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Oral health-related quality of life in children: Part I. How well do children know themselves? A systematic review

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Dates:

Accepted 24 September 2007

To cite this article:

Int J Dent Hygiene 6, 2008; 93–99
Barbosa TS, Gavião MBD. Oral health-related quality of life in children: Part I. How well do children know themselves? A systematic review.

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Abstract: *Objective:* Paediatric oral disorders are likely to have a negative effect on the quality of life. Until recently, children's oral health-related quality of life (OHRQoL) was measured using parents as informants. Instruments have now been developed, which have demonstrated that with appropriate questionnaire techniques, valid and reliable information can be obtained from children. The aim of this study was to make a systematic review of the existing literature about child perceptions of OHRQoL and their validation. *Methods:* A computerized search was conducted using Medline, ISI, Lilacs and Scielo for children's perception of OHRQoL. The inclusion criteria were: the articles should contain well-validated instruments and provide child perceptions of OHRQoL. *Results:* From 89 records found, 13 fulfilled the criteria. All studies included in the critical appraisal of the project suggested good construct validity of overall child perceptions of OHRQoL. However, children's understanding of oral health and well-being are also affected by variables (age, age-related experiences, gender, race, education, culture, experiences related to oral conditions, opportunities for treatment, childhood period of changes, back-translating questionnaire, children self-perceived treatment need). *Conclusions:* The structure of children's self-concept and health cognition is age-dependent as a result of their continuous cognitive, emotional, social and language development. By using appropriate questionnaire techniques, valid and reliable information can be obtained from children concerning their OHRQoL.

Key words: children; oral health; perceptions; quality of life; systematic review

Introduction

Theory and research in psychology indicate a continual process of cognitive, emotional, social and language development throughout childhood (1, 2). The structure of children's self-concept and health cognition is age-dependent, as a result of their continuous cognitive, emotional, social and language development.

According to child developmental psychology, the age of six marks the beginning of abstract thinking and self-concept (3). Children start to compare their physical features and personality traits with those of other children or against a norm. Their ability to make evaluative judgments of their appearance, the quality of friendships and other people's thoughts, emotions and behaviours gradually develops through middle childhood (6–10 years) (2, 3).

Gradually, children develop the ability to use a wider spectrum of internal cues to identify their illnesses. By the age of 11 or 12, they view health as a multidimensional concept organized around the following constructs: being functional, adhering to good lifestyle behaviours, a general sense of well-being and relationships with others (4). How these concepts are settled varies by age and by the kind of experiences to which children are exposed in their lives (4).

Nowadays, there is interest in children's quality of life (QoL) (5, 6), which includes social, psychological as well as functional aspects (7), as well as oral health (7, 8). Until recently, children's health-related quality of life was measured using parents as informants. This was based on concerns that children's reports of their health and quality of life would not meet accepted psychometric standards of validity and reliability, because of limitations in their cognitive capacities and communication skills (9).

However, a number of recently developed instruments (10–12) have demonstrated that with appropriate questionnaire techniques, it is possible to obtain valid and reliable information from children concerning their health-related quality of life. These instruments were intended to be applicable to children with a wide variety of oral and orofacial conditions, to conform to contemporary concepts of child health, and to accommodate developmental differences among children of different ages (13, 14).

Since there are numerous paediatric oral disorders (15) and these are likely to have a negative effect on the quality of life, there is a need for a measure to register oral health outcomes in child populations. According to literature, children's understanding of complex concepts, such as health and well-being are also affected by variables such as gender,

age and the age-related experiences to which they are subject (16).

The purpose of this study was to identify the literature on child perceptions of oral health-related quality of life (OHR-QoL) and validation of these reports and reviewing and discussing the findings.

Methods

The questions addressed by this review are: (i) 'How well do children know themselves?' and (ii) 'Is children's perception of oral health-related quality of life validated?'

Studies were eligible for review if they matched the following inclusion criteria: (i) they used well-validated instruments; and (ii) they provided child perceptions of OHRQoL.

A well-validated OHRQoL instrument was considered to be one that was able to assess the patient's self-reported perception of oral health status and that had been shown in the scientific literature to be valid, reliable and responsive. Thus, articles that used scoring methods by surgeons or independent observers were not considered, as well as studies that have used adult quality of life measures, because the questionnaires should be specific and validated for children.

A computerized search was conducted using Medline, ISI, Lilacs, Scielo (from January 1985 to March 2007) for child perception of OHRQoL. Two reviewers selected and reviewed the articles. First, each one independently selected the articles from their abstracts and checked their contents. Next, they looked for the articles without abstracts. Articles that did not clearly fulfil the inclusion criteria were excluded. During the evaluation process, reference lists were searched by hand. In this phase, 100% agreement between the two reviewers was obtained.

