Health-Related Quality of Life in Craniofacial Conditions

Concordance Between Child and Parent Reports

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Introduction: Craniofacial conditions (CFCs) profoundly influence health-related quality of life (HRQoL). In children with CFCs, patient-reported outcome measures have become an integral adjunct to more objective surgical outcome measures. Patient-reported outcome measures are designed to assess HRQoL domains. Few studies have evaluated parent and child agreement about HRQoL in the context of CFCs. The aims of this study were to explore the impact of CFCs on HRQoL domains in children and their parents and to determine whether patient and parent perspectives converge.

Methods: The Craniofacial Conditions Quality of Life Scale (CFC-QoL) is a newly developed 5-domain survey available in child self-report and parent report and in English- and Spanish-language versions. The 5 domains are the following: social impact, psychological function, physical function, family impact, and appearance impact. Children with CFCs (ages 7–21 years) and parents of children with CFCs were recruited via the craniofacial care team clinic at a major metropolitan children's hospital. All children and parents completed the CFC-QoL Scale in their preferred language of English or Spanish. Scale internal consistencies were calculated for child patients and parents, for English and Spanish versions. Scores on the 5 domains were compared for children and parents across English versus Spanish versions.

Results: For children with CFCs (N = 75), the sex was distributed almost equally. Patients were mostly Hispanic (69.3%), and their ages ranged from 7 to 21 years old (M = 13.2, SD = 3.62). The mean values for patient and parent scores were low, suggesting good HRQoL across all 5 domains. Pearson correlation coefficients were computed to explore the interrelationships between patient and parent report for each of the 5 CFC-QoL subscales. For the total sample, patient and parent scores were significantly and moderately positively correlated for all subscales. When analyzed separately based on sex, ethnicity, and diagnostic group, the correlation patterns were not identical to those found for the total sample. When analyzed separately for diagnostic group, there was less consistency in patterns, with patient-parent dyads showing different levels of agreement based on child's diagnostic grouping.

Conclusions: Although there is substantial agreement between parents and patients when considered on a group level, there is moderate agreement between patients and parents when considered at the dyadic level, underscoring the importance of measuring and considering both perspectives.

Key Words: health-related quality of life, pediatric, patient-reported outcome measure, quality of life, craniofacial conditions, craniofacial

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The face is a unique portal of the human body that allows us to communicate social, personal, and even genetic characteristics.[1–3] Deformities of the face have the ability to significantly impact an individual's development in multiple domains. Genetic or acquired deformities of the bones and soft tissues of the head and face are known as craniofacial conditions (CFCs). Some CFCs, such as cleft palate, are common with an incidence of 5.9 in 10,000 live births.[4] Other CFCs, such as craniosynostosis, hemifacial microsomia, and microtia, are less common. Craniofacial conditions are known to have a profound impact on health-related quality of life (HRQoL), affecting psychosocial development and function in the growing child.[5–8] Treatment of CFCs is often complex and long-lasting, with the average child undergoing 8.6 surgical procedures for cleft lip and palate before the age of 21 years,[9] contributing to the need for multidisciplinary care by surgeons, nurses, speech pathologists, psychologists, and orthodontists.

To examine outcomes for pediatric patients with diverse CFCs, self-reported questionnaires, known as patient-reported outcome measures (PROMs), have become an integral adjunct to more objective tools, such as anatomical evaluations, serial photography, morbidity, and mortality.[10] Patient-reported outcome measures are designed to assess HRQoL domains, which generally include physical, social, and psychological metrics.[11,12] Patient-reported outcome measures have been successfully applied to identify subsets of patients with CFCs who may be at higher risk for psychosocial dysfunction.[13] The results of PROMs provide information about what the patient finds the most important and can be an invaluable tool for determining the best treatment plans and further improving quality of care.

Parental perspectives are an important consideration in the management of diverse CFCs and the evaluation of HRQoL. Many areas of pediatric research rely on HRQoL information observed and reported by the parent or guardian.[14] The parent often acts as a proxy reporter when age, condition, or capacity prevents children from reporting directly on their own, or the parent's perspective is measured in addition to the child's. However, in many cases where the child is able to self-report, the proxy report may differ significantly from the patient's.[15,16] The current literature finds disagreement between child and parent proxy reports with parents often reporting more negative levels of HRQoL compared with their child.[17] One study found nuance among domains of HRQoL in which parents and children mostly agreed when it came to physical functioning but disagreed when reporting unobservable domains, such as social or emotional function.[18] However, these studies all focused on HRQoL among children with chronic conditions such as cancer and cystic fibrosis.[19,20] Few studies have evaluated parent and child agreement about HRQoL in the context of CFCs, although there is some evidence for congruency between children's and caregivers' perceptions in cases of orofacial clefts.[21,22] It is crucial to understand the relationship between parent- and patient-reported HRQoL among patients with CFCs to better understand the degree to which perspectives overlap or disagree across various domains, as this may impact decision-making about treatment needs and options.

