the COHIP scale statistically differed between the surgical recommendation group and those without recommendation (p<0.0001), while the PedsQL scales did not reveal significant differences between the two groups (p=0.0642 and p=0.2443).

A post-hoc comparison assessed impact scores by type of surgical recommendation by examining the participant responses in the two subscales with the highest correlations (Tables 5a and 5b). Those reporting 'sometimes,' 'fairly often,' and 'almost all of the time' were identified and combined to form a total Severity Prevalence score (last column) for each item. Those participants with a recommendation for surgery within one year had greater impact scores across every item on the COHIP Socioemotional Well-being subscale than individuals without a surgical recommendation. This finding was in the expected direction. The proportion of those participants reporting severity impact in the recommended surgery group was 35–56% across the COHIP Socioemotional Scale items. The greatest impact items (in which at least 50% reported a Severity Prevalence score) were: 'felt you look different' and 'been worried about what other people think.' Table 5b illustrates the findings from the PedsQL Emotional Functioning subscale. The impact score of the surgery recommended group differed among the scales compared to the no recommendation group (the total impact score in the surgery recommended group was greater in three scales and essentially equal in two scales). It is also noteworthy that the Severity Prevalence scores endorsement rate ranged from 30-49% in the surgery group. In summary, the Severity Prevalence scores were greater on the COHIP measure than on the comparable PedsQL

subscale. Further, those in the no surgical recommendation group had, on average, lower severity scores than the surgery recommended group across both measures.

Discussion

This paper furthers our understanding of the association between youths' responses to the PedsQL and the COHIP. While our first hypothesis that participant scores on the two instruments would be significantly correlated is supported, the subscales of these QoL instruments have small to moderate associations with one another with the COHIP showing larger effect sizes than the PedsQL in this large study sample. Support was also found for our second hypothesis in that the differences between the surgical recommendation and non-recommendation groups were greater for the COHIP than for the PedsQL.

One explanation for this difference may be in how the respondents react to the focus of the questions. In comparing the items with similar constructs in the Emotional Functioning domain of the PedsQL and the Socioemotional Well-being domain of the COHIP, the results differ. The PedsQL has an item, 'I feel sad or blue,' which is well matched with the COHIP question, 'Been unhappy or sad because of your teeth, mouth or face.' While the stem questions are similar, the COHIP item specifically attributes feelings to oral health while the PedsQL item does not. Thus, the larger effect size found with the COHIP could be due to the fact that these youth with oral-facial anomalies have stronger feelings regarding well-being associated with the mouth or face.

The results of this study are consistent with two other studies that compared results using a generic HRQL and an OHRQoL measure. One study, which included community-based adolescents who completed the SF-36 (the most widely used adult HRQL measure) as well as the Oral Health Impact Profile (OHIP 14) (the most-widely used OHRQoL measure in adults) found that the OHIP is more sensitive than the SF-36 when examining unmet dental needs (e.g., caries)[26]. The other study examined parental responses using the PedsQL and another OHRQoL measure for preschool children. The authors reported better discriminant validity by disease status using the OHRQoL measure [27].

Within the Social and Emotional Well-being domain where the strongest correlations between the two measures were observed, the Severity Prevalence scores (endorsement ratings) on the PedsQL items are uniformly lower than the Severity Prevalence scores on the COHIP items. Additionally individuals with no surgical needs had lower OHRQoL scores across the COHIP scales. Our results support previous cross-sectional reports using smaller study samples [28,29]. The stigmatization and impact on QoL has been reported cross-sectionally in smaller samples among those with facial differences. Additionally, a consistent pattern was observed on the COHIP scales indicating that those with no surgical needs reported the lowest impact scores on each item compared to those with current surgical needs. This pattern was inconsistent on the PedsQL. These findings likely represent the sensitivity of the COHIP items to patients' current needs and support prior research findings relating to the importance of condition-specific measures for understanding treatment needs in specific patient populations [30–33].

