Measuring Parental Perceptions of Child Oral Health-related Quality of Life

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Abstract

Objectives: The aim of this study was to develop and evaluate the P-CPQ, a measure of parental/caregiver perceptions of the oral health-related quality of life of children. This forms one component of the Child Oral Health Quality of Life Questionnaire (COHQOL). Methods: An item pool was developed through a review of existing child health questionnaires and interviews with parents/caregivers of children with pedodontic, orthodontic, and orofacial conditions. The resulting 47 items were used in a study in which 208 parents/caregivers provided data on their frequency and importance. The 31 items rated the most frequent and important were selected for the final questionnaire (P-CPQ). The P-CPQ validity and reliability were assessed by a new sample of 231 parents, 79 of whom completed two copies for the assessment of test-retest reliability. Results: The P-CPQ discriminated among the three clinical groups included in the expected direction. Within-group analyses using clinical data provided some evidence that scores were associated with the severity of the condition. The P-CPQ also showed good construct validity. It had excellent internal consistency reliability with a Cronbach's alpha of 0.94 and demonstrated perfect test-retest reliability (ICC=0.85). Conclusion: The study provides data to indicate that the P-CPQ is valid and reliable. [J Public Health Dent 2003;63(2):67-72]

Key Words: children, oral health, quality of life, validity, reliability.

A number of instruments are now available that can be used to measure the functional and psychosocial outcomes of oral disorders (1). However, all were designed for adult populations and no comprehensive work in this area has yet been undertaken with respect to children. This is probably due to the complex conceptual and methodological issues involved in developing self-report health status indicators for child populations (2,3).

This is a significant omission. First, children are subject to numerous oral and orofacial conditions that can impact on their quality of life. Second, it is unlikely that any of the adult measures are suitable for children given their conceptual basis and content (4). Issues of growth, development, and dependence on parents and caregivers also render them inappropriate for children (5). Third, since children are a major focus of dental public health research and practice, measures of oral health-related quality of life (OHR-QoL) applicable to this population group are essential.

One issue that continues to receive a great deal of attention with respect to measuring the health-related quality of life (HRQoL) of children is that of parent versus child reports (5-9). Until recently, measurement of child health status and HRQoL was based on proxy reports by parents or caregivers (10,11). The reason for this was concern about the ability of children to provide assessments that met conventional psychometric standards (2). However, several child HRQoL measures have now been developed which indicate that, with appropriate questionnaire techniques, valid and

reliable information can be obtained from children (12).

Moreover, concerns have been raised about the accuracy of parental assessments, particularly with respect to the older children. While some studies indicated relatively high agreement for some health domains (5,11), others have found low concordance (7-9) between parent and self-assessments. Nevertheless, there is still value in obtaining parent/caregiver reports. Parsons et al. (8) have suggested that parents/caregivers are often the principal decision makers with respect to a child's health and their perceptions can have a major influence on treatment choices. Further, health care often provides for parents' needs rather than those of children. For example, the motivation for orthodontic treatment often comes from parents (13). Consequently, leading investigators in the field have suggested that the views of both groups of informants are necessary as they provide complementary information (12,14-17). Where both parental and child reports are used, the former should be regarded as adding to, rather than substituting for the latter to provide a comprehensive profile of a child's health and well-being.

Consequently, when constructing the Child Oral Health Quality of Life Questionnaire (COHQOL)[©] we decided to design analogous parental/caregiver and child components: Parental-Caregiver Perceptions Questionnaire (P-CPQ) and Child Perceptions Questionnaire (CPQ). This paper describes development of the P-CPQ and its performance in terms of validity and reliability. The development and performance of the CPQ and a study of the agreement between par-

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ent/caregiver and child assessments of OHRQoL are being reported in additional papers.

