REVIEW ARTICLE

TS Barbosa
MBD Gavião

Oral health-related quality of life in children: Part III. Is there agreement between parents in rating their children's oral health-related quality of life? A systematic review

Authors' affiliations:
TS Barbosa, MBD Gavião, Department of Pediatric Dentistry, Piracicaba Dental School, State University of Campinas, Piracicaba, SP, Brazil

Correspondence to:
Maria Beatriz Duarte Gavião
Faculdade de Odontologia de Piracicaba/UNICAMP
Departamento de Odontologia Infantil
Área de Odontopediatria
Avenida Limeira 901 CEP 13414-903 Piracicaba, SP
Brazil
Tel.: +55 19 2106 5200/2106 5368
Fax: +55 19 2106 5218
E-mail: mbgaviao@fop.unicamp.br

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Barbosa TS, Gavião MBD. Oral health-related quality of life in children: Part III. Is there agreement between parents in rating their children's oral health-related quality of life? A systematic review.

Abstract: *Objective:* One issue that receives a great deal of attention is the comparison between measurement of children's oral health-related quality of life (OHRQoL) reports with those of their parents. However, the extent to which parents understand the effects of ill-health on their children's lives remains unanswered. The purpose of this systematic review was to identify the literature on the nature, extent and the pattern of agreement/disagreement between parent and child reports about child OHRQoL and assess the association between them. *Materials and methods:* The literature was searched using MEDLINE, ISI, Lilacs and Scielo, from January 1985 to March 2007. The selected studies used well-validated instruments and provided children's and parent's perceptions of child OHRQoL. *Results:* A total of 87 articles were retrieved and five were selected for the review, which showed that children and parents do not necessarily share similar views about child OHRQoL. Some parents may have limited knowledge about their children's OHRQoL, particularly the impact on social and emotional well-being. *Conclusions:* Valid and reliable information can be obtained from parents and children using appropriate questionnaire techniques. Although the parents' reports may be incomplete due to lack of knowledge about certain experiences, they still provide useful information.

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

Introduction

Over the past two decades, there has been substantial development of oral health-related assessments of quality of life (QoL) (1), usually generated by adult participants. More recently, there has been increasing interest in the QoL of children (2, 3), including oral health (4, 5).

Quality of life measurement in children involves special methodological problems, such as changes in children's ability to understand at different ages, the difficulty of separating the child's perceptions from the parents and the variation in the number of activities with age (6, 7). An important question is whether reliable and valid data can best be obtained from children themselves or from their parents.

Until recently, children's health-related quality of life (HRQoL) was measured using parents as informants. This was based on concerns that children's reports of their health and QoL would not meet accepted psychometric standards of validity and reliability because of limitations in their cognitive capacities and communication skills (8). However, a number of recently developed instruments (5, 9, 10) have demonstrated that with appropriate questionnaire techniques, it is possible to obtain valid and reliable information from children concerning their HRQoL.

One issue with respect to measuring the HRQoL of children, which continues to receive a great deal of attention, is that of parent versus child reports (11–14). One reason for studying parent-child agreement is to determine whether the parent can be used as a proxy for the child. The results of studies conducted to date are equivocal. While some studies indicated relatively high agreement for some health domains (11, 15), others have found low concordance (8, 13, 14) between parent and self assessments.

To date, the extent to which parents understand the effects of ill-health on their children's lives remains unanswered. The validity of parents' reports and, therefore, whether or not parents can serve as proxies for children depends on this understanding.

Thus, the purpose of this study was to identify literature on the nature, extent and the pattern of agreement/disagreement between parent and child reports about child oral health-related quality of life (OHRQoL), review the findings systematically and assess the association between them.

Materials and methods

The authors searched MEDLINE from January 1985 to March 2007, supplemented by manual searching of reference lists from each relevant paper identified.

The main search terms were 'children', 'oral health' and 'quality of life'. A total of 87 records were originally identified. Two reviewers independently checked and then selected only articles about parental and child perceptions of child OHRQoL, which resulted in nine articles. A 100% of agreement was obtained between the two researchers.