Our findings also support the use of other pediatric disease-specific instruments like the Childhood Asthma Questionnaires [31] and the Pediatric Cancer Quality of Life Inventory [34] in that children with symptoms or current needs to be addressed have lower scores than those with generic concerns. Given the size of the study sample, subgroups will be examined as well as our ability to utilize sophisticated analytic techniques of the longitudinal data. While surgeons purport that surgical procedures improve quality of life, to date we are unclear whether outcomes impact specific quality of life issues for this patient population

and/or whether the impact extends to general quality of life. Theoretically, enabling factors and sociodemographic factors have been associated with unmet surgical needs [22] which is not addressed in this paper. Given the relevance of body image and facial attractiveness as it relates to teasing and social and emotional well-being [35], post-treatment analyses will provide insight regarding clinically meaningful change and test the evaluative properties of generic as well as condition-specific quality of life outcomes in this population. Such data are needed to support current theoretical models [36].

Because individuals with clefts are followed regularly until adulthood regardless of their current needs these findings are not likely attributable to the fact that these patients were specifically treatment-seeking and thus represent individuals with greater needs or concerns. Despite the fact that the vast majority of US children (80–85%) receive treatment for clefts at ACPA recognized cleft/CFA centers, these results may not be generalizable to individuals with clefts who are not served at tertiary care centers.

On a practical level, it is imperative for cleft/craniofacial teams to routinely address quality of life issues for their patients as well-being and satisfaction may be beyond the millimeters of tissue and bone that are addressed through surgery. Given the risk factors for psychological well-being in this population, the American Cleft Palate Association's Parameters for Care [37] endorses that cleft teams have multidisciplinary membership including mental health specialists to routinely address social and emotional QOL issues during patient and family evaluations and treatment. Such screening may lead to creating interventions that focus on patient and caregiver-based perspectives [35].

In short, a limitation in this study is that no data are yet available regarding the instruments' responsiveness to the effect of treatment on QoL. Therefore, longitudinal analyses can be increasingly relevant when examining impact of care and increased understanding of current theoretical models [36,3]. Given the variable trajectory of care across this patient population, it is unclear whether patients who have no immediate surgical needs may later require surgical intervention and whether there are optimal ages in which improvements in patient well-being scores occur subsequent to surgical intervention. Future study will reveal responsiveness of the measures to treatment as well as potential effect size differences. Additionally this study has not addressed potential mediating and moderating effects of other factors like gender and age as well as psychological factors like resilience that may be associated with quality of life [38,35]. The longitudinal piece will be the first study to examine efficaciousness of surgery on QoL in this population. Further investigation will examine whether surgery that addresses 'invisible' defects like speech or dentition versus visible issues like facial appearance have a varying impact on specific quality of life domains as well as overall well-being.

Conclusion

This study supports the theoretical model that QoL and OHRQoL are interrelated [3]. Yet the Child Oral Health Impact Profile, an OHRQoL measure, reveals greater sensitivity to issues of clinical importance to cleft populations among youth followed by treatment centers in this cross-sectional study.