Methods

Measurement Goals. In developing the COHQOL, we aimed to produce a measure applicable to children with a wide range of dental, oral, and orofacial disorders that conforms to concepts of child health as suggested by the American Academy of Pediatrics and the American Cancer Society. The latter defines child health as " ... the ability to fully participate in developmentally appropriate physical, psychological, and social tasks " This means the COHQOL needed to be sensitive to children's cognitive, emotional, and social development. Consequently, two Child Perceptions Questionnaires were developed, one for children aged 6-10 years and one for children aged 11–14 years. Because the COHOOL was intended to be used as an outcome measure in intervention studies, it needed to be sensitive to change in addition to being valid and reliable.

Development Process. The P-CPQ was constructed according to a process derived from the theory of measurement and scale development (18,19). The specific procedures used were those described by Guyatt et al. (20) and Juniper et al. (21) for the development and evaluation of HRQoL measures. They are summarized in Figure 1.

All aspects of the study were approved by the Human Subjects Certification Committee, University of Toronto, the Ethics Research Board, the Hospital for Sick Children, Toronto, and the Education and Research Office, Toronto Public Health.

Item Generation and Selection. The conceptual framework for the CO-HQOL was developed through a review of generic and disease-specific child HRQoL measures. The following health domains were identified: symptoms, functional limitations, emotional well-being, and social-well being. The last encompassed the subdomains of schooling, peer interaction, and leisure activities.

The items for the P-CPQ were generated in two stages. In the first, a preliminary pool of 46 items was developed by abstracting items from existing questionnaires. In the second, a face and content validation study was FIGURE 1 Diagrammatic Representation of the Developmental Process



Validity and reliability study

conducted. This involved interviews with 17 clinicians who treat children with oral and orofacial conditions and 41 parents of child patients. The preliminary item pool was reviewed for its comprehensiveness, relevance, and clarity. Based on the responses and comments, a modified pool was developed by excluding irrelevant items, writing additional items, and combining items. It consisted of 11 items concerning oral symptoms, 12 items concerning functional limitations, 9 concerning emotional well-being, and 15 concerning social well-being.

Items for the final questionnaire were selected from the modified pool using an item impact study (20-22). This identifies items that are most important to the target population. Participants were the parents/caregivers of children with the clinical conditions of interest. A convenience sample was recruited from the patient populations at the Pediatric and Orthodontic Clinics, Faculty of Dentistry, University of Toronto, the Craniofacial Unit, the Hospital for Sick Children, Toronto, and Toronto Public Health Dental Clinics. Three clinical groups were identified: pediatric dentistry patients, orthodontic patients, and patients with orofacial conditions (predominantly cleft lip or palate). The inclusion criteria were: restorative and orthodontic treatment not initiated or in early stage, absence of child cognitive

impairment or other diagnoses, and parental/caregiver fluency in English. An attempt was made for the sex and age (6–10 and 11–14 years) of the children to be equally represented and for a variety of cases with different levels of severity to be included.

Data were collected in face-to-face interviews conducted on the clinics' premises at the time of dental visits. The parent/caregiver was asked how often in the past three months his/her child had experienced the problem described by each item. If the problem occurred sometimes, often, or all the time, the parent/caregiver rated its importance to the child on a four-point Likert scale ranging from 0 ("Does not bother my child at all") to 3 ("Bothers my child very much"). For each item, an impact score was calculated by multiplying the percentage of parents/caregivers with a positive response to the item and its mean "bother" rating. Item impact scores were calculated for each clinical group.

Items were then ranked within the domains (symptoms, functional limitations, emotional well-being, social well-being) according to these impact scores. Any item that was above the median in at least one clinical group was selected. This process ensured that items that were frequent and bothersome in any of the three clinical groups appeared in the final question-

naire: P-CPQ.

In the P-CPQ questions were asked only about the frequency of events in the previous three months. Based on the comments of the item impact study participants, the response options were: never=0, once or twice=1, sometimes=2, often=3, every day or almost every day=4. A "don't know" response also was allowed. Global ratings of the child's oral health and impact of the oral/orofacial condition on his or her overall well-being also were obtained. They had a five-point response format from "excellent" to 'poor" for oral health and from "not at all" to "very much" for well-being.

