What do measures of 'oral health-related quality of life' measure?

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Abstract - The terms 'health-related quality of life' and 'quality of life' are now in common use to describe the outcomes of oral health conditions and therapy for those conditions. In addition, there has been a proliferation of measures designed to quantify those outcomes. These measures, which were initially designated as socio-dental indicators or subjective oral health indicators are now more usually referred to as measures of oral health-related quality of life (OH-QoL). This is based on the assumption that the functional and psychosocial impacts they document must, of necessity, affect the quality of life. While this assumption has been subject to critical scrutiny in medicine, this is not the case with dentistry. Consequently, exactly what is being measured by indexes of OH-QoL is somewhat unclear. Based on the debate between Gill and Feinstein and Guyatt and Cook, we outline a number of criteria by means of which the construct addressed by measures of OH-QoL may be assessed. These are concerned with how the measures were developed and validated. These criteria are then used to appraise five of the many measures that have been developed over the past 20 years - the GOHAI, OHIP, OIDP, COHQoL and OH-QoL. The main conclusion is that while all document the frequency of the functional and psychosocial impacts that emanate from oral disorders they do not unequivocally establish the meaning and significance of those impacts. Consequently, the claim that oral disorders affect the quality of life has yet to be clearly demonstrated. Verifying this claim requires further qualitative studies of the outcomes of oral disorders as perceived by patients and persons, and the concurrent use of measures that more explicitly address the issue of quality of life.

Medicine in the last 30 years has seen the increasing use of the terms 'health-related quality of life' and 'quality of life' in relation to the outcomes of health conditions and therapy for those conditions (1). This emerged out of a growing recognition that traditional clinical measures of health need to be supplemented by data obtained from patients and/or persons that captures their experiences and concerns (2). It reflects the fact that we are no longer aiming just to prolong life or to render it free of disease, but to make it better (3), and acknowledges that the issues addressed by the terms health-related quality of life and quality of life are important determinants of care seeking, adherence to treatment regimens and satisfaction with the care received (4). Conse© 2007 The Authors. Journal compilation © 2007 Blackwell Munksgaard



Commentary

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quently, there has been a tremendous growth in the literature concerned with these constructs.

This is also the case in dentistry, where there has been a proliferation of instruments and scales seeking to assess what has come to be called oral health-related quality of life (OH-QoL) and/or the quality of life of patients with various oral conditions. Ten such measures were described in a monograph reporting the proceedings of a major conference on measuring oral health and quality of life (5). Since then at least six additional measures have been developed and more are in the process of development (see Table 1).

However, the development of so many measures, to be welcomed when the field was in its Table 1. Oral health outcome measures developed to date

Pre-1997 (Presented at the 1997 conference)
Social Impacts of Dental Disease (38)
General (Geriatric) Oral Health Assessment Index
(GOHAI) (21)
Dental Impact Profile (DIP) (39)
Oral Health Impact Profile (OHIP) (22)
Oral Impacts on Daily Performances (OIDP) (23)
Subjective Oral Health Status Indicators (SOHSI) (40)
Oral Health-Related Quality of Life Measure (12)
Dental Impact on Daily Living (DIDLS) (41)
Oral Health Quality of Life Inventory (25)
Rand Dental Questions (42)
Post-1997
OHQoL-UK (43)
Child Oral Health Quality of Life Questionnaire
(COHQoL) (24)
Child OIDP (28)
OHRQOL for Dental Hygiene (44)
Orthognathic QOL Questionnaire (45)
Surgical Orthodontic Outcome Questionnaire (SOOQ)
(46)

infancy, has lead to a certain lassitude and a failure to continue to address the conceptual and methodological issues involved in measuring perceptions of oral health and the outcomes of oral disorders at the individual and population levels. The existence of numerous measures which appear to be appropriate for a wide variety of contexts and purposes seems to have given rise to the assumption that these theoretical and measurement problems have been satisfactorily addressed and/or solved. This is not the case in medicine where critical reviews of the state of the art continue to appear that question the theoretical basis of measures that claim to assess health-related quality of life or quality of life (1–4, 6).