Among patients with CFCs, a significant proportion are Hispanic. Hispanics make up 46% of patients with cleft lip and/or palate treated in California.[23] Approximately 13% of the US population overall uses Spanish as their primary language at home,[24] and the US Census

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Bureau estimates a 233% increase in Spanish language speakers (11–37 million) in the United States from 1980 to 2010.[25] However, few self-report HRQoL tools exist in Spanish for either pediatric patients or their parents to evaluate CFCs within this population. Spanish-speaking and Hispanic patients and/or parents may perceive and interpret HRQoL in different ways than their English-speaking and non-Hispanic peers; research is needed to explore the perspectives of Hispanic patients with CFCs and their parents.

The aims of this study was to explore the impact of CFCs on HRQoL domains in children and their parents and to determine whether patient and parent perspectives converge. Through administration of a new HRQoL measure with parallel patient and parent report forms in English and Spanish, we assessed the degree of correspondence in responses between children with CFCs and their parents in a diverse population from Rady Children's Hospital in San Diego. Additional comparisons of degree of patient-parent concordance across HRQoL domains were made on the basis of sex, ethnicity, and primary diagnosis.

METHODS

Participants

Patients diagnosed with CFCs and their parents were recruited to the study from the multidisciplinary craniofacial clinic at Rady Children's Hospital San Diego, San Diego, CA. Craniofacial condition–eligible diagnoses included the following: bilateral cleft lip and palate, unilateral cleft lip and palate, isolated cleft lip, dermatological conditions (including vascular anomalies, congenital nevi, and other visible dermatologic diagnoses), craniosynostosis, microsomia, microtia, and acquired conditions (including traumatic deformities such as scars, deformities after facial fractures, burns, and other visible signs of injury or necessary intervention). Recruitment activities occurred from March 2017 to April 2019. Patients (7–21 years old) and parents were recruited as dyads during routine clinic visits and asked to complete the survey in their preferred language of English or Spanish. Research assistants asked both patients and parents to complete their respective surveys independently. Patients were eligible if they were 7 years or older, diagnosed with one of the previously mentioned CFC diagnoses, had normal cognition appropriate for their age, and were able to communicate with staff regarding HRQoL questions. Among eligible patients, only one parent was required to complete the parent proxy report. Patients and/or parents who did not speak either English or Spanish were excluded from the study.

Measures

The Craniofacial Condition Quality of Life Scale (CFC-QoL) was used for this study. The CFC-QoL is a multidimensional HRQoL scale, newly developed at Rady Children's Hospital-San Diego. The CFC-QoL consists of parallel patient and parent reports in English and Spanish. The scale was developed through an iterative process evaluating areas of importance in quality life for CFC patients. Focus interviews were conducted in English and Spanish with children with CFCs and their parents. Qualitative analysis was used to identify scale domains. Items were written and reviewed via cognitive interviewing with English- and Spanish-speaking participants to yield parallel bilingual and bicultural child self-report and parent-report scales. The scales yield subscale scores in the following 5 domains: social impact (eg, *I/My child has trouble talking with other kids*), psychological function (eg, *I/My child handles problems better than other kids*), physical function (eg, *I/my child has trouble saying some words*), family impact (eg, *People in the family are proud of me/my child because of how he/she deals with his/her face*), and appearance impact (eg, *I/My child wants my/his/her face to look different*). Responses are provided on a 5-point scale from 1 or "never" to 5 or "almost always." The mean scores are calculated across items for each subscale, and higher scores represent worse HRQoL. Responses to the subscales were internally consistent, with α levels of ranging from 0.71 to 0.89 for the CFC-QoL in both patients and parents.

Statistical Analyses

Survey data were double entered and analyzed using SPSS (Version 25, IBM). Descriptive statistics were used to describe the sample. Independent sample *t* tests were used to compare mean subscale scores between patients and parents for the total sample and separately for sex (boys vs girls), ethnicity (Hispanic vs non-Hispanic), and diagnosis (cleft lip and palate condition [CLP] vs other). Associations of patient-parent scores for subscales were analyzed by computing Pearson correlation coefficients for the total sample and separately by sex, ethnicity, and diagnosis. The α level was set to 0.05.