Validity and Reliability Testing. The performance of the P-CPQ was assessed in a validity and reliability study. A new convenience sample of parents/caregivers was recruited from the same clinics. For assessment of test-retest reliability, the P-CPQ was completed two times at a two-week interval. With reliability being defined as the ratio of between-subject variance and total variance in stable patients (8), the follow-up questionnaire asked parents/caregivers if the condition or its impact on the child had changed since recruitment. Since pediatric dental patients are likely to exhibit short-term change as a result of dental treatment, only parents/ caregivers of orthodontic and orofacial patients participated in the retest component of the study. The P-CPQ scores, total and subscale, were generated by summing the numerical response codes. Clinical data pertaining to the oral and/or orofacial conditions were abstracted from the dental charts. The aim was to obtain diagnostic categories or other information, which would allow children in each group to be ranked in terms of clinical severity.

Data from the validity study were used to evaluate feasibility, measurement sensitivity, validity, and internal consistency reliability of the P-CPQ. Feasibility was assessed by examining the number of missing values and floor and ceiling effects for the scale and subscales (24). For a questionnaire including a "don't know" response option, the number and distribution of such responses also needs to be taken into account. Measurement sensitivity was assessed by examining the range of total and subscale scores to ascertain whether or not the P-CPQ detected

	Item Impact Study (n=208) No. (%)	Validity (<i>n</i> =231) No. (%)	Reproducibility (n=79) No. (%)
Informant			
Child's mother	129 (62.0)	159 (68.8)	61 (77.2)
Child's father	66 (31.7)	65 (28.1)	16 (20.3)
Other	13 (6.3)	7 (3.0)	2 (2.5)
Clinical group	• •		
Pedodontic	57 (27.3)	60 (26.0)	0 (0)
Orthodontic	75 (36.1)	98 (42.4)	36 (44.6)
Orofacial	76 (36.5)	73 (31.6)	43 (54.4)
Sex of child			
Male	103 (49.5)	104 (45.0)	31 (39.2)
Female	105 (50.5)	127 (55.0)	48 (60.8)
Age of child (years)			
6–10	92 (44.2)	103 (44.6)	28 (35.4)
11–14	116 (55.8)	128 (55.4)	51 (64.6)

variations in parental/caregiver perceptions of child OHRQoL. Internal consistency reliability of the scale and subscales was assessed by means of Cronbach's alphas, and test-retest reliability by means of intraclass correlation coefficients (ICC) calculated using the one-way random effect parallel model (23).

To test discriminant validity, the hypothesis tested was that the scores would be highest in the orofacial, lower in the orthodontic, and lowest in the pediatric dentistry group. Withingroup variation in scores according to the severity of the child's condition also was examined as this was feasible given the clinical data that were collected. Construct validity was assessed by means of associations between the scale scores and the global indicators of oral health and overall well-being. It was hypothesized that they would be positively correlated and that scores would be highest where the child's oral health was rated by the parent as poor and the condition assessed as affecting the child's overall well-being very much.

Results

Characteristics of Participants. A total of 208 parents/caregivers were interviewed for the item impact study and 231 took part in the study to assess validity and internal consistency reliability. Of the latter, 79 provided data for the assessment of test-retest reli-

ability. The majority of the informants were the mothers in all three studies. The characteristics of the children in terms of sex, age, and clinical group are shown in Table 1.

Item Impact Scores. Table 2 provides data from the item impact study. It shows for each item in the modified pool the percentage of parents reporting that their child experienced the problem described by the item, the mean importance rating for the item and the item impact score. In general, the most frequent and important items (n=31) were selected for the P-CPQ.