Results

A total of 89 records were originally identified. In accordance with the inclusion criteria, only 13 articles (17–29) were included in this systematic review. The commonest reason for exclusion was either reports other than child perceptions of OHRQoL or no validated instrument.

Nine (17, 20–25, 27, 28) of 13 selected articles used the child perceptions questionnaire (CPQ) in their methodology. As regards the CPQ instrument, two groups of age-specific questionnaires (CPQ_{8–10} and CPQ_{11–14}) were selected. Four studies (18, 19, 26, 28) used child-oral impacts on daily performances (Child-OIDP). A summary of methodology is presented in Table 1.

Table 1. **Selected articles: summary of methodology**

Reference	Study design	Selected sample	No. subjects	Age (year)	OHRQoL instruments
17	CS	Patient	271	11–14	CPQ _{11–14} [*]
18	CS	General population	2613	11–12	Child-OIDP [†]
19	CS	General population	1126	11–12	Child-OIDP [†]
20	CS	Patient	101	8–10	CPQ _{8–10} [‡]
21	CS	Patient	174	10–12	CPQ _{11–14} [*]
22	CS	Patient	430	12–13	CPQ _{11–14} [*]
23	CS	Patient	71	11–14	CPQ _{11–14} [*]
24	CS	Patient	132	11–14	CPQ _{11–14} [*]
25	CS	General population	208	12	CPQ _{11–14} [*]
26	CS	General population	476	10	Child-OIDP [†]
27	CS	Patient	174	11–14	CPQ _{11–14} [*]
28	CS	Patient	25	11–15	CPQ _{11–14} [*]
29	CS	General population	228	10–11	Child-OIDP [†]

OHRQoL, oral health-related quality of life; CS, cross-sectional.

*Child perception questionnaire 11–14 years.

†Child-oral impacts on daily performances.

‡Child perception questionnaire 8–10 years.

All studies (17–29) included in the critical appraisal of the project suggested good construct validity in all child perceptions of OHRQoL. However, children's understanding of oral health and well-being are also affected by variables. Six studies (17, 19, 20, 22, 28, 29) suggested that the structure of children's self-concept and health cognition is age-dependent. Age-related experiences to which children are subject seemed to affect children's perception of healthy concepts in two articles (19, 21). One study (22) took in account the influence of gender, to get the sample representativeness of the population, because one of the markers for this was the census estimate for gender and population. One study showed that race and education influence child understanding of health conceptions (27). Three studies (17, 20, 23) suggested that children's experiences regarding clinical conditions shaped their conceptions of oral health and well-being, one article (24) showed poor construct validity in relation to clinical variables. Culture, social and material deprivation mediated children's self-assessment of impacts on their QoL (24). Difference in child self-assessment, because of the distinct opportunities for treatment was observed in two studies (17, 25). Translating and adapting a questionnaire developed in one country for use in another usually result in some wording changes which facilitated the development of culturally relevant instrument (17, 18, 26, 27, 29), being strong point of the methodology for using an instrument in a different setting. Three studies (20, 21, 23) suggested that childhood was a period with immense changes in psychosocial awareness (20) and children's dental and facial features changed rapidly (21, 23). Two studies (18, 21) showed that child self-perceived treatment needs were significantly associated with OHRQoL. The differences in the characteris-

tics of the selected samples and the considerable variation in the number of participants ($n = 25$ –1126) determined contradictory outcomes between the different studies. A summary of the results of each selected article is presented in Table 2.

Discussion

The present review found a number of recent studies (17–29) that developed and assessed the validity and reliability of child self-reports on their OHRQoL.

For adequate sample representativeness, census estimate for gender and population was used for comparisons with child population in general (22). While there was an apparent sex difference in overall CPQ scores, it did not quite reach statistical significance, however, the mean emotional well-being domain score for girls was higher than that for boys.

With regard to the influence of age on children's understanding of OHRQoL, one article (20) showed that 8-year-old children were able to report higher impacts on emotional well-being because of oral conditions, whereas children aged 10 years related effects on social well-being because of oral conditions. However, in the study of Yusuf *et al.* (29), 10-year-old children related low-impact on social contact and doing schoolwork, because they do not attach much importance to those activities. An alternative explanation for these contradictory outcomes is that enjoying contact with people might be an inherently unstable construct to children, which varies with time (30). The social domain questions may be less important at young age when the effect of schooling should be considerably diminishing any potential for social isolation, unlike what appears to be the case in older age groups. Other explanation

