

## Oral health–related quality of life in Dutch children with cleft lip and/or palate

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### ABSTRACT

**Objective:** To investigate the oral health–related quality of life (OH-RQoL) of Dutch cleft lip and palate patients. It was hypothesized that (1) there is no difference between cleft patients' and their parents' reports of patients' OH-RQoL; (2) there are no gender differences; (3) there are no differences in OH-RQoL between cleft patients with regard to their symptoms; and (4) there is no difference between patients above and below 12 years of age.

**Materials and Methods:** The sample consisted of 122 patients with clefts (age range, 8–15 years) and their parents. Respondents were recruited from the cleft palate team of Amsterdam. They completed the Child Oral Health–Related Quality of Life questionnaire (COHIP). Items were divided into five different subscales, and scores on all subscales were compared between and within groups.

**Results:** Patients' and parents' perceptions differed significantly on three of the five subscales. Girls and boys did not differ significantly with regard to their perception of reported OH-RQoL. The cleft lip and cleft lip and alveolus [CL(A)] subgroup scored significantly higher on the functional well-being subscale. The cleft patients aged 12 years and older scored significantly lower on the emotional well-being and oral symptoms subscales when compared with their younger peers.

**Conclusions:** Only the second hypothesis was not rejected in this study. This means that parents are not interchangeable with regard to reporting on their children's perceptions related to OH-RQoL, that OH-RQoL changes with age, and that it is important that subgroups are respected when investigating OH-RQoL in cleft patients. (*Angle Orthod.* 2011;81:865–871.)

**KEY WORDS:** Oral health–related quality of life; Cleft lip and/or palate; COHIP

### INTRODUCTION

Children with cleft lip and palate (CLP) may suffer from impaired functions and facial appearance, and multiple treatments are often required to reconstruct and/or improve the situation. Although psychopathology has not been shown to be an associated feature, for children with CLP, studies<sup>1–3</sup> have reported the prevalence of anxiety, depression, inhibition, low self-esteem, reduced cognitive function and achievement

in school, and parental stress. A recent Dutch study<sup>4</sup> demonstrated that better social well-being was associated with fewer speech problems but not with a different facial appearance and lower self-image.

The impact of CLP on quality of life (QoL) is considerable for affected children. Unfortunately, at the beginning of the millennium there was still an urgent need for QoL measures for patients with craniofacial anomalies such as CLP.<sup>5–7</sup> Several research groups have published<sup>8,9</sup> on the development of QoL instruments, but up until now only one has developed an “internationally” validated instrument for children. As part of a large international research project to measure oral health–related QoL (OH-RQoL) in children, the Child Oral Health Impact Questionnaire (COHIP) was designed and developed.<sup>10</sup> Two versions of the COHIP were developed, one for children and one for parents.<sup>11</sup> The COHIP was tested and validated using reports on QoL from normal children and children recruited from pediatric, orthodontic, and craniofacial centers.<sup>12–14</sup> In addition, concordances between caregiver and child reports were investigated.<sup>15</sup> In The Netherlands, a Dutch version of

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the COHIP has been tested and used in four previous studies<sup>16-19</sup> reporting on OH-RQoL in Dutch craniofacial patients, schoolchildren, and orthodontic patients, but this measure has not yet been utilized in children with CLP.

The aim of the present study was to investigate the OH-RQoL of Dutch cleft lip and/or palate patients. For this purpose the shortened version of the COHIP was used. The reliability and validity of the questionnaire were analyzed and four hypotheses were tested. First, it was hypothesized that no differences would be found between cleft patients' and their parents' reports of patients' OH-RQoL. Second, it was hypothesized that no gender differences would be found. Third, it was hypothesized that no differences between the cleft palate (CP), cleft lip and cleft lip and alveolus [CL(A)], unilateral cleft lip and palate (UCLP), and bilateral cleft lip and palate (BCLP) subgroups would be found. Fourth, it was hypothesized that in terms of OH-RQoL, there is no difference between the ages above and below 12 years.

## MATERIALS AND METHODS

### Data Collection

The COHIP consists of two parallel questionnaires, one for children and one for parents. Patients (between the ages of 8 and 15 years) and parents from the cleft palate team of Amsterdam were recruited by mail to complete the COHIP questionnaire that was sent to them before the summer of 2009. Because of a low response rate the questionnaire was sent once more to the nonrespondents in September 2009 in an attempt to recruit as many participants as possible. Of the 232 pairs of questionnaires (each pair comprising one questionnaire for the patient and one for the parent) that were mailed, 122 pairs were returned (response rate 53%). This resulted in a sample of 122 patients (53 girls and 69 boys) with a mean age of 11.9 years (standard deviation [SD] = 2.2) and 122 parents (101 female and 18 male caretakers; gender was not known for three adult participants).