Feasibility and Measurement Sensitivity. Although the PPQ was selfcompleted, only eight questionnaires had one missing value each. The number of "don't know" responses was quite high. Almost half the participants (46.8%) had ≥1 "don't know" responses, with a mean=1.8 (SD=3.0). Six items had a "don't know" response from ≥ 10 percent of respondents and four of those were in the social well-being domain. Accordingly, only the 120 questionnaires with no missing values or "don't know" responses were included in the analyses of validity and internal consistency reliability.

The total scale score ranged from 0 to 80, with a mean=25.1 (SD=8.7), indicating that the P-CPQ was detecting substantial variability in parent/caregiver perceptions of child OHRQoL. A floor effect was almost

TABLE 2 Results of Item Impact Study: Item Impact Scores for Each Item by Domain

During the last 3 months, how often has your child (had/been)	Prevalence (%)	Mean Importance†	Impact Score
Oral symptoms			
Food caught between teeth*	64.4	1.04	67.0
Pain in teeth/mouth*	46.6	1.40	65.2
Bad breath*	55.4	0.90	49.9
Mouth sores*	21.6	1.38	29.8
Bleeding gums*	24.5	1.05	25.7
Food stuck to roof of mouth*	26.7	0.93	24.8
Drooling	23.2	0.67	15.5
Clenching/grinding of teeth	35.8	0.38	13.6
Lower jaw shifting to one side	7.2	0.93	6.7
Jaw joint popping/grinding	9.4	0.79	7.4
Lip/mouth numbness	1.9	0.03	0.1
Functional limitations			
Difficulty chewing firm foods*	51.4	1.58	81.2
Unclear speech*	32.9	1.30	42.8
Difficulty drinking/eating hot/cold foods*	25.6	1.43	36.6
Difficulty eating foods would like to eat*	24.5	1.48	36.3
Slow eating*	32.4	1.04	33.7
Breathing through mouth*	39.8	0.78	31.0
Restricted diet*	18.3	1.16	21.2
Trouble sleeping*	13.0	1.56	20.3
Difficulty opening mouth wide	9.7	1.20	11.6
Difficulty playing musical instrument	6.3	1.92	12.1
Difficulty drinking with straw	2.9	1.00	2.9
Lower jaw stuck open/closed	1.9	1.25	2.4
Emotional well-being			
Upset*	54.3	1.69	91.8
Irritable/frustrated*	49.0	1.74	85.3
Worried he/she is less attractive than others*	42.6	1.69	72.0
Shy/embarrassed*	42.0	1.56	65.5
Anxious/fearful*	38.2	1.62	61.9
Worried that is different from other people*	38.2	1.60	61.1
Worried about having fewer friends*	19.9	1.63	32.4
Worried that he/she is less healthy than others	17.8	1.78	31.7
Worried that will have fewer life opportunities	13.1	1.88	24.6
Social well-being			
Teased/called names by other children*	51.4	1.58	81.2
Avoided smiling when around other children*	35.1	1.79	62.8
Asked by other children about condition*	46.4	1.07	49.6
Not wanted to speak/read aloud in class*	18.5	1.73	32.0
Not wanted to talk to other children*	12.7	1.65	21.0
Left out by other children*	10.6	1.86	19.7
Had hard time paying attention in school*	13.4	1.44	19.3
Not wanted/unable to be with other children*	9.7	1.60	15.5
Missed school*	29.3	0.48	14.1
Not wanted/unable to take part in activities (sport, drama, clubs)*	7.7	1.56	12.0
Avoided eating with other children	7.5	1.53	11.5
Difficulty doing homework	4.3	1.89	8.1
Not allowed by parents to join other children	1.9	2.00	3.8
Not wanted/unable to go out with family	1.0	2.00	2.0
Not wanted/unable to go to gatherings of family/friends	1.0	2.00	2.0

*Items selected for the final questionnaire. †Importance scale: does not bother my child at all=0; bothers my child a little=1; bothers my child quite a bit=2; bothers my child very much=3. ‡Range of possible values: 0–300. nonexistent, with only 0.8 percent of participants having zero scores; there was no ceiling effect. Subscale scores also showed substantial variability with modest floor effects and no ceiling effects.