RESULTS

Descriptive Statistics

Sample characteristics for the patients can be found in Table 1. The sex of patients was distributed almost equally; 50.7% of the patients were female and 49.35 were male. Nearly half of patients (49.3%) were white, and most of them (42.7%) self-reported their races as "other" than white, Asian, black, Native American, and Native Hawaiian/Asian Pacific Islander. Patients were mostly Hispanic (69.3%), and their ages ranged from 7 to 21 years old (M = 13.2, SD = 3.62).

TABLE 1. Patient Demographics

Characteristics	For Patients (N = 75)
Age	13.20 (3.62)
Sex	
Female	38 (50.7%)
Male	37 (49.3%)
Race	
White	37 (49.3%)
Other	32 (42.7%)
Asian	2 (2.7%)
Black	2 (2.7%)
Native Hawaiian	1 (1.3%)
Other	27 (36%)
Missing	6 (8.0%)
Ethnicity	
Hispanic	52 (69.3%)
Non-Hispanic	22 (29.3%)
Missing	1 (1.3%)
Diagnosis	
CLP	44 (58.7%)
Bilateral CLP	17 (22.7%)
Cleft Lip	3 (4.0%)
Unilateral CLP	24 (32.0%)
Other	31 (41.3%)
Acquired	2 (2.7%)
Craniosynostosis	12 (16.0%)
Derm condition	7 (9.3%)
Microsomia	3 (4.0%)
Microtia	7 (32.0%)

Relationship of Patient to Parent Scores for CFC-QoL Subscales

The mean values for patient and parent ratings on HRQoL domains are listed in Table 2. In general, scores were low, suggesting good HRQoL across all 5 domains. When patient and parent ratings were compared across the 5 HRQoL domains using independent samples *t* tests, there were no significant differences.

Pearson correlation coefficients were computed to explore the interrelationships between patient and parent report for each of the 5 CFC-QoL subscales. The results for the total sample and for subsamples are listed in Table 3. For the total sample, patient and parent scores were significantly and moderately positively correlated for all subscales.

When analyzed separately for sex, the correlation patterns were not identical to those found for the total sample. Associations between patient and parent ratings for each of the 5 subscales were significant and similar for both boys and girls for social impact and physical function. For psychological function and appearance, boys' reports were significantly positively associated with those of their parents but girls' reports were not significantly correlated. For family impact, the opposite pattern was found. Girls' family impact ratings were significantly associated with those of their parents, whereas boys' ratings were not significantly associated. When patient and parent ratings were compared separately for boys and girls using *t* tests, there were no statistically significant differences (all *P*s > 0.05).

When analyzed separately for the 2 ethnic groups (Hispanic, non-Hispanic), patterns of associations between patient and parent ratings were similar to patterns found for the total sample. For social impact, psychological function, and physical function, patients' and parents' ratings were moderately significantly positively correlated for both Hispanic and non-Hispanic dyads. For appearance, patients' and parents' ratings were significantly correlated for both ethnic groups, but the correlation was much stronger in non-Hispanic dyads. For family impact, the correlation was moderate and statistically significant for Hispanic dyads and near zero and nonsignificant for non-Hispanic dyads. When patient and parent ratings were compared separately for Hispanic and non-Hispanic subgroups using *t* tests, there were no statistically significant differences (all *P*s > 0.05).

When analyzed separately for diagnostic groups (CLP vs other diagnoses combined), there was less consistency in patterns, with patient-parent dyads showing different levels of agreement based on child's diagnostic grouping. Social impact ratings were significantly moderately positively associated for dyads in which the child had a non-CLP diagnosis but not for dyads in which the child had a CLP diagnosis. For psychological function, the opposite pattern was found. For physical function and appearance, the positive associations between patient and parent ratings were significant for both CLP and non-CLP diagnostic groups, but stronger in the non-CLP group. Family impact ratings were significantly moderately positively associated for dyads in which the child was diagnosed with CLP but not significantly associated for dyads in which the child was diagnosed with a non-CLP condition. When patient and parent ratings were compared separately for CLP and non-CLP diagnostic groups using *t* tests, there were no statistically significant differences (all *P*s > 0.05).