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References

- Skevington SM, Lotfy M, O'Connell KA. The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial - A report from the WHOQOL group. Quality of Life Research. 2004; 13(2):299–310. [PubMed: 15085902]
- Allen PF. Assessment of oral health related quality of life. Health and Quality of Life Outcomes. 2003; 1:40. 1477-7525-1-40 [pii]. 10.1186/1477-7525-1-40 [PubMed: 14514355]
- Sischo L, Broder HL. Oral health-related quality of life: what, why, how, and future implications. Journal of Dental Research. 2011; 90(11):1264–1270.10.1177/0022034511399918 [PubMed: 21422477]
- 4. Cella DF. Quality-of-Life Concepts and Definition. Journal of Pain and Symptom Management. 1994; 9(3):186–192.10.1016/0885-3924(94)90129-5 [PubMed: 8014530]
- Broder HL, Smith FB, Strauss RP. Effects of Visible and Invisible Orofacial Defects on Self-Perception and Adjustment across Developmental Eras and Gender. Cleft Palate-Craniofacial Journal. 1994; 31(6):429–436. [PubMed: 7833334]
- Rumsey N, Harcourt D. Visible difference amongst children and adolescents: issues and interventions. Developmental Neurorehabilitation. 2007; 10(2):113–123. [PubMed: 17687984]
- Bilboul MJ, Pope AW, Snyder HT. Adolescents with craniofacial anomalies: Psychosocial adjustment as a function of self-concept. Cleft Palate-Craniofacial Journal. 2006; 43(4):392–400. [PubMed: 16854195]
- Canfield MA, Ramadhani TA, Yuskiv N, Davidoff MJ, Petrini JR, Hobbs CA, et al. Improved national prevalence estimates for 18 selected major birth defects - United States, 1999–2001 (Reprinted from MMWR, vol 54, pg 1301–1305, 2006). Jama-Journal of the American Medical Association. 2006; 295(6):618–620.
- Broder HL, Wilson-Genderson M. Reliability and convergent and discriminant validity of the Child Oral Health Impact Profile (COHIP Child's version). Community Dentistry and Oral Epidemiology. 2007; 35(Suppl 1):20–31. COM402 [pii]. 10.1111/j.1600-0528.2007.0002.x [PubMed: 17615047]
- Ware JE, Kosinski M, Keller SD. A 12-item short-form health survey. Construction of scales and preliminary tests of reliability and validity. Medical Care. 1995; 34:220–233. [PubMed: 8628042]
- 11. Landgraf JM, Maunsell E, Speechley KN, Bullinger M, Campbell S, Abetz L, et al. Canadian-French, German and UK versions of the Child Health Questionnaire: methodology and preliminary item scaling results. [Research Support, Non-U.S. Gov't]. Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation. 1998; 7(5):433– 445.
- McGrath C, Broder H, Wilson-Genderson M. Assessing the impact of oral health on the life quality of children: implications for research and practice. Community Dentistry and Oral Epidemiology. 2004; 32(2):81–85. [PubMed: 15061856]
- Edwards TC, Huebner CE, Connell FA, Patrick DL. Adolescent quality of life, part I: conceptual and measurement model. J Adolesc. 2002; 25(3):275–286. S0140197102904707 [pii]. [PubMed: 12128038]
- Ravaghi V, Ardakan MM, Shahriari S, Mokhtari N, Underwood M. Comparison of the COHIP and OHIP- 14 as measures of the oral health-related quality of life of adolescents. Community Dental Health. 2011; 28(1):82–88. [PubMed: 21485241]
- Dunlow N, Phillips C, Broder HL. Concurrent validity of the COHIP. Community Dentistry and Oral Epidemiology. 2007; 35(Suppl 1):41–49. COM404 [pii]. 10.1111/j.1600-0528.2007.00404.x [PubMed: 17615049]
- 16. Ralstrom, E. The Impact of Oral Health in Adolescents with Sickle Cell Disease. The Ohio State University; Columbus: 2010.
- Landgraf JM, Maunsell E, Speechley KN, Bullinger M, Campbell S, Abetz L, et al. Canadian-French, German and UK versions of the Child Health Questionnaire: methodology and preliminary item scaling results. Quality of Life Research. 1998; 7(5):433–445.10.1023/A: 1008810004694 [PubMed: 9691723]