### Dutch Version of the COHIP

A detailed description of the development and validation of the COHIP can be found in a previous publication.<sup>19</sup> In its present form, the Dutch version of the COHIP comprises 30 items, which are divided over five conceptually different subscales (oral symptoms, functional well-being, emotional well-being, school, and peer interaction).

Items were scored on a five-point scale (1 = 'never' to 5 = 'constantly'), with the additional response option of 'I don't know' (DK response; 0 = 'I don't know').

Items were formulated negatively, with two exceptions. In line with earlier studies<sup>5-7</sup> in which the COHIP was used, six items regarding treatment expectations and one global health perception item were added to the questionnaire. These items were not included in the COHIP scores but were used for clinical reasons only. They were answered on a five-point scale (1 = 'totally disagree' to 5 = 'totally agree'), with the additional response option of 'I don't know' (DK response; 0 = 'I don't know').

### Data Analysis

First, the scores on the two positively worded items were reversed. Then, in order to render our results easier to interpret and better comparable with results from other studies, all scores were recoded, so that a high score on the subscales of the COHIP implies a good OH-RQoL.

Frequencies of the DK responses on each item were analyzed. The internal consistency of the entire questionnaire and of the subscales was examined using Cronbach alpha. Subscale scores were determined by summing up the responses of all items of each subscale, and the overall OH-RQoL score was calculated by summing up the subscale scores. Concordance between patients and parents was determined by comparing their overall and subscale scores using paired-sample *t*-tests. Pearson correlations and intraclass correlation coefficients (ICCs) between subscales of children and parents were computed. Differences between boys and girls were examined using independent-sample *t*-tests, and for differences between cleft subgroups an analysis of variance was used. In the exploratory analyses independent-sample *t*-tests were also used. Finally, stepwise regression analyses were done in the patient and parent samples, with the five subscales, age, and gender as predictors and the score on the global health perception items as a dependent variable.

## RESULTS

### Analyses of DK Responses

Frequency analyses showed that for all questions, the DK response was given only five times or fewer per item. However, on two items, the DK response was given more often in both the parent and the patient samples. On the item 'Been confident because of your teeth, mouth or face,' patients responded with 'Don't know' 15 times, while parents chose this option 18 times. On the item 'Felt that you were attractive (good looking) because of your teeth, mouth or face,' patients had 12 DK responses and parents had 25 DK responses. On two other items, patients answered

**Table 1.** Internal Consistency of the COHIP<sup>a</sup> and its Subscales in the Patient and Parent Sample

	Cronbach Alpha for Patients	Cronbach Alpha for Parents
COHIP (overall; n = 29)	.81	.88
Oral symptoms (n = 10)	.50	.68
Functional well-being (n = 6)	.73	.75
Emotional well-being (n = 8)	.78	.83
School (n = 3)	.45	.41
Peer interaction (n = 2)	.03	.35

<sup>a</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire and contains 29 items divided into five subscales.

'Don't know' more than five times ('Had bleeding gums,' n = 7; 'Had bad breath,' n = 9). In the parents sample, the only other item with more than five DK responses was 'Not wanted to speak/read out loud in class' (n = 8). The DK responses were excluded from further analyses and were treated as missing values.

### Reliability Analysis

In Table 1, the internal consistency of the subscales and the overall COHIP are given. Internal consistency turned out to be sufficient to good, except for the 'Peer interaction' subscale. Alpha coefficients in the parent sample were somewhat higher than in the patient sample. One item on the 'School' subscale had a negative corrected item-total correlation with the other items on the subscale ('Missed school for any reason because of your teeth, mouth or face'), thereby decreasing the Cronbach alpha. Therefore, this item

was deleted in the analyses. All further analyses were done with the remaining 29 items.

### Differences Between the Patient and Parent Samples

The maximum overall score that respondents could obtain on the COHIP was 145. The mean overall score of patients turned out to be 119, and that of parents was 117. This indicates that for both patients and parents, the OH-RQoL was relatively high. However, differences were found between patients and parents on subscales. In Table 2, scores for both patients and parents are presented. Paired-sample *t*-tests showed a significant difference between parents and patients on the 'Oral symptoms,' 'Emotional well-being,' and 'School' subscales. In Tables 3 and 4, correlations between subscales and the overall COHIP scores are presented. As expected, many significant correlations were found. The Pearson correlations and ICCs between subscales of children and parents are shown in Table 5. All correlations were significant. The ICCs indicate moderate to high agreement between child and parent reports, except for the 'School' and 'Peer interaction' subscales.