Discriminant and Construct Validity. As predicted, the mean total scale score was highest in the orofacial group and lowest in the pediatric dentistry group (P<.0001) (Table 3). The orofacial patients also had significantly higher mean scores for three of the four subscales. In the pediatric dentistry group, as expected, there was a significant correlation between total scale scores and the number of decayed tooth surfaces (r=.54; P<.01). The mean score for children with isolated cleft lip or palate (n=11) was 25.2 compared to 30.4 for those with unilateral cleft lip or palate (n=14) and 39.0 for those with bilateral cleft lip or palate (n=10). The differences were not statistically significant, which could have been due to small numbers in the subgroups. Testing of discriminant validity for the orthodontic group was not undertaken because the diagnostic categories were in the form of a nominal rather than an ordinal scale.

Both hypotheses concerning construct validity were confirmed. That is, significant associations in the expected direction between the total scores and global ratings of oral health (P < .05) and overall well-being (P<.0001) were found in the one-way analysis of variance. For example, the mean score for those reporting that their child's well-being was "not at all" affected by their oral/orofacial condition was 12.61 and for those reporting that it was affected "very much" was 43.6. Rank correlation coefficients were, also as expected, stronger for ratings of overall well-being (r=0.61; P<.001) than ratings of oral health (r=.28; P<.001). Significant positive rank correlations were also observed between the global ratings of oral health and scores on the functional limitations, emotional well-being, and social well-being subscales, and between global ratings of overall wellbeing and scores on all four subscales.

Internal Consistency and Test-retest Reliability. Cronbach's alpha for the total scale was 0.94 and for the subscales it ranged from .69 to .92. These statistics indicated good internal consistency reliability.

The test-retest reliability was based

TABLE 3
Discriminant Validity: Mean Total Scale and Subscale Scores by Clinical Group

Scale	Range	Pedodontic	Orthodontic	Orofacial	P*
Total scale	(0-124)	15.86	23.84	31.83	<.0001
Subscale Oral symptoms	(0–24)	5.78	5.77	6.25	NS
Functional limitations	(0–32)	6.58	5.97	8.82	<.05
Emotional well-	(0–28)	2.90	6.89	8.56	<.0001
Social well-being	(0-40)	2.89	5.45	8.45	<.001

*P-values obtained from one-way analysis of variance.

TABLE 4 Internal Consistency Reliability and Test-retest Reliability Statistics				
	No. of Items	Cronbach's Alpha	Intraclass Correlation Coefficient (95% CI)*	
Total scale	31	0.94	0.85 (0.74, 0.91)	
Subscales				
Oral symptoms	6	0.69	0.69 (0.47, 0.82)	
Functional limitations	8	0.79	0.79 (0.65, 0.88)	
Emotional well-being	7	0.92	0.85 (0.74, 0.91)	
Social well-being	10	0.89	0.79 (0.65, 0.88)	

*One-way random effect parallel model: P<.001 for all values

on data from 56 parents/caregivers whose children had orthodontic or orofacial conditions. The remaining 23 cases were not included because a change in the child's condition between the two administrations of the questionnaire was reported or a different parent/caregiver participated at the follow-up. The ICC for the total scale was .85, indicating perfect agreement, while for the subscales ICCs were .69 to .85 indicating substantial to perfect agreement (Table 4).

Managing "Don't Know" Responses. The exclusion of cases with "don't know" responses leads to the loss of valuable data. To include these cases, the following method of calculating scores was used. All "don't know" responses were given the value 0. The P-CPQ score was then calculated by summing the response codes to all 31 items and dividing this sum by the number of items for which a valid response was obtained. In effect, this adjusted score represents the mean item score for those items that were answered. The analyses of discriminant and construct validity using these adjusted scores confirmed all hypotheses. For example, the mean adjusted score was .65 for the pedodontic group, .87 for the orthodontic group, and 1.07 for the orofacial group (P<.001). The correlation between the adjusted score and the number of decayed tooth surfaces was .43 (P<.01).