- Varni JW, Seid M, Kurtin PS. PedsQL (TM) 4.0: Reliability and validity of the pediatric quality of life Inventory (TM) Version 4.0 generic core scales in healthy and patient populations. Medical Care. 2001; 39(8):800–812.10.1097/00005650-200108000-00006 [PubMed: 11468499]
- Juniper EF, Guyatt GH, Cox FM, Ferrie PJ, King DR. Development and validation of the Mini Asthma Quality of Life Questionnaire. European Respiratory Journal. 1999; 14(1):32–38. [PubMed: 10489826]
- Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. [Multicenter Study Research Support, Non-U.S. Gov't Validation Studies]. Medical care. 2001; 39(8):800–812. [PubMed: 11468499]
- McCarthy ML, MacKenzie EJ, Durbin DR, Aitken ME, Jaffe KM, Paidas CN, et al. The pediatric quality of life inventory: An evaluation of its reliability and validity for children with traumatic brain injury. Archives of Physical Medicine and Rehabilitation. 2005; 86(10):1901–1909.10.1016/ j.apmr.2005.03.026 [PubMed: 16213229]
- 22. Broder HL, Wilson-Genderson M, Sischo L. Health Disparities Among Children With Cleft. American Journal of Public Health. 201210.2105/AJPH.2012.300654
- 23. Cohen J. A Power Primer. Psychological Bulletin. 1992; 112(1):155-159. [PubMed: 19565683]
- Lambert, RG.; Flowers, C. A Procedure for Testing the Difference between Effect Sizes. Paper presented at the Annual Meeting of the American Educational Research Association; San Diego, CA. April 13–17, 1998; 1998.
- 25. Sanders AE, Slade GD, Lim S, Reisine ST. Impact of oral disease on quality of life in the US and Australian populations. Community Dentistry and Oral Epidemiology. 2009; 37(2):171– 181.10.1111/j.1600-0528.2008.00457.x [PubMed: 19175659]
- Broder HL, Slade G, Caine R, Reisine S. Perceived impact of oral health conditions among minority adolescents. Journal of Public Health Dentistry. 2000; 60(3):189–192. [PubMed: 11109217]
- Lee GHM, McGrath C, Yiu CKY, King NM. A comparison of a generic and oral health-specific measure in assessing the impact of early childhood caries on quality of life. Community Dentistry and Oral Epidemiology. 2010; 38(4):333–339.10.1111/j.1600-0528.2010.00543.x [PubMed: 20406271]
- Masnari O, Schiestl C, Rossler J, Gutlein SK, Neuhaus K, Weibel L, et al. Stigmatization predicts psychological adjustment and quality of life in children and adolescents with a facial difference. Journal of Pediatric Psychology. 2013; 38(2):162–172. jss106 [pii]. 10.1093/jpepsy/jss106 [PubMed: 23172874]
- Patrick DL, Topolski TD, Edwards TC, Aspinall CL, Kapp-Simon KA, Rumsey NJ, et al. Measuring the quality of life of youth with facial differences. Cleft Palate-Craniofacial Journal. 2007; 44(5):538–547. 06-072 [pii]. 10.1597/06-072.1 [PubMed: 17760483]
- Juniper EF, Guyatt GH, Willan A, Griffith LE. Determining a minimal important change in a disease-specific Quality of Life Questionnaire. Journal of Clinical Epidemiology. 1994; 47(1):81– 87. 0895-4356(94)90036-1 [pii]. [PubMed: 8283197]
- Christie M, French D, Sowden A, West A. Development of child-centered, disease-specific questionnaires for living with asthma. Psychosomatic Medicine. 1993; 55:541–548. [PubMed: 8310115]
- Wiebe S, Guyatt G, Weaver B, Matijevic S, Sidwell C. Comparative responsiveness of generic and specific quality-of-life instruments. Journal of Clinical Epidemiology. 2003; 56(1):52–60. Pii S0895-4356(02)00537-1. 10.1016/S0895-4356(02)00537-1 [PubMed: 12589870]
- Patrick DL, Deyo RA. Generic and Disease-Specific Measures in Assessing Health-Status and Quality of Life. Medical Care. 1989; 27(3):S217–S232.10.1097/00005650-198903001-00018 [PubMed: 2646490]
- Varni JW, Katz ER, Seid M, Quiggins DJL, Friedman-Bender A, Castro CM. The Pediatric Cancer Quality of Life Inventory (PCQL). I. Instrument development, descriptive statistics, and crossinformant variance. Journal of Behavioral Medicine. 1998; 21(2):179–204.10.1023/A: 1018779908502 [PubMed: 9591169]