In contrast, while the monograph referenced above (5) contained comprehensive descriptions of the first oral disease specific measures to be developed, the descriptions were largely concerned with their content, scoring methods and technical properties rather than with the more fundamental question of what a measure actually measures and the values on which it is based (7). Although the issue of what is being measured would seem to be encompassed by the notion of construct validity, the fact that scores derived from a measure discriminate between the dentate and the edentulous or that they show associations with global ratings of oral health, tells us little about the underlying construct being addressed. Similarly, the fact that scores change in the expected direction after a therapeutic intervention tell us only that change has occurred; change scores do not, in and of themselves, indicate exactly what it is that has changed. This is primarily a conceptual and methodological issue linked to how the attribute being measured is defined and how a measure of that attribute was developed.

Definitional issues in measuring health-related quality of life

A number of authors have commented on the plethora of terms used in the literature on health and associated phenomena (2). In addition, there is a tendency for key concepts, such as health status, health-related quality of life and quality of life to be used interchangeably with little consensus about what they mean and how they should be defined (2). In the dental field, measures that draw on the patient's perspective were originally referred to as socio-dental indicators or measures of oral health status, subjective oral health or the social impacts of oral disease. Subsequently, these terms were replaced with the term OH-QoL, with measures being characterized as such irrespective of their content. This change in terminology is evident in the naming of measures (see Table 1). While, the names of measures have changed, the type of items comprising the measures and the way in which they are scored has not. Some have argued that the notion of quality of life was adopted as it has a broader appeal than that of health status (3) and claim that most health-related quality of life measures used in medicine are in reality measures of functional status in a new guise (4).

The relatively loose way in which terminology is used, and new labels applied to old endeavours, is also apparent in definitions of oral health and OH-QoL. For example, an early definition of oral health indicated that it was concerned with 'the functioning of the oral cavity and the person as a whole...and with subjectively perceived symptoms, such as pain and discomfort' (8). A later definition offered by the same author was both more specific and more comprehensive: 'when talking about oral health, our focus is not on the oral cavity itself but on the individual and the way in which oral disorders, diseases and conditions threaten health, well-being and quality of life' (9). In later contributions, OH-QoL was defined in relatively simple terms as 'the extent to which oral disorders affect functioning and psychosocial wellbeing' (10) and 'the symptoms and functional and psychosocial impacts that emanate from oral diseases and disorders' (11). Kressin (12) defined OH-QoL in broad terms, as 'a broad conception of health, encompassing the traditional definition of health, as well as an individual's subjective impact of health on well-being and functioning in everyday life', and also more simply as 'the impact of oral conditions on daily functioning'. Clearly, some of these definitions suggest that health-related quality of life equates with health, while others imply that it is something more than health, encompassing additional and broader dimensions of human experience.

While there appears to be a consensus that disease, health and the quality of life are distinct concepts, as reflected in contemporary models of disease and its outcomes, exactly what is meant by health-related quality of life (and by extension OH-QoL) has not been entirely resolved. Consequently, 'whether the measures developed for use in oral research and practice should be considered to be indicators of health status or indicators of healthrelated quality of life is somewhat uncertain' (11).

The shift in nomenclature from 'oral health status' to 'oral health-related quality of life' appears to be based on the assumption that since measures address aspects of functioning that are compromised by oral diseases and disorders of various kinds, they must necessarily indicate how these diseases and disorders affect the quality of life (4). This is not the case; as Leplege and Hunt (4) suggest, the 'implications of measuring health status are quite different from those of measuring quality of life'. Moreover, studies of those with chronic conditions have indicated that many report that their quality of life is good, in spite of quite severe physical limitations (13). This 'disability paradox' suggests that health and quality of life are not only conceptually distinct but also empirically distinct (14).