Discussion

This paper describes the development and evaluation of a questionnaire measuring parental/caregiver perceptions of the OHRQoL of children. The measure is not intended to be a classic proxy measure, i.e., a substitute for children's own reports of their oral health and well-being. It is rather intended to supplement the information obtained from children with the conditions of interest. The main rationale for developing such a questionnaire is that parents/caregivers are intimately involved in the health and health care of their children and that the treatment of children's health problems is as likely to be influenced by parental perceptions of a child's needs as it is by the needs of the child. Accordingly, the Child Oral Health Quality of Life Questionnaire consists of a questionnaire for parents/caregivers and ageappropriate questionnaires for children.

Since the ultimate goal was to develop a measure that could be used in clinical trials and evaluation research, the process described by Guyatt et al. (20) and Juniper et al. (21) was used. Its defining characteristic is the use of the impact method to select items for the questionnaire. As illustrated in this paper, this results in a questionnaire consisting of items describing problems that occur most frequently and cause the most bother to patients. The selection of high prevalence items promotes responsiveness—i.e., the ability of the measure to detect small but important changes (25). In conceptual terms, the item impact approach ensures that a questionnaire measures HRQoL rather than health status. A health status questionnaire consists of items that assess the impact of a health condition on physical and psychosocial functioning. An HRQoL questionnaire consists of items assessing the impact of a health condition on aspects of daily life that patients value. Consequently, Guyatt and Cook (26) suggest that when considering a measure for use in clinical practice or clinical trials, clinicians and investigators should look for evidence that the outcomes it addresses are in fact important to the target population. The item impact method produces such evidence in the form of frequency and importance ratings.

The cross-sectional analyses reported here indicated that the measure discriminates among the three clinical groups included in the study, even though it is composed of high prevalence items. It may be that the ability of the P-CPQ to discriminate can be improved further by the addition of some of the lower prevalence items that were excluded and which are listed in Table 2. Effectively, this means the content of the measure can be adjusted to suit the particular purpose of an investigation. The withingroup analyses were limited, but also provided some evidence to suggest that the P-CPQ scores were associated with the severity of the clinical condition in the expected direction. However, further research is needed concerning the association between the P-CPQ scores, clinical measures of oral disorders, and/or diagnostic classifications that are ordered in terms of severity.

The analyses presented here also demonstrated that the P-CPQ has good construct validity, good internal consistency reliability, and excellent test-retest reliability. While further testing of the measure is warranted, these data provide initial evidence that it has good technical properties. Further testing of the measure is also necessary because the parents and children in the study are not necessarily representative of the populations of interest.

A final issue deserving comment is that of the frequency and management of "don't know" responses. A "don't know" response option is essential in studies in which participants report their perceptions of the health or quality of life of another individual. The use of a "don't know" option is not an issue in longitudinal studies where the aim is to assess within-subject change. It is an issue in cross-sectional studies, where differences between groups are being explored. One option is to exclude subjects with such responses. This was the approach in the main analyses reported here. However, this leads to the loss of valuable information and may compromise studies with small sample sizes. Consequently, we explored the use of adjusted scores and showed that these demonstrated equally good discriminant and construct validity. This suggests that "don't know" responses can be accommodated and do not substantially affect the performance of the questionnaire. A third option is to drop items from the questionnaire that have a high proportion of "don't know" responses. These items will be considered for deletion when developing a short form of the P-CPQ. At a minimum, the possibility that a proportion of parents/caregivers may be unable to answer some of the items comprising the P-CPQ because of limitations in their knowledge of their children's activities and feelings should be

taken into account when planning data collection and analysis. In this regard, the high proportion of participants with at least one "don't know" response reflects an essential characteristic of the phenomenon being measured rather than a limitation in the questionnaire.

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