- 35. Feragen KB, Kvalem IL, Rumsey N, Borge AIH. Adolescents with and without a facial difference: The role of friendships and social acceptance in perceptions of appearance and emotional resilience. Body Image. 2010; 7(4):271–279.10.1016/j.bodyim.2010.05.002 [PubMed: 20541483]
- Wilson IB, Cleary PD. Linking Clinical-Variables with Health-Related Quality-of-Life a Conceptual-Model of Patient Outcomes. Jama-Journal of the American Medical Association. 1995; 273(1):59–65.10.1001/jama.273.1.59
- American Cleft Palate Association. Parameters for the evaluation and treatment of patients with cleft lip/palate or other craniofacial anomalies (Revised Edition--November 2009). Cleft Palate Craniofac J. 1993; 30(Suppl 1)
- 38. Moksnes UK, Espnes GA. Self-esteem and life satisfaction in adolescents-gender and age as potential moderators. Qual Life Res. 201310.1007/s11136-013-0427-4

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Recommendation
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Peds

SCALEAll SubjectsPhysical Functioning Scale85.2 (15.4)Emotional Functioning Scale73.4 (20.2)Social Functioning Scale79.4 (19.6)School Functioning Scale70.5 (18.6)	No SURG REC Mean ± SD 86.0 (15.3) 74.2 (20.0) 70.0 (10.0)	SURGREC T Mean ± SD 83.7 (15.6) 2.47 71.9 (20.4) 1.85	Т	DF	Р
<u></u>	86.0 (15.3) 74.2 (20.0) 79.9 (19.0)	83.7 (15.6) 71.9 (20.4)			
ale	74.2 (20.0) 79.9 (19.9)	71.9 (20.4)	2.47	1133	0.0138
	70 0 (10 0)	70 2 110 12	1.85	1132	0.0642
	((((1))))	1.124 01.1 (1.61) 0.8/	1.16	1124	0.2443
	71.6 (19.0)	68.7 (17.8)	2.48	1132	0.0132
Psychosocial Health Summary 74.5 (16.1)	75.3 (16.5)	73.1 (15.3)	2.23	1124	0.0260
Physical Health Summary85.2 (15.4)	86.0 (15.3)	83.7 (15.6)	2.47	1133	0.0138
TOTAL 78.2 (14.4)	79.0 (14.8)	76.8 (13.5) 2.57 1124	2.57	1124	0.0102

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Table 2

COHIP by Surgical Recommendation

Being	Mean ± SD Mean ± SD 25.8 (6.5) 24.5 (6.4)		•		
		Mean ± SU			•
		24.5 (6.4)	3.36	3.36 1183	0.0008
	18.3 (4.5)	17.2 (4.6)	4.23	1187	<0.0001
	24.5 (6.5)	21.8 (7.6)	5.95	1186	<0.0001
School/Environment 13.3 (2.9)	13.6 (2.8)	13.0 (3.0)	3.26	1186	0.0011
Self-Esteem 16.9 (4.5)	17.0 (4.6)	16.7 (4.5)	06.0	1184	0.3686
TOTAL 96.9 (18.7)	99.0 (18.2)	93.2 (19.0)	5.24	5.24 1188	<0.0001

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TOTAL

Self-Esteem 0.190.260.250.210.290.19

			COHIP		
PedsQL	Oral Health	Functional Well-being	Socio- Emotional Well-being	School/Environment	
Physical Functioning Scale	0.22	0.32	0.21	0.25	
Emotional Functioning Scale	0.34	0.36	0.47	0.36	
Social Functioning Scale	0.28	0.36	0.43	0.35	
School Functioning Scale	0.30	0.33	0.28	0.32	
Psychosocial Health Summary	0.37	0.42	0.48	0.42	
Physical Health Summary	0.22	0.32	0.21	0.25	
TOTAL					
NOTE:					

* All correlations are statistically significant p<0.0001.