### Differences in the Patient Sample With Regard to Gender, Age, and Cleft

Second, our hypotheses concerning gender, age, and cleft subgroups were tested. Mean subscale scores and overall scale scores of girls and boys are

**Table 2.** Mean Subscale and Overall Scale for Both Patients and Parents, *t* and *P* Values

Subscale	Patients		Parents		<i>t</i>	<i>P</i>
	Mean	SD	Mean	SD		
Oral symptoms (10 items)*	39.10	4.48	40.52	5.04	-3.36	.001
Functional well-being (6 items)	24.98	3.82	24.51	4.36	1.64	.103
Emotional well-being (8 items)*	31.22	5.21	29.31	7.02	3.17	.002
School (3 items)*	14.64	0.90	14.06	2.08	3.10	.002
Peer interaction (2 items)	9.26	1.09	8.97	1.70	2.03	.045
COHIP <sup>a</sup> (overall = 29 items)	119.29	11.55	117.67	15.36	1.33	.187

<sup>a</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire and contains 29 items divided into five subscales; SD, standard deviation.

\* Difference in mean scores is significant at .01 level (two-tailed).

**Table 3.** Correlations Between Overall and Subscale Mean Scores in Patient Sample

	Oral Symptoms	Functional Well-Being	Emotional Well-Being	School	Peer Interaction	COHIP <sup>a</sup>
Oral symptoms	1.00					
Functional well-being	.40**	1.00				
Emotional well-being	.38**	.32**	1.00			
School	.26**	.22*	.43**	1.00		
Peer interaction	.24*	.24**	.45**	.34**	1.00	
COHIP <sup>a</sup>	.74**	.68**	.81**	.47**	.49**	1.00

<sup>a</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire.

\* Correlation is significant at the .05 level (two-tailed); \*\* Correlation is significant at the .01 level (two-tailed).

**Table 4.** Correlations Between Overall and Subscale Mean Scores in Parent Sample

	Oral Symptoms	Functional Well-Being	Emotional Well-Being	School	Peer Interaction	COHIP <sup>a</sup>
Oral symptoms	1.00					
Functional well-being	.41**	1.00				
Emotional well-being	.41**	.34**	1.00			
School	.21*	.26**	.48**	1.00		
Peer interaction	.39**	.25**	.60**	.58**	1.00	
COHIP <sup>a</sup>	.73**	.69**	.86**	.64**	.71**	1.00

<sup>a</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire.

\* Correlation is significant at the .05 level (two-tailed); \*\* Correlation is significant at the .01 level (two-tailed).

**Table 5.** Correlations and ICCs<sup>a</sup> Between Subscales and Overall Scores of Patients and Parents

	Pearson <i>r</i>	ICC
Oral symptoms	.65**	.78
Functional well-being	.73**	.84
Emotional well-being	.47**	.62
School	.23*	.29
Peer interaction	.44**	.57
COHIP <sup>b</sup> overall	.68**	.79

<sup>a</sup> ICC indicates intraclass correlation coefficient (average measure).

<sup>b</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire.

\* Correlation is significant at the .05 level (two-tailed); \*\* Correlation is significant at the .01 level (two-tailed).

presented in Table 6. No significant gender effects were found. Next, age effects were tested. The sample of patients was split at the age of 12 years (median = 11.7 years, mean = 11.9 years) in order to create two comparable groups. The results are presented in Table 7. Three small but significant age differences were found: younger patients scored higher on the subscales 'Oral symptoms' ( $t = -2.25$ ,  $P < .05$ ) and 'Emotional well-being' ( $t = -2.40$ ,  $P < .05$ ) and on the overall COHIP ( $t = -2.48$ ,  $P < .05$ ). Finally, cleft subgroup scores on subscales and the overall COHIP were compared (see Table 8). Only on the 'Functional well-being' subscale was a significant difference between subgroups found ( $F = 3.15$ ,  $P < .05$ ).

### Exploratory Analysis

In Table 9, the results of the six items regarding treatment expectations and the global health percep-

tion for both patients and parents are presented. There was only one small but significant difference: parents believed more often than patients that their children will have good health in the future ( $t = -2.06$ ,  $P < .05$ ).