DISCUSSION

As conditions that are largely diagnosed and managed in childhood, CFCs significantly impact not only patients but also their parents as well. A comprehensive measure of HRQoL in these patients necessitates an understanding of the patient's perspective, the parents' perspective, and the interplay between them. This study used a novel, bilingual, and bicultural HRQoL instrument that examines both the patient and parent perspective in children with CFCs. Using this instrument, we examined how children with CFCs, and their parents, reported on the following 5 domains of HRQoL: social impact, psychological function, physical function, family impact, and appearance impact. Our results show that patients and parents show moderate levels of agreement across HRQoL domains, although agreement varied by sex, ethnicity, and diagnostic group.

As groups, both patients and parents agreed that their HRQoL was, in general, good, with mean item scores averaging approximately 2 on a 5-point scale ranging from 1 to 5 (high scores represent worse HRQoL). For the total sample, dyadic agreement levels were moderate for all 5 domains. This suggests that there is concordance of perspectives between patients and parents, although it also simultaneously underscores that their perspectives are not identical. Interestingly, there were stronger levels of agreement in the physical and appearance domains, perhaps reflecting that these are the 2 domains that are more observable.

Examination of dyadic agreement by demographic characteristics revealed interesting differences in degree of shared perspective.

TABLE 2. Mean Comparisons for Patients and Parents for the 5 HRQoL Domains

	Social Impact		Psychological Function		Physical Function		Family Impact		Appearance	
	Patient	Parent	Patient	Parent	Patient	Parent	Patient	Parent	Patient	Parent
Sex										
Female	2.06 (0.62)	2.15 (0.72)	2.20 (0.52)	2.18 (0.53)	1.83 (0.53)	1.87 (0.60)	2.55 (0.77)	2.45 (0.74)	2.48 (0.63)	2.45 (0.77)
Male	1.85 (0.73)	2.17 (0.89)	2.04 (0.53)	2.17 (0.72)	1.73 (0.46)	1.91 (0.76)	2.47 (0.74)	2.45 (0.79)	2.18 (0.72)	2.33 (0.98)
Race										
White	1.78 (0.65)	1.99 (0.65)	2.05 (0.53)	2.03 (0.58)	1.70 (0.53)	1.85 (0.59)	2.74 (0.70)	2.52 (0.76)	2.15 (0.73)	2.21 (0.82)
Other	2.15 (0.72)	2.33 (0.79)	2.16 (0.49)	2.30 (0.59)	1.83 (0.45)	1.91 (0.71)	2.26 (0.75)	2.32 (0.72)	2.49 (0.60)	2.63 (0.78)
Ethnicity										
Hispanic	2.00 (0.65)	2.21 (0.81)	2.16 (0.53)	2.21 (0.61)	1.83 (0.49)	1.90 (0.68)	2.37 (0.72)	2.37 (0.74)	2.33 (0.61)	2.38 (0.79)
Non-Hispanic	1.91 (0.76)	2.07 (0.82)	2.08 (0.50)	2.09 (0.68)	1.69 (0.50)	1.82 (0.68)	2.88 (0.70)	2.66 (0.78)	2.38 (0.85)	2.46 (1.07)
Diagnosis										
CLP	1.91 (0.64)	2.10 (0.82)	2.10 (0.56)	2.10 (0.64)	2.10 (0.64)	1.87 (0.64)	2.72 (0.72)	2.55 (0.71)	2.32 (0.70)	2.38 (0.87)
Other	2.03 (0.75)	2.27 (0.77)	2.15 (0.49)	2.28 (0.60)	2.28 (0.60)	1.92 (0.74)	2.22 (0.69)	2.30 (0.82)	2.35 (0.68)	2.42 (0.90)
Total	1.96 (0.68)	2.17 (0.80)	2.12 (0.53)	2.28 (0.60)	2.28 (0.60)	1.92 (0.74)	2.51 (0.75)	2.30 (0.82)	2.33 (0.69)	2.42 (0.90)

Data are presented as mean (standard deviation).

There were no statistically significant differences between patient and parent means (all *P*s > 0.05).

TABLE 3. Pearson Correlations between Parent and Patient CFC-QoL Subscale Scores for the Total Sample and by Sex, Ethnicity, and Diagnostic Group