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0.52

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Table 4

Effect size Comparisons between the PedsQL and COHIP by Domain

PedsQL Scale	Effect Size	COHIP Scale	Effect Size	Z	Р
Physical Functioning	0.15	Functional Well-Being	0.24	1.49	1.49 0.135
Emotional Functioning	0.11	Socioemotional	0.39	4.64	<0.0001
Social Functioning	0.07	Socioemotional	0.39	5.30	<0.0001
School Functioning	0.16	School/Environment	0.21	0.83	0.406
Psychosocial Summary	0.14	Socioemotional	0.39	4.14	<0.0001
TOTAL	0.15	TOTAL	0.31	2.65	0.008

Table 5a

Severity Prevalence for PedsQL Emotional Functioning Domain Items by Surgical Recommendation Group

			Severity Prevalence	ence	
Item	Group	Sometimes N (%)	Fairly Often N (%)	Almost All of the Time N (%)	Total Severity Prevalence N (%)
المشموم معالم المحلي	Surgery Rec	115 (28)	16 (4)	7 (2)	138 (33)
	No Surgery	192 (25)	28 (4)	19 (3)	239 (32)
الفيما ممطحه المحال	Surgery Rec	125 (30)	21 (5)	4 (1)	150 (36)
T TEEL SAU OF DIME	No Surgery	185 (24)	33 (4)	15 (2)	233 (30)
T fool on one	Surgery Rec	153 (37)	35 (8)	13 (3)	201 (49)
	No Surgery	250 (33)	47 (6)	23 (3)	320 (42)
ممنامده ام المانيمية مبيدها ا	Surgery Rec	77 (19)	28 (7)	20 (5)	125 (30)
	No Surgery	155 (21)	41 (5)	28 (4)	224 (30)
Trinomer about what will have to mo	Surgery Rec	104 (25)	49 (12)	29 (7)	182 (44)
т wony acout what whit happen to me	No Surgery	175 (23)	49 (6)	52 (7)	276 (36)

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Table 5b

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Severity Prevalence for COHIP Socioemotional Well-being Domain Items by Surgical Recommendation Group

			Severity Prevalence		
Item *	Group	Sometimes N (%)	Fairly Often N (%)	Almost All of the time N (%)	Total Severity Prevalence N (%)
Been unhappy or sad because of your teeth, mouth, or face	Surgery Rec	101 (23)	40 (9)	39 (9)	180 (42)
	No Surgery	120 (16)	53 (7)	32 (4)	205 (27)
Felt worried or anxious because of your teeth, mouth, or face	Surgery Rec	101 (23)	38 (9)	20 (5)	159 (37)
	No Surgery	146 (19)	35 (5)	21 (3)	202 (27)
Felt shy or withdrawn because of your teeth, mouth, or face	Surgery Rec	107 (25)	27 (6)	35 (8)	169 (40)
	No Surgery	118 (16)	48 (6)	28 (4)	194 (26)
Avoided smiling or laughing with other children because of your teeth, mouth or face	Surgery Rec	79 (18)	23(5)	22(5)	142 (29)
	No Surgery	101 (13)	38 (5)	35 (5)	174 (23)
Been teased, bullied or called names by other children because of your teeth, mouth or face	Surgery Rec	72 (16)	38 (9)	42 (10)	152 (35)
	No Surgery	109 (14)	39 (5)	53 (7)	201 (26)
Felt that you look different because of your teeth, mouth or face	Surgery Rec	126 (29)	57 (13)	57 (13)	240 (56)
	No Surgery	157 (21)	73 (10)	53 (7)	283 (38)
Been worried about what other people think about your teeth, mouth or face	Surgery Rec	122 (28)	42 (10)	52 (12)	216 (50)
	No Surgery	168 (22)	61 (8)	58 (8)	287 (38)
Been upset or uncomfortable with being asked questions about your teeth, mouth, or face	Surgery Rec	113 (26)	40 (9)	58 (13)	211 (49)
	No Surgery	156 (21)	52 (7)	64 (8)	272 (36)

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