Table 2. Results of references appraised

Reference	Characteristics of children	Variables of children understanding OHRQoL	Validated child reports about their OHRQoL
17	Canadian with dental, orthodontic and orofacial conditions	Age Oral conditions-related experiences Opportunities for treatment	Children aged 11–14 years were able to give psychometrically acceptable accounts of impacts on OHRQoL Orofacial group had the highest impacts on QoL and paedodontic group, the lowest Children attending a paedodontic specialist referral clinic related better OHRQoL Good validity and reliability
18	Thai students in a municipal area	Back-translating questionnaire Children self-perceived treatment need	Children with a need for treatment have a worse quality of life
19	Thai students with variable oral and dental conditions	Age Age-related experiences	Children aged 11–12 years have clear understanding of complex emotions, such as shame Natural processes of oral health contribute largely to the high incidence of impacts in pre-adolescence
20	Pedodontic patients Orofacial patients	Age Oral conditions-related experience Childhood period of changes	8-year-old children develop the concept of time and understand emotional symptoms 10-year-old children are concerned about their oral appearance Different clinical conditions had distinct characteristics that affect children's experiences Acceptable test–retest reliability, except for the social well-being Any retesting was undertaken because it is acknowledged that people may adapt or habituate to their (health) conditions over time
21	Students with different needs of orthodontic treatment	Childhood period of changes Children self-perceived treatment need	Children with self-perceived treatment needs had worse emotional impacts on QoL Preadolescents have higher impact on their emotional and social well-being Girls related higher impacts on QoL than boys
22	Children with different categories of dental caries and malocclusion	Age Gender	Paediatric and orofacial patients had similar impacts on QoL because the latter group had social and emotional support
23	Patients with dental caries and orofacial conditions	Oral conditions-related experiences Childhood period of changes	Pedodontic patients are likely to exhibit short-term change as a result of dental treatment Cultural, social and material deprivation mediated children's self-assessment of impacts on QoL
24	Children with oro and orofacial conditions	Culture	Cultural, social and material deprivation mediated children self-assessment of impacts on QoL
25	Rural students with dental caries and fluorosis	Opportunities for treatment	Caries experience self-assessment was worse in communities where opportunities for treatment were fewer
26	French children with decayed, missing and filled teeth	Age-related experiences Back-translating questionnaire	Younger children experienced many problems related to dental eruption Good validity and reliability
27	Arabian children with dental caries and malocclusion	Race and education Back-translating questionnaire	Many of Arabian students had difficulty with reading and/or understanding the questions In spite of good validity and reliability, the questionnaire was too long for many of the medically compromised patients
28	Patients with severe hypodontia	Age	The period of early adolescence is characterized by increased preoccupation with others' views of self
29	English students	Age Back-translating questionnaire	Enjoying contact with people might be an unstable construct to children in the middle childhood Culture and location of the sample influenced in child self-report of OHRQoL

OHRQoL, oral health-related quality of life; QoL, quality of life.

for these variations is related to the differences in the characteristics of the selected samples between the studies (20, 29), patient and general population samples respectively.

Although 8-year-old children had related difficulty with understanding the introductory/transition statement: 'In the past 4 weeks, because of your teeth or mouth...' when answering the questions, making the aforementioned statement part of each question provided good construct validity in one study (20).

Gherunpong *et al.* (19) showed that the difficulty with smiling was an important aspect of children's OHRQoL. It affected 40% of children aged 11–12 years. The most prevalent cause was alignment of tooth positions. It is evident that children's concern about their oral appearance is important when they reach adolescence (31).

Children then enter a period of early adolescence (11–14 years), characterized by the increasing centrality of peer crowd and clique dynamics in children's lives, and their preoccupation with others' views of self (2, 3). Wong *et al.* (28) noted that all preadolescents with severe hypodontia experienced one or more social impacts. However, accounting for retained primary teeth, the number of missing teeth was highly correlated with the OHRQoL. This pertinent finding suggested the value of retaining primary teeth in the management of severe hypodontia in children and adolescents. Furthermore, the prevalence of oral impacts on QoL is dependent of the nature of the evaluated sample. In this sense, it is well expected that if this study included a 'patient' sample (28), the prevalence of impacts will be extremely high. In this context, clinical samples, particularly when recruited from one clinical facility, are more often than not convenience samples, highly selected and likely to be subject to various biases. Consequently, the results should not be generalized to all children with specific needs (32). Moreover, in communities where oral problems are widespread, it is possible that self-assessment differs from that in communities where oral health status and opportunities for treatment are better (27). Other factor that should be taken in consideration related to sample in different studies is the age of the children, particularly the stage of development, as it influences the perceptions about oral health and illness, unavoidably affecting HRQoL between childhood and adolescence (18, 33). This might make younger children more sensitive to oral symptoms than older age groups in Gherunpong *et al.* study (18).

Foster-Page *et al.* (22) observed a clear ascending gradient for emotional ('being teased' or 'avoiding smiling or laughing') and social well-being ('being upset' or 'worrying about being different') among orthodontic patients aged 11–14 years, infer-

ring that malocclusion is as much a social phenomenon as an anatomical one.

Jokovic *et al.* (17) showed that the impact of child oral and orofacial conditions on functional and psychosocial well-being is substantial and that children aged 11–14 years were able to give psychometrically acceptable accounts of that impact. However, Brown and Al-Khayal (27), encountered problems with administering the same questionnaire in Arabian children aged 11–14 years. Many of these children had difficulty with reading and/or understanding the questions. Some of the children were not in school, and therefore, unable to answer several questions. So, it has been suggested that global self-rating of health items varies with race and education (34).

Another variable that seems to affect children's understanding of health concepts is age-related experiences to which they are subjected. Gherunpong *et al.* (19) showed that an important reason for the high prevalence of oral impacts in children aged 11–12 years is natural processes, such as exfoliating primary teeth, or space because of a non-erupted permanent tooth. They contributed largely to the high incidence of impacts in these preadolescent children. On the other hand, these conditions were not reported as important causes of oral impacts in other age groups (35, 36). Tubert-Jeannin *et al.* (26) found high prevalence of oral impacts in a population with a low incidence of caries. According to the authors, this higher prevalence could be explained by the younger age of the children (10-year-old). These children experienced many problems related to dental eruption.

Different clinical conditions have distinct characteristics that affect children's experiences, and in turn, these experiences shape their conceptions of health and well-being (16). Thus, Jokovic *et al.* (17) found significant differences among three clinical groups (orofacial, orthodontic and paedodontic groups) in overall scale scores, with those of the orofacial group having the highest and those of the paedodontic group having the lowest scores.

However, two studies (20, 23) showed that although the orofacial children (primarily cleft lip and/or palate) may encounter more challenges in daily life, their overall QoL is no different from that of children with more common oral conditions, such as dental decay. One explanation for the lack of difference between these groups was that the former had received high-quality clinical and psychological care that provided social and emotional support to children and their families from birth, in addition to surgical and orthodontic intervention.

Another article (24) showed poor construct validity in relation to clinical variables and the inconsistencies may not be due to the psychometric properties of the measure, but

because impacts are mediated by others factors, such as culture, social and material deprivation. Cultural norms and expectations influence children's perception of their oral health and its effect on their QoL. In communities where oral problems are widespread, it is possible that self-assessment differs from that in communities where oral health status and opportunities for treatment are better. Oral health-related quality of life among rural Ugandan children with dental caries experience (25) was significantly worse than that of Canadian children attending a paedodontic specialist referral clinic in Canada (17). Therefore, the need to test the psychometric properties of instruments, such as those for measuring OHR-QoL in a new environment, has been stressed (37). The linguistic and cultural context in which a measure is used can have a bearing on the validity, as can the intended purpose of the measure.

Jokovic *et al.* (17) found that CPQ₁₁₋₁₄ applied in Canadian children was valid and has excellent reliability and its test-retest reliability was acceptable, except for the social well-being subscale, showing that children are more likely to experience variability over time in social functioning and experiences than in physical and emotional effects of oral and orofacial conditions. In spite of acceptable validity and reliability of the Arabic translation (27) of the same questionnaire, problems were encountered in Saudi Arabia as regards self-reporting of age, and the questionnaire was too long for many of the medically compromised patients. Yusuf *et al.* (29) found lower oral health-related impact on daily performance among children in UK than in other studies with subjects of similar ages and using similar instruments (18, 26), which could partly be explained by different culture and location of the sample.

Kok *et al.* (21) did not undertake any retesting in their study, because it is acknowledged that people may adapt or habituate to their (health) conditions over time. Thus, they may respond with lower impact scores when a questionnaire is re-administered at a later time (37). For the authors, this is particularly important in conditions that may have an immediate large impact, such as the loss or fracture of an anterior tooth.

According to Locker *et al.* (23), paediatric patients are likely to exhibit short-term change as a result of dental treatment, so this group could be excluded from test to retest reliability analysis.

Another variable that seems to be correlated with oral impacts on QoL is children self-perceived treatment need. Two studies (18, 21) showed that children who expressed concern about their dental alignment and wanted treatment had worse emotional and social impacts when compared with children who were only slightly bothered and did not want treat-

ment. Furthermore, in the study of Kok *et al.* (21), children with a need for treatment, as assessed by the examiner, did not have a worse psychosocial QoL than those with a low score. Thus, this suggests that it is more appropriate to supplement normative indices, such as examiner evaluation, with a QoL measure to identify patients with a clear psychosocial need, because it reflects real subjects' concerns about malocclusions and perceived need for treatment.

Conclusions

Based on this systematic review, it can be concluded that the structure of children's self-concept and health cognition is age-dependent, as a result of their continuous cognitive, emotional, social and language development. In addition, the present findings suggest that with appropriate questionnaire techniques, valid and reliable information can be obtained from children concerning their OHRQoL.

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