Only one significant difference between boys and girls was found: the item 'I am anxious about the treatment I will get' resulted in higher scores for girls (girls: mean = 2.69, SD 1.37; boys: mean = 1.78, SD = 1.19;  $t = -3.90$ ,  $P < .01$ ), indicating that girls are more worried about the treatment than are boys. A stepwise regression analysis showed that the subscales 'Oral symptoms,' 'School,' and 'Emotional well-being' and age were significant predictors of the patient's perception of general health, accounting for 54% of the variance. In the parent sample, the subscales 'Functional well-being' and 'Oral symptoms' were the only significant predictors, accounting for 43% of the variance on the global health perception item.

### DISCUSSION

The first hypothesis—that there were no differences in COHIP scores between patients and parents—was rejected. From previous studies<sup>16,19</sup> reservations existed regarding the interchangeability of parent and patient reports. This study had sufficient power to reject the first hypothesis. Parents are limited in their interchangeability. The present findings are also in agreement with findings from a recent American study<sup>15</sup> using COHIP, in which children scored significantly higher than their caregivers.

**Table 6.** Mean Subscale and Overall Scale Scores for Girls and Boys, *t* and *P* Values

Subscale	Girls (n = 53)		Boys (n = 69)		<i>t</i>	<i>P</i>
	Mean	SD	Mean	SD		
Oral symptoms (10 items)	38.22	4.82	39.69	4.31	1.61	.111
Functional well-being (6 items)	25.06	3.41	24.91	4.14	-0.21	.836
Emotional well-being (8 items)	30.69	5.35	31.74	5.01	1.10	.275
School (3 items)	14.54	1.11	14.72	0.68	1.14	.258
Peer interaction (2 items)	9.23	1.23	9.28	0.97	0.26	.792
COHIP <sup>a</sup> (overall = 29 items)	118.20	11.63	119.81	11.54	0.69	.493

<sup>a</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire and contains 29 items divided into five subscales; SD, standard deviation.



**Table 7.** Mean Subscale and Overall Scores for Patients 8 to <12 Years of Age and 12–15 Years of Age, *t* and *P* Values

Subscale	8 to <12 y (n = 64)		12–15 y (n = 58)		<i>t</i>	<i>P</i>
	Mean	SD	Mean	SD		
Oral symptoms (10 items)*	40.04	4.57	38.04	4.34	−2.25	.026
Functional well-being (5 items)	25.16	3.54	24.78	4.12	−0.55	.582
Emotional well-being (6 items)*	32.36	4.65	30.14	5.47	−2.40	.018
School (3 items)	14.69	0.62	14.60	1.22	−0.49	.629
Peer interaction (2 items)	9.36	0.93	9.14	1.25	−1.10	.272
COHIP <sup>a</sup> (overall = 29 items)*	121.77	10.18	116.19	12.36	−2.48	.015

<sup>a</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire; SD, standard deviation.

\* Difference is significant at .05 level (two-tailed).

**Table 8.** Mean Subscales and Overall Scale Scores for the Cleft Subgroups: Cleft Palate (CP), Cleft Lip and Cleft Lip and Alveolus [CL(A)], Unilateral Cleft Lip and Palate (UCLP), and Bilateral Cleft Lip and Palate (BCLP)

Subscale	CP (n = 33)		CL(A) (n = 38)		UCLP (n = 32)		BCLP (n = 19)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Oral symptoms (10 items)	37.90	4.92	40.44	4.35	38.88	4.14	38.94	4.61
Functional well-being (5 items)*	23.85	4.62	26.46	3.31	24.52	3.13	24.78	3.59
Emotional well-being (6 items)	30.91	4.57	30.74	5.59	32.06	5.23	31.78	5.34
School (3 items)	14.48	1.28	14.74	0.76	14.66	0.70	14.72	0.57
Peer interaction (2 items)	9.47	0.98	9.34	1.02	9.09	1.20	9.00	1.20
COHIP <sup>a</sup> (overall = 29 items)	116.29	11.61	121.65	11.30	119.20	11.38	119.25	12.11

<sup>a</sup> COHIP indicates Child Oral Health Impact Profile Questionnaire; SD, standard deviation.

\* Difference is significant at .05 level.