There is also a compelling rationale for suggesting that measures of health status and measures of health-related quality of life are distinct. This view emerges out of the debate between Gill and Feinstein (1) and Guyatt and Cook (3) with respect to the appropriateness of patient-based outcome measurements in clinical trials. Gill and Feinstein (1), in their critical appraisal of the face validity of such measures, identified a number of criteria that must be met if a measure is to be used to assess what they call 'quality of life', but which Guyatt and Cook (3) more properly characterize as 'healthrelated quality of life'. These criteria are listed in Table 2. Relatively, few of the studies examined by

Table 2.	Criteria	for	evaluating	health-related	quality of
life meas	sures		0		

Criteria of Gill and Feinstein (1)
Did the investigators conceptually identify what they meant by quality of life?
Did they state the domains they wanted to measure as components of guality of life?
Did the investigators give reasons for choosing the instruments they used?
Did the investigators aggregate the results from
multiple items, domains or instruments into a single composite score?
Were patients asked to give their own global rating for quality of life?
Was overall quality of life distinguished from
health-related quality of life?
Were patients invited to supplement the items listed in the instruments offered by the investigators?
If so, were these supplemental items incorporated
into the final rating?
Were patients asked to indicate which items were
personally important to them?
If so, were these importance ratings incorporated into
the final rating?
Criteria of Guyatt and Cook (3)
Do the authors show that aspects of patients' lives they
have measured are important to the patients?
If not, have previous studies demonstrated their
importance?
bo the investigators examine aspects of patients' lives that clinical experience indicates patients value?
Are there aspects of HRQL that are important to
patients that have been omitted?
Were individual patients asked to directly place a
value on their lives?

Gil and Feinstein (1) that claimed to measure quality of life met these criteria. Guyatt and Cook (3) believe that these criteria are too stringent and offer a more limited set by means of which measures may be evaluated (also listed in Table 2).

Although there are differences between the two approaches, both imply that two broad and overlapping questions need to be considered when evaluating a measure in terms of the underlying construct being assessed: First, is the measure patient- or person-centred, and second, does it incorporate aspects of daily life that are important to patients or persons which may be compromised by disorders of various kinds?

The importance of patient or person centering

Despite considerable disagreement over definitions there is an emerging consensus that measures addressing overall or components of quality of life should reflect the perspectives of patients and or the lay public (4, 15, 16). Measures that meet this criterion are patient or person-centred rather than expert-centred (4, 16).

Many measures that claim to assess healthrelated quality of life or quality of life have been criticized because they reflect the values and concerns of physicians, social scientists or other experts rather than patients or persons and what they consider to be relevant (4, 14, 17). Leplege and Hunt (4) have gone so far as to claim that 'there has been some confusion between questionnaires that are completed by patients and those that reflect the concerns of the patients. Too often patients are asked to complete questionnaires that do not reflect their concerns'.

The main mechanism by means of which patient or lay perspectives can be accommodated is through the use of qualitative interviews. According to Guyatt et al. (18, 19), the items comprising questionnaires that claim to capture quality of life issues must be derived from in-depth interviews with those who will ultimately be expected to complete the questionnaire. Consequently, one way of evaluating OH-QoL measures is the way in which the items comprising the measure where developed. Were they derived from qualitative interviews with the target population? If not, and since items may legitimately be obtained from other sources such as literature reviews or clinical opinion (19), is there any evidence from these other sources or elsewhere that the items do fully address the concerns of those who will be expected to complete the questionnaire? That is, did the investigators achieve content coverage, a component of content validity that is as important as criterion validity but most often neglected?

Establishing importance

The discussion so far implies that the main distinction between a measure of oral health status and a measure of OH-QoL is a simple one. As Gill and Feinstein (1) state: 'The need to incorporate patient's values and preferences is what distinguishes quality of life from all other measures of health'. That is, do the items comprising the questionnaire refer to aspects of daily life that are important to the target population?