The studies were eligible for review if they matched the following inclusion criteria: (i) they used a well-validated instrument and (ii) they provided children's and parent's perceptions of child OHRQoL.

A well-validated HRQoL instrument was considered to be an instrument that had the ability to assess the patient's self-reported perception of health status and that had been shown in the scientific literature to be valid, reliable and responsive.

Studies that evaluated children's oral health and quality of life through other perceptions (such as teacher and professional) instead of parents were discarded. Several studies that used non-validated questionnaires were also excluded.

A consensus was reached regarding the articles that actually fulfilled the inclusion criteria (only five articles), and were finally included in this systematic review. Figure 1 shows the screening process to select articles for the review.

Results

Out of the 87 articles that were critically assessed, five (16–20) studies identified during the search were included in the project critical appraisal, on the grounds that they did measured parental perceptions of child OHRQoL. Despite the number of evaluated conditions was not the same in all selected studies, it was considered in the present review the agreement or disagreement between parental and child reports about the impact of oral conditions on child QoL and the validity of these information. The main reasons for excluding 82 of the

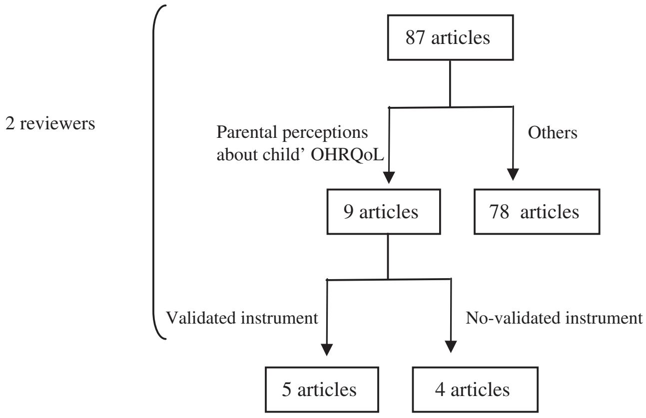

Fig. 1. The screening process to select articles for the review

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

Reference	Study design	Subjects	Parents instruments	Child instruments
(16)	CS	42 pairs of parents and children	PPQ*	CPQ‡
(17)	CS	512 parents	PPQ*	-
(18)	CS	221 parents	PPQ*	CPQ‡
(19)	CS	90 pairs of parents and children	PPQ*	CPQ‡
(20)	CS	450 parents	PPQ* FIS†	-

*Parental Perceptions Questionnaire; †Family Impact Scale; ‡Child Perception Questionnaire; CS, cross-sectional.

articles were the use of other reports instead of parents and no application of validated questionnaires.

The following well-validated instruments were used in the selected studies: Parental Perceptions Questionnaire (PPQ), Child Perceptions Questionnaire (CPQ) and Family Impact Scale (FIS). Out of five studies (16–20) that used PPQ, three studies (16, 18, 19) used CPQ and only one paper (20) used FIS (Table 1).

As children are subject to numerous oral and orofacial conditions with potential to significantly impact on their QoL, two studies (17, 19) found a statistical difference between the groups with variable oral conditions throughout parent's perceptions. However, regarding the severity of the child's condition, both studies (17, 19) found no statistical difference. All of the studies (16–20) suggested that parents' knowledge about their children is limited, with one article (18) showing the importance of the 'don't know' response option in studies, in which participants report their perceptions of the health or QoL of another individual. The limitation of parents' knowledge was particularly with respect to activities or relationships that exist outside the home and with respect to internal feeling states (16, 18). In spite of the majority of informants being the mothers in all five studies (16–18), one study showed statistically lower knowledge for fathers than mothers about impacts on child QoL (18). The influence of the child's characteristics on proxy-patient agreement was shown by two studies (16, 18). Out of the five studies, three (16–18) suggested that proxy reports can supplement children's evaluation, one (19) showed significant agreement between children and their parents as regards the impact of the oral condition on child QoL, and one (20) suggested that parents' responses reflect the truth as they perceive it, which is not necessarily identical to that of their children. A summary of the results of each selected article is presented in Table 2.

Discussion

The present review was the first to systematically search and critically appraise the substantial literature on the nature, extent and pattern of agreement/disagreement between parent and child reports about child OHRQoL. Systematic reviews are an important tool for studying the relationship between proxy and self reports about the influence of child oral conditions on their QoL. They can also provide information on the validity of parents' reports and, therefore, whether or not parents can serve as proxies for children. It is also important that this review will contribute towards the explanation of the extent to which parents understand the effects of ill-health on their children's lives.

Children are subjected to numerous oral and orofacial conditions, including dental caries, malocclusions, cleft lip and palate and craniofacial anomalies, which have the potential to influence the QoL significantly. It is suggested that the impact on QoL would be highest in the orofacial conditions, lower in the orthodontic and lowest in the paediatric dentistry group. The study of Jokovic *et al.* (17) corroborated this suggestion, showing statistically significant difference between the groups through the parent's perceptions. Given that orofacial disorders tend to be the most severe and have entailed clinical care since birth, it may be that the parent–child relationship is somewhat closer when children have these conditions, so that parents are more familiar with their activities and feelings.

Parents of children in the increased horizontal overlap and spaced dentition groups reported statistically significant greater negative impacts on QoL than parents of children in the control group, with normal occlusion (19). Furthermore, no such differences were found between parents' reports of children in the increased overjet and spaced dentition groups, suggesting that both malocclusion and spaced dentition, in spite of the difference in severity, have a similar impact on QoL (19). Although it has been suggested that impact on the QoL may vary according to the severity of the child's condition, Jokovic *et al.* (17), evaluating parents' perception about ranking children in terms of the clinical severity of orofacial conditions (isolated cleft lip or palate compared with bilateral cleft lip or palate), also showed no statistical difference between the groups. However, it could have been due to the small numbers in the groups.

Table 2. **Results of references appraised**

Reference	Characteristics of informants	Characteristics of children	Material and files	Validated parents reports about child OHRQoL	Association between parents and child reports about child OHRQoL
(16)	42 Mothers	1. Paedodontic 2. Orthodontic 3. Orofacial 4. 11–14 years	PPQ* CPQ†	It was suggested that mothers tended to under-report the impact of oral/orofacial conditions on the QoL of their children.	The level of agreement ranges from excellent for oral symptoms to moderate for both emotional and social well-being. Gender, age and oral condition influenced the agreement between parents and children.
(17)	349 Mothers 147 Fathers 22 Others	1. Paedodontic 2. Orthodontic 3. Orofacial 6–10 years 11–14 years	PPQ*	Measure of parents' reports discriminated among the three clinical groups. The intragroup analyses about severity of oral conditions were not statistically significant.	–
(18)	**Study 1** 129 Mothers 66 Fathers 13 Others	1. Paedodontic 2. Orthodontic 3. Orofacial 6–10 years 11–14 years	PPQ* PPQ* CPQ†	'Don't know' responses were associated with child's age and clinical condition, and parental gender. Parents have limited knowledge about their children's OHRQoL	–
	Study 2 53 Mothers 11 Fathers		PPQ* CPQ†	-	Parental and child reports measure different realities
(19)	90 parents	1. Children with: increased overjet 2. Spaced dentition 3. Control 13–15 years	PPQ* CPQ†	Parents of children in the increased overjet and spaced dentition groups reported statistically significant greater impacts on QoL than parents of children in the control group Both malocclusion traits have a similar highly significant impact on QoL	The finding of agreement between the child and its parents, with regard to the impact of malocclusion was significant.
(20)	313 Mothers 121 Fathers 16 Others	1. Paedodontic 2. Orthodontic 3. Orofacial 6–10 years 11–14 years	PPQ* FIS‡	Parents' responses reflect the truth as they perceive it, which is not necessarily identical to that of their children.	–

*Parental Perceptions Questionnaire; †Child Perception Questionnaire; ‡Family Impact Scale; OHRQoL, oral health-related quality of life; QoL, quality of life.

However, it is plausible that parents' knowledge of their children is limited, particularly with respect to activities or relationships that exist outside the home and with respect to internal feeling states. Thus, a 'don't know' response option is essential in studies in which participants report their perceptions of the health or QoL of another individual, as demonstrated by Jokovic *et al.* (18). In this study, almost half of the parents gave a 'don't know' response to at least one of the 37 questionnaire items and a quarter gave this response to three or more items. Such responses were most frequent with respect to the social well-being subscale, with one-tenth of parents unable to answer one-third of the 10 items comprising this domain. 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.

Concerns have been raised about the accuracy of parental assessments, particularly with respect to older children. Corresponding with this suggestion, one article (18) found that parents had more knowledge about younger children than older children. This reflects the fact that as children get older, they spend more time away from parental supervision and share their experiences with parents to a lesser extent.

Discrepancies between parental and child reports may reflect real differences in perspectives. However, they may also reflect a lack of insight on the part of parents into their children's lives. This hypothesis is supported by evidence suggesting lower levels of agreement in items for which the parent and child have access to different information (e.g. peer relationships and school activities) and where the items have abstract rather than concrete referents (e.g. pain and emotions) (13, 21).

Parental gender has been suggested as predictor of the knowledge of child OHRQoL. The majority of the informants were the mothers in all five studies. Conversely, one study showed less knowledge for fathers than mothers about impacts on child QoL (18). Another study (16) suggested that as the participants included only a small number of fathers, only mother-child pairs should be considered for the analysis. On the other hand, evaluating agreement between mothers and children perceptions about child OHRQoL, Jokovic *et al.* (16) showed scores ranging from excellent to moderate, with the latter being observed for the emotional and social well-being domains. These findings suggest that mothers should not be used as proxies when the main concern is the child's emotional and social well-being. Further research into parental gender knowledge about child OHRQoL needs to be conducted using larger samples to determine who the better informant is.

A number of studies have indicated that proxy-patient agreement is influenced by the patient's characteristics (22–24). Jokovic *et al.* (16) observed lower levels of agreement for girls, older children, orofacial patients and children, whose QoL was most compromised. However, all these estimates should be treated with a high degree of caution because of the small sample size involved.

It has been suggested in the literature that proxy reports do not represent the reality experienced by the child but they can supplement the children's evaluation (25, 26). There was a tendency on the part of mothers to under-report the impact of oral/orofacial conditions on the QoL of their children, as children's reports about their OHRQoL were worse than their mothers (16). However, a significant agreement between the child and its parent in relation to the impact of oral condition in child QoL was found, because not only does the oral condition have a direct impact on the child itself, but it also has an effect on parents and other family members (19). Locker *et al.* (20) found strong correlation between family impact scores and those derived from the items that measured parental-caregiver perceptions of the child's OHRQoL.

Thus, parents' responses reflect the truth as they perceive it, which is not necessarily identical to that of their children. Nowadays, it is recognized that parental and child questionnaires measure different realities. This means that parental and child reports should be seen as complementary, and that useful information may be lost if parental reports are not obtained in addition to those provided by their children.

Conclusion

Based on this systematic review, it can be concluded that with appropriate questionnaire techniques, valid and reliable information can be obtained from parents and children. Moreover, children and parents do not necessarily share similar views about OHRQoL. After all, some parents may have limited knowledge about their children's HRQoL, particularly the impact on their social and emotional well-being.

Although parents' reports may be incomplete due to lack of knowledge about certain experiences, they still provide useful information. Thus, proxy reports do not represent the reality experienced by the child but they can supplement or complement the children's evaluation and useful information may be lost if parental reports are not obtained in addition to those provided by their children.

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