The second hypothesis could not be rejected, as no significant gender differences on the COHIP were found. In an earlier study<sup>19</sup> in which the COHIP was used in a slightly different form in the same age group as ours but in a sample of orthodontic patients, gender differences were found on the 'Emotional well-being' and 'Peer interaction' subscales. This difference indicates that the OH-RQoL of cleft lip patients differs from that of orthodontic patients. This is also supported by the fact that in the orthodontic study, the COHIP subscales explained only 5% of the variance on the general health item, while in the cleft patient group, they explained 54% of the variance. Further research is needed to explain these findings. In the present study, only one small gender difference was found in the exploratory analyses: girls were slightly more worried about the treatment to come than were boys.

The third hypothesis revealed a significant difference between the different cleft types and the 'Functional well-being' subscale, for which the CL(A) group had the highest scores. It should be kept in mind that different cleft types require different treatment protocols. These facts may explain, at least in part, the difference we found. Studies by different authors<sup>20–24</sup> also have suggested differences between cleft subgroups with respect to psychological variables and QoL. Although different aspects were investigated with respect to our study, and although inconsistent findings were reported, cleft subgroups should be considered when reporting on QoL, and future studies with larger samples are required.

The fourth hypothesis was also rejected, since differences were found between patients younger and older than 12 years of age. Cleft patients aged

**Table 9.** Results on Treatment Expectations and Global Health Perception Items of Patients and Parents

Item	Patients		Parents		<i>t</i>	<i>P</i>
	Mean	SD	Mean	SD		
I have nice teeth.	2.98	1.36	3.16	1.20	−1.36	ns
I think in the future I will have nice teeth.	3.90	1.31	3.94	1.18	−0.33	ns
I think in the future I will have good health.	3.83	1.61	4.18	1.16	−2.06	<.05
I am satisfied about myself.	4.16	0.88	4.16	1.03	0.00	ns
I think I will be more satisfied with myself when orthodontic treatment is finished.	3.44	1.57	3.45	1.60	−0.10	ns
I am anxious about the treatment I will get.	2.19	1.34	2.31	1.28	−0.99	ns
I have good general health.	4.20	0.80	4.25	0.89	−0.50	ns

<sup>a</sup> ns indicates not significant; SD, standard deviation.

12 years and older scored significantly lower on the 'Emotional well-being' and 'Oral symptoms' subscales. Previous studies<sup>25,26</sup> have shown that age is significantly associated with compliance, and it has been reported<sup>27</sup> that orthodontic patients become less compliant when they are older than 12 years of age. These earlier findings indicate that preadolescent children may be more receptive and obedient to parental influence. Our present findings seem to indicate that younger patients are less aware of themselves and their symptoms than are patients who are 12 years of age and older. However, older children will have more treatment experience than younger patients, and this may also explain the age difference we found.

The use of the COHIP ensures a validated instrument and results that can be used cross culturally. A suggestion for future research would be an overall assessment of the current status of QoL in CLP and the achievement of consensus within the profession about normal values for CLP patients. Other important questions to be answered are related to the timing and psychosocial efficacy of treatment of CLP with regard to the psychosocial influence of an improved facial appearance and function or a subsequent change in self-perception. Broder<sup>2</sup> recommended that a psychological assessment be undertaken as part of the evaluation of a CLP patient in order to identify or verify particular concerns in patients or their significant others, to evaluate health care effectiveness, to screen for psychological distress, and to assess specific skill areas. The assessment can result in referrals for further psychological evaluation or recommendations for subsequent treatment. In practice, assessment could lead to prevention, detection of unrealistic treatment outcome expectations, and early detection of social, psychological, or cognitive problems, all of which guard and/or improve QoL. For instance, if psychological assessments are undertaken at predetermined ages simultaneously with other standardized records, they can also be used for evaluation of the treatment effects. It is possible that values from the subscales of the COHIP could serve as baseline data for the important domains in CLP. With regard to clinicians, we recommend that they address themselves to a child directly with questions about OH-RQoL and that they take special care when they explain future treatment plans to girls.

## CONCLUSIONS

- Parents' reports on their children's OH-RQoL were not in agreement with reports of cleft lip and/or palate patients.
- No significant differences could be found between girls and boys with cleft lip and/or palate.

- There seems to be a significant difference in the perceived OH-RQoL regarding perceived OH-RQoL between the <12-year and the 12–15-year age groups. The 12–15-year age group had significantly lower scores.
- The cleft lip and cleft lip and alveolus [CL(A)] subgroup scored significantly higher than the other subgroups on the 'Functional well-being' subscale.

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