How can importance be established? Although qualitative studies are a first step in eliciting the views of patients and persons regarding what is important, they are insufficient in and of themselves. The reason for this is that while qualitative interviews can reveal what is salient to the interviewees, the interview may reveal a range of experiences some of which are relatively more and some relatively less important.

Moreover, if the questionnaire is to be used in clinical trials or other studies where the unit of analysis is the group, some way has to be found of identifying which experiences are of most importance on average to the group who will be participating in the study. The solution proposed by Guyatt et al. (19) is an item impact study. Here items derived from qualitative interviews are given to a group of patients or persons who indicate if they experience the problem described by the item and, if so, how much bother or distress it causes. Item impact scores are calculated by multiplying the prevalence of the problem by its mean bother rating, items ranked according to these scores and the top ranking items selected for the final questionnaire.

The limitation of this approach is that a high prevalence and low impact item may be more highly scored than a low prevalence high impact item, so that items of importance to a minority of patients or people may not make it into the final questionnaire. Consequently, the item-impact approach produces a group-centred rather than a patient-centred questionnaire (20). This much is recognized by Guyatt and Cook (3). While groupcentred questionnaires may be appropriate for clinical trials, they concede that they may not be appropriate for clinical practice. When clinicians are making treatment decisions they should consider an individual patient's values since these may differ from or be masked by the aggregated values of those participating in an item impact study. This points to the fact that 'quality of life - even when health-related - has different components, significance and meaning that are unique to the individual' (20). In fact, the main 'challenge to measuring quality of life lies in its uniqueness to individuals' (14).

A solution to this dilemma is to be found in the recommendations of Gill and Feinstein (1) for improving the measurement of health-related quality of life. These are: rate frequency, severity and importance; allow respondents to add supplemental items, and use global ratings which are summary variables and can reflect the differing values and preferences of a group of individuals. This means that a questionnaire must have a complex structure – questions that document experiences; importance ratings that indicate the value an individual attaches to those experiences; open-ended questions to elicit experiences not covered by the questionnaire, and global ratings of quality of life and health-related quality of life. If these requirements are not met a measure is not addressing health-related quality of life; rather it is a measure of health status.

Carr et al. (14), make essentially the same point in arguing for the use of individualized measures. These measures allow respondents to select issues and concerns that are affected by health rather than providing a standardized predetermined list (2). However, they acknowledge that the completion of such questionnaires is time consuming and difficult. Moreover, the aggregation, analysis and interpretation of the data are challenging, particularly with respect to group comparisons and change over time. This raises the interesting question of whether or not we can legitimately refer to the quality of life of a group and, if so, how quality of life might be measured at the group level.

Evaluating measures of 'oral health-related quality of life'

Although the arguments concerning the individualized nature of quality of life and health-related quality of life are compelling, we tend to agree with Guyatt and Cook (3) and find the criteria of Gill and Feinstein (1) somewhat demanding. Accordingly, when evaluating so-called measures of 'oral health-related quality of life', particularly with respect to what they measure, we devised a set of criteria more akin to those of Guyatt and Cook (3) than Gill and Feinstein (1). These were:

- (1) Is the stated aim to measure health-related quality of life or quality of life and is this explicit? If so, are these constructs defined and their constituent domains identified?
- (2) If not, is an alternative construct measured by the instrument specified and defined and its constituent domains identified?
- (3) Do the investigators specify the contexts in which the measure is to be used? Was it developed to be used with groups (as in surveys or clinical trials) or individuals (as in clinical practice)?
- (4) Were the items comprising the questionnaire derived from qualitative interviews with those who will be completing the questionnaire?

- (5) Is there evidence that the aspects of life the items address are important to those who will be completing the questionnaire?
- (6) Does the questionnaire contain global ratings of health-related quality of life or quality of life?
- (7) How was the measure validated? Was it tested against oral health indicators or were broader indicators that may capture aspects of quality of life used?