		Social Impact	Psychological Function	Physical Function	Family Impact	Appearance
Total		0.389* $P = 0.001$	0.396* $P = 0.000$	0.571* $P = 0.000$	0.317* $P = 0.006$	0.549* $P = 0.000$
Sex						
	Female	0.404* $P = 0.012$	0.259 $P = 0.116$	0.649* $P = 0.000$	0.373† $P = 0.021$	0.279 $P = 0.09$
	Male	0.390† $P = 0.017$	0.511* $P = 0.001$	0.527* $P = 0.001$	0.258 $P = 0.129$	0.739* $P = 0.000$
Ethnicity						
	Hispanic	0.333† $P = 0.016$	0.352* $P = 0.010$	0.601* $P = 0.000$	0.342† $P = 0.014$	0.419* $P = 0.002$
	Non-Hispanic	0.522† $P = 0.013$	0.491† $P = 0.020$	0.591* $P = 0.004$	0.095 $P = 0.675$	0.700* $P = 0.000$
Diagnosis	CLP	0.290 $P = 0.056.$	0.420* $P = 0.005$	0.466* $P = 0.002$	0.343† $P = 0.025$	0.466* $P = 0.002$
	Non CLP	0.509* $P = 0.003$	0.349 $P = 0.054$	0.726* $P = 0.000$	0.216 $P = 0.242$	0.663* $P = 0.000$

*Correlation is significant at the 0.01 level (2-tailed).

†Correlation is significant at the 0.05 level (2-tailed).

Boys' perspectives on psychological and appearance issues were more strongly associated with those of their parents than were girls'. In contrast, girls, Hispanic children, and children with CLP diagnoses agreed more with their parents when reporting on family impact. The most varied patterns of dyadic agreement were found for CLP versus other diagnoses, with non-CLP dyads showing stronger agreement on social, physical, and appearance issues, and CLP dyads showing stronger agreement on psychological and family issues.

Although multiple studies have examined HRQoL in the craniofacial population, few have analyzed the experiences of both patients and parents.[22] In addition, no existing study captures such a demographically and diagnostically diverse sample.[2,5,6] Despite Turner et al[7,8] evaluating both patients and parents, their diagnostic inclusions were limited to patients with some variant of a cleft lip or palate. Furthermore, their sample did not distinguish outcomes based on racial or ethnic differences, perhaps due to the more homogenous demographic makeup of southwest England.[7] Our purpose in including such diverse patients and parents, both clinically and demographically, was to capture HRQoL experiences across a widely applicable standardized questionnaire that can be applied to the diverse patient population cared for by craniofacial teams.

Both the perceptions of pediatric patients and their parents contribute to utilization of and adherence to treatment.[26] Parents' assessments of their children's HRQoL take into account what the parent believes to be in the patient's best interest and are thus essential in evaluating the potential success of treatment options from the family's perspective.[25] However, the level of satisfaction reported by the parent does not necessarily reflect the happiness of the child. As the patient, the child's self-reported outcomes are arguably the most important measure of success. Children may have different expectations and levels of preparedness for treatment plans, such as surgery. Depending on family dynamics, this may or may not affect treatment decisions and, ultimately, outcomes.

Our study had specific limitations and strengths that need to be considered. A significant strength of our study is the use of the CFC-QoL, a HRQoL measure with parallel patient and parent versions in English and Spanish. Limitations of this study include a relatively small sample size. Future studies with a larger sample of dyads would provide more robust conclusions and may be able to examine nuances between parent and child agreement with the CFC-QoL and within each domain of the CFC-QoL. In addition, expanding the patient population would increase the generalizability of results and provide valuable insight into HRQoL perceptions and how they may vary by demographic factors not well represented in this study, such as black and Asian racial identities.

Another limitation of this study is the possible influence of patient responses on parent responses and vice versa. Because of the nature of the clinic in which the tool was administered, it was impossible to be with respondents at all times while they completed the questionnaire or to separate respondents into separate rooms. This in theory allowed for the potential introduction of bias if patients and parents were collaborating, although this behavior was actively discouraged and infrequently observed. Furthermore, although we generally included only one parental questionnaire for each patient, 2 parents' opinions contribute to the patient's HRQoL in many households. When applicable, the concordance between 2 separate parental responses with patient responses and with each other is another compelling area for future research.

There is inherent complexity to measuring and interpreting HRQoL outcomes in patients with CFCs because of the need to address both patients' and parents' perspectives, the diversity of conditions encompassed by this category, and the influence of cultural differences on perceptions. In this study, we used the CFC-QoL Scale to demonstrate that there is significant parent-child agreement on HRQoL when looking at an ethnically, racially, and linguistically diverse population with CFCs. We also showed that responses were less congruent in some domains on the basis of sex, ethnicity, and diagnosis. Further studies are needed to further evaluate the potential reasons for this variation in responses and further explore patient-parent concordance on a larger scale.

CONCLUSIONS

Although there is substantial agreement between parents and patients when considered on a group level, there is moderate agreement between patients and parents when considered at the dyadic level, underscoring the importance of measuring and considering both perspectives.

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