

Quality of life in patients with dental conditions: comparing patients' and providers' evaluation

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Objective. To measure the agreement between patients and their caregivers in evaluating patients' oral quality of life. **Basic research design.** Cross-sectional study. **Clinical setting.** Data collected in four Swedish dental clinics in 2004. **Participants.** Consecutive patients. Data were completed for 444 patients. Fifteen dentists and 12 dental hygienists agreed to participate. **Interventions.** For each patient, the patient him/herself and his/her caregiver completed the 14-item Oral Health Impact Profile (OHIP-14), a specific instrument used to measure quality of life in oral conditions, with higher scores indicating a worse quality of life. Information on personal and clinical characteristics of patients were also collected. **Main outcome measures.** Median OHIP-14 scores given by caregivers and patients were calculated and compared in different subgroups of patients. Cohen's kappa was calculated to measure the agreement between the evaluation of patients and caregivers. **Results.** OHIP-14 scores median values were 3.0 among patients and 9.0 among caregivers. Caregivers always gave a higher score than patients, especially in older patients and patients with lower education. The concordance between patients' and caregivers' evaluation was very low (for different OHIP-14 cutoffs: Cohen's kappa from 0.10 to 0.15). **Conclusions.** In this study, great discrepancies were observed between patients and caregivers in the evaluation of patients' oral quality of life, with caregivers overestimating the burden of dental conditions on patients. It is important to improve patient-caregiver communication, in order to increase patient satisfaction and provide better care. A good patient-caregiver relationship is essential for the patients' well-being and their adherence to treatment.

Keywords: Communication, odontology, quality of life.

Introduction

In recent years, the concept of quality of life has become an important public health focus. The idea underlying this concept is that health is not just the absence of disease, but a status of general well-being, that includes emotional and psychosocial issues, i.e., positive health. In the field of dentistry, the concept of oral health-related quality of life (OHRQOL) captures the aim of this new perspective on health (Locker and Gibson, 2006). Many instruments have been developed to specifically measure OHRQOL (Atchison and Dolan, 1990; Klages *et al.*, 2006; Slade, 1997), even though there is no complete consensus on the conceptual content of it.

Oral conditions can have a strong impact on the quality of life of patients (Jones *et al.*, 2006), both from a physical and a psychosocial point of view. The interactions between oral and systemic health are bi-directional and complex, involving many pathways (Johnson *et al.*, 2006), as some systemic conditions have oral manifestations, while oral disease is a risk factor for a number of systemic conditions (Southerland *et al.*, 2006).

Clinical evaluation alone is not sufficient for a comprehensive assessment of the burden of a dental disease on a patient. It has been shown that clinicians' ratings of oral health often do not correspond to patient self-ratings (Atchison *et al.*, 1993). This is due to the fact that the individual perception of health is strictly correlated with his/her QOL. It is important for clinicians to be aware of

the problems associated with QOL, in order to provide ratings of the patients' oral health more similar to those given by the subjects (Yamalick, 2005). The dentist's positive attitudes and communicative skills, and thus patients' understanding, are closely related to patients' satisfaction (Schouten *et al.*, 2003) and outcome of care (Sondell *et al.*, 2002).

In the framework of a large Swedish study (Johansson *et al.*, 2007) on quality of life and psychological characteristics of patients with oral conditions, the aim of the present study was to measure the agreement between patients and their caregivers on the patients' quality of life, using the 14-item Oral Health Impact Profile (OHIP-14) (Slade, 1997).

Materials and Methods

This study was performed in the region of Värmland, Sweden, from June to December 2004. It consisted of a simultaneous assessment of patients' oral quality of life, performed both by patients themselves and by their caregivers. Three clinics in the largest city in the region were randomly chosen and, to counterbalance, one clinic in a small town was chosen, giving a total of four clinics. Each caregiver had to evaluate 20 patients, for a total of 540 consecutive patients. Selection criteria of patients were: age 19 years or more; ability to write and speak Swedish; at least two previous visits with the caregiver. The questionnaires were sent to the

clinics in June 2004 and were returned between August and December 2004.

To measure oral quality of life, the short form of the OHIP measure, the OHIP-14, (Slade, 1997) was used for assessment both by the patient and by the caregiver. The Swedish version of this instrument has been recently validated (Hagglin *et al.*, 2007). The OHIP measure is one of the most developed available oral quality of life measures. It contains measures of physical, psychological and social abilities, general physical function, ability of speech and eating, symptoms of pain and discomfort, and appearance and social embarrassment. The questionnaire was originally addressed to the patients. However, in this study the same questionnaire was administered to the caregivers, wording the questions in order to assess how caregivers thought each patient experienced his/her oral problems. For example, the question "How often have you had painful aching into your mouth?" was for the dentist transformed into "How often do you think your patient has had painful aching into his/her mouth?"

Answers to the OHIP questions were given on a five-point scale: 0="never", 1="hardly ever", 2="occasionally", 3="fairly often", 4="very often". The total OHIP score was calculated summing the score of each question, and thus higher scores indicate worse quality of life impairment. When one or two answers were missing, the total score was calculated by replacing the missing answers with the mean value of the completed items, while for more than two answers missing, the total score was considered as missing.

Other information was collected by both the patients and the caregivers. The patients answered to demographic questions, i.e., gender, age, and educational level (primary school, secondary school, or college/university). The caregivers assessed the patients' oral condition on the basis of the visit and the patient records. They were also asked to classify the patient's periodontal status, on the basis of the number of bleeding gums, the caries status and previous fillings, and the number of remaining teeth (Axtelius *et al.*, 2002). Moreover, patients were assigned to a risk group classification, according to a set scheme, based on four categories: general, technical, caries, and periodontal risk (Johansson *et al.*, 2007).

Age was grouped into the categories <30, 30-39, 40-49, 50-59, 60 or more years. The number of caries lesions in enamel was grouped into 3 categories: 0, 1-4, and ≥ 5 lesions; the number of caries lesions in dentine, as 0, 1 or 2, and ≥ 3 ; the number of fillings/crowns into 0-8, 9-16, and ≥ 17 . A summary score was created, summing the number of caries lesions in enamel, in dentine, and fillings/crowns, and categorized as 0-9, 10-19, and ≥ 20 .

Differences in quality of life evaluation were analyzed comparing the OHIP median scores and its single item scores in patients and providers. The median was chosen, instead of mean values, because of the skewed distribution of the measure. OHIP-14 median scores in the two groups were compared in the described independent variables, and the difference between patients' and caregivers' scores in each group were tested by the non-parametric Wilcoxon test for paired data. The non-parametric Mann Whitney test for independent data was used to test if the OHIP-14 difference was higher in a group of patients

compared to another (e.g., in men compared to women, in different groups of age, etc).

Cohen's kappa was calculated to measure the agreement between the evaluations of patients and caregivers. A value of 1 indicates perfect agreement, while a value of 0 indicates that agreement is no better than chance. Cohen's kappa corrects for the possibility that responses coincide by chance. For the purpose of the study, in order to calculate Cohen's kappa, the OHIP score was dichotomized using as cutoffs the scores 1, 3, 5, 9, 10, and 14, alternatively.

A factor-analysis of the OHIP-14 was then performed, to see whether there were any meaningful underlying dimensions, and to investigate whether concordance rates were different for possible different aspects of quality of life.

Spearman correlation coefficient was calculated between the OHIP-14 scores and the risk assessment, and the OHIP-14 scores and the number of caries/fillings.

In order to study the internal consistency (i.e., to test whether items were sufficiently interrelated to justify their combination in an index) of the OHIP-14 both in patients' and in caregivers' questionnaires, Cronbach's alpha was calculated.

All statistical analyses were performed using SPSS 13.0 for Windows.

Results

Data were collected for 485 patients. The response rate was thus 80.8%. The study population consisted of 444 patients with complete data, due to internal non-response. Fifteen dentists and 12 hygienists participated, each being visited by 10 to 20 patients. Among patients, 54.3% were women, and the mean age (sd) was 43.3 (13.1) years.

Median values (and range) of patients and caregivers OHIP-14 scores were 3 (0-25) and 9 (0-42), respectively. Table 1 shows the frequency of all the OHIP items, as evaluated by patients and by caregivers. In general, caregivers tended to give higher scores (indicating a worse quality of life) in the evaluation of oral health quality of life of their patients than the patients themselves. Thus, the correlation between patients' and caregivers' answers was low (Spearman's $\rho=0.21$).

Cronbach's alpha was 0.95 for the caregivers' OHIP and 0.87 for the patients' OHIP, showing an excellent intercorrelation among the items.

We used different cutoffs (i.e., 1, 5, 10, and 14, and the median values 3 and 9) of the OHIP scores to calculate Cohen's kappa. In all cases, concordance between providers and patients was quite low, from 0.10 to 0.15 (see Table 2).

Factor analysis on the patients' OHIP-14 gave as a result two main dimensions, one mostly clinical (six items), and the other psychosocial (eight items). We calculated Cohen's Kappa for patients and caregivers separately for the two dimensions, but we obtained low values as well. For example, kappa was 0.09 for the symptom dimension, with cutoff 6, and 0.10 for the psychosocial dimension with cutoff 8.

In Table 3, the median OHIP scores observed for different levels of some independent variables are reported. In general, caregivers gave higher scores than

Table 1. Frequency (%) of answers to the fourteen Oral Health Impact Profile (OHIP) items, in patients and in caregivers

Frequency of items	Never		Hardly ever		Occasionally		Fairly often		Very often	
	patients	caregivers	patients	caregivers	patients	caregivers	patients	caregivers	patients	caregivers
trouble pronouncing words	90.5	48.6	7.0	42.3	2.5	8.2	0.0	0.9	0.0	0.0
taste worsened	88.0	45.1	7.9	45.8	4.1	7.7	0.0	1.2	0.0	0.2
painful aching	41.0	19.1	33.0	48.9	24.4	30.0	1.6	1.8	0.0	0.2
uncomfortable to eat foods	51.1	30.6	27.0	50.9	20.5	16.2	1.4	2.3	0.0	0.0
self-conscious	59.8	38.8	18.5	45.6	18.7	12.0	2.0	2.7	0.9	0.9
felt tense	58.3	33.3	20.3	43.3	16.9	18.4	3.6	3.9	0.9	1.1
diet unsatisfactory	85.4	43.9	11.0	46.8	3.4	8.6	0.2	0.5	0.0	0.2
interrupt meals	86.9	50.5	9.7	44.1	3.4	5.2	0.0	0.2	0.0	0.0
difficult to relax	74.5	40.7	16.5	46.2	7.0	10.4	1.1	2.0	0.9	0.7
a bit embarrassed	68.9	50.0	20.0	40.7	8.8	7.7	1.8	0.9	0.5	0.7
a bit irritable	91.2	62.1	5.9	33.4	2.3	4.1	0.2	0.2	0.5	0.2
difficulty in jobs	89.9	58.5	8.8	37.5	1.1	3.6	0.2	0.2	0.0	0.2
life less satisfying	79.2	60.9	13.3	31.8	6.5	5.9	0.9	0.9	0.0	0.5
unable to function	91.7	62.5	7.2	33.6	1.1	2.9	0.0	0.5	0.0	0.5

their patients. This was true especially for older people, and patients with lower education. Also, when patients had complicated periodontitis, caregivers evaluated the quality of life of patients as significantly more impaired than did the patients themselves. The discrepancy was particularly high when the number of decayed and filled teeth were high, and for a low number of teeth. The same result was obtained for the risk assessment: for higher risks the median values were six and 16 for patients and caregivers, respectively.

The correlation between the risk assessment score and OHIP-14 was 0.17 in patients' and 0.48 in caregivers' evaluation. The correlation between the summary caries- fillings/crowns score and the OHIP-14 was 0.06 in patients and 0.25 in caregivers.

Discussion

In this study, we observed large discrepancies between patients and caregivers in the evaluation of patients' OHRQOL. In particular, caregivers tended to overestimate the burden of the dental conditions on patients' life.

In a previous study, concerning patient and provider evaluation of QOL in people with dermatological conditions, we observed, too, that in some diseases the dermatologist tended to overestimate the burden of the condition in patients (Sampogna *et al.*, 2003). These discrepancies were particularly high in some severe conditions, such as skin tumours. This can be due to the fact that generally melanoma, which is not a particularly visible cutaneous condition, has a limited direct influence on psychosocial life. However, it may have very severe clinical consequences, up to death, and caregivers are usually more aware of it than patients. This is similar to the periodontitis results here, where severe periodontitis can have serious consequences.

As we observed in the dermatological study, the caregivers may have overestimated the burden of the disease on patients, either because they were more aware than patients of all possible complications and implications of the diseases, or because they thought that a "no" answer would indicate they would classify the problems of their patients as trivial or non-existent. The overestimation of poor quality of life was particularly striking when patients had more severe conditions, in complicated periodontitis and in patients with many decayed and filled teeth. Caregivers may have answered according to their general opinion on the disease, without really empathising with patients. Thus, they usually considered that a high risk assessment score or a severe dental condition

Table 2. Sensitivity analysis of agreement in the evaluation of oral health-related quality of life by patients and caregivers. Cohen's kappa coefficient is calculated using 6 different cut-offs for OHIP-14 total scores.

OHIP cutoffs	1 (0 /1+)	3 (≤3 /4+)	5 (≤5 /6+)	9 (≤9 /10+)	10 (≤10 /11+)	14 (≤14 /15+)
Cohen's kappa	0.15	0.10	0.10	0.13	0.14	0.14

was associated with a low quality of life, while for the patients this was not always true.

A possible explanation of this low correlation could be a poor communication between patients and caregivers (Sondell *et al.*, 2002). The lack of a mutual understanding of patients and providers, due to a non-efficient communication, can lead to severe consequences, for example concerning the adherence to treatment. Dentists who communicate with patients have better results on the treatment of fearful adult dental patients (Berggren, 2001). The communicative behaviour of dentists is re-

lated to patients' satisfaction with treatment outcome, also because it helps patients to reach a well-informed decision about the treatment (Schouten *et al.*, 2003). It can also influence the choice of treatment. In a study exploring which factors affected patients' decisions to pursue either surgical or non-surgical periodontal treatment (Patel *et al.*, 2006), it was observed that the more the patients trusted their provider and felt they had good rapport, the more likely they were to accept surgical periodontal treatment. Thus, there is a real need for dental care providers of being able to communicate effectively

Table 3. Median OHIP scores in patients and caregivers according to different variables.

		<i>n</i>	<i>patients</i>	<i>caregivers</i>	<i>p-value*</i>	<i>p-value[§]</i>
<i>overall</i>			3	9	<0.001	---
<i>gender</i>	men	203	3	7	<0.001	Ref
	women	241	4	10	<0.001	0.119
<i>age (years)</i>	<30	71	4	4	0.225	Ref.
	30-39	121	4	5	0.003	0.226
	40-49	110	3	9	<0.001	0.015
	50-59	87	2	13	<0.001	<0.001
	60+	54	3	14	<0.001	<0.001
<i>education</i>	primary school	92	4	12	<0.001	Ref.
	secondary school	163	3	8	<0.001	0.050
	college/university	189	4	7	<0.001	0.010
<i>periodontal condition</i>	healthy	330	3	7	<0.001	Ref.
	general gingivitis	57	4	10	0.001	0.440
	moderate periodontitis	40	3	14	<0.001	0.003
	severe periodontitis	5	6	8	0.345	0.650
	complicated periodontitis	3	3	17	0.109	0.034
<i>No. of teeth</i>	<26	72	3	14	<0.001	Ref.
	26+	371	3	7	<0.001	<0.001
<i>No. caries lesions in enamel</i>	0	146	3	12	<0.001	Ref.
	1-4	154	4	7	<0.001	0.004
	5+	71	4	3	0.015	<0.001
<i>No. caries lesions in dentine</i>	0	183	3	8	<0.001	Ref.
	1-2	137	3	7	<0.001	0.385
	3+	59	6	12	<0.001	0.679
<i>No. fillings/crowns</i>	0-8	120	3	5	0.001	Ref.
	9-16	206	4	8	<0.001	0.101
	17+	109	3	13	<0.001	<0.001
<i>No. caries lesions fillings/crowns</i>	0-9	80	3	6	<0.001	Ref.
	10-19	172	4	7	<0.001	0.786
	20+	98	3	11	<0.001	0.381
<i>risk classification</i>	0-5	154	3	3	0.010	Ref.
	6-8	186	3	10	<0.001	<0.001
	9+	90	6	16	<0.001	<0.001

* From Wilcoxon test for paired data: comparison between patients' and caregivers' score in each group.

§ From Mann Whitney test for independent data: comparison of the OHIP difference in each group compared to a reference group.

Note: totals may vary because of missing figures

with their patients in order to build a positive rapport and trust (Kaplowitz, 1999).

Another hypothesis about the discrepancies in the two evaluations could be the different frame of reference of patients and caregivers. Patients live their lives as a whole, and thus give less importance to a single component of their well-being. A tooth problem might become a secondary problem for a person, even though it is objectively a severe condition.

A possible limitation of this study could be the caregivers' voluntary participation. It is possible that those who participated, on average, had a better perception of patients' status than the non-participants. Lacking a comparison group, this explanation cannot be excluded, although we regard it as unlikely.

The OHIP-14 is a widely used OHRQOL instrument, however it presents some limitations. For example, in our data the so called "floor effect" was particularly evident, i.e., many answers were zero (=no impact) or very low. In previous studies of edentulous patients (Allen and McMillan, 1999; Locker *et al.*, 2001) it was observed that patients with poor oral health had low scores in the OHIP-14. The measure does not seem to be suitable for all dental conditions. For example, the shortened version of the OHIP does not contain any item relating to chewing difficulties, which is a frequent problem in patients wearing removable dentures (Allen and Locker, 2002).

However, for the purposes of our study, the limitations of the OHIP-14 questionnaire should affect measurements equally in patients and providers, and thus the problems of the measure do not seem to justify the poor correlation observed.

Our results suggest that it may be important to provide dentists and hygienists with improved training, in patient-caregiver communication, which could increase patient satisfaction and ultimately result in better care.

Further analyses will be necessary to thoroughly explore the caregiver-patient relationship in oral health. Multivariate analyses will be performed in order to evaluate the possible determinants of the discrepancies observed, taking into account all the studied variables simultaneously.

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