In order to illustrate the application of these criteria, we reviewed the four mostly widely used measures of the outcomes of oral disorders; namely, the Geriatric Oral Health Assessment Index (21), the Oral Health Impact Profile (OHIP) (22), the Oral Impacts on Daily Performances (OIDP) (23) and the Child Oral Health Quality of Life Questionnaires (24). In addition, we also review the Oral Health Quality of Life Inventory (25). Although not widely used, this measure has some distinct features which make it of interest from a conceptual point of view. The 'data' were the initial papers describing the development and psychometric evaluation of these measures. Where such papers were not available, the summaries presented in the monograph of papers from the 1997 conference (22) were used.

Geriatric/General Oral Health Assessment Index

The GOHAI is a 12 item measure of 'patientreported oral functional problems' and 'psychosocial impacts associated with oral diseases' intended for use in the assessment of the effectiveness of dental treatment (26). It is unclear whether this means it is intended for use in clinical practice with individual patients, or, with groups of patients in clinical trial settings. The overall construct being assessed by the GOHAI is not specified though it is 'based on a patient-centred definition of oral health'. Its 12 items were derived from an initial pool of 36 items developed following a literature review, consultations with health care providers and qualitative interviews with people attending seniors' centres and dental clinics. The precise nature of these consultations was not specified in the development paper nor was the qualitative research process described. Considering the item selection, the rationale for selecting the final 12 items and excluding the remaining 24 items is not apparent. However, items were chosen to reflect three distinct hypothesized dimensions, namely

physical function, psychosocial function and, pain and discomfort. Accordingly, the item selection process appears to have followed an expert rather than patient- or person-centred approach. Although the items selected address issues that are likely to be important, the authors provide no evidence that this is the case. Given that there are only 12 items, it is likely that the concerns of some patients will not be captured by this measure. This is recognized by the authors when they suggest that the measure could be expanded to 'reflect more of the elements of quality of life' (26). Initial validation of the measure was based on the association of GOHAI scores and clinical measures of oral health status. A study of an institutionalized elderly population took a broader approach and reported a significant but weak correlation between GOHAI scores and a life satisfaction scale, although the association barely reached significance when controlling for other predictors of life satisfaction (11). Consequently, the measure meets few of the criteria required of a measure of healthrelated quality of life. As its title suggests, the GOHAI is best regarded as a measure of subjective oral health status.

Oral health impact profile

The OHIP (22) was based on the ICIDH model of disease and its consequences. It intends to assess the 'social impact' of oral disorders, that is, the dysfunction, discomfort and disability caused by these conditions. The purpose of the measure is broad; assessing priorities of care by documenting social impact among individuals and groups, understanding oral health behaviours, evaluating dental treatment and providing information for advocating for oral health. As such the intention was to develop a measure of self-perceived oral health.

In developing the measure, an initial set of 535 statements were obtained from open-ended interviews with 64 dental patients recruited from private practices and dental hospital clinics. This item pool was reduced to a set of 46 unique statements based on their form and content and ability to represent one of six domains derived from the conceptual model. Three additional statements representing the concept of handicap were taken from an existing generic health status measure (27).

While the qualitative component of the development process suggests that the OHIP is patient-centred, the item reduction process was expert-centred, designed to select items according to their fit with a conceptual framework rather than on the basis of their importance to the patients from whom they were derived. Why some statements were retained and others discarded is not described. Severity weights for each of the statements, designed to reflect their relative importance, were provided, but these were based on the judgments of a panel comprised of members of community groups, dental practitioners and students. Consequently, the weights may not reflect the severity and/or importance of the events described by the items as perceived by individual dental patients or dental patients as a group (14).

The OHIP was initially validated by demonstrating an association between scale and sub-scale scores and perceived need to visit a dentist. Further validation of the OHIP as a measure of oral health status has been provided by numerous investigators; scores distinguish between the dentate and edentulous and show small to moderate correlations with a wide range of traditional clinical indicators and self-perceived oral conditions, such as xerostomia. Some evidence that the events captured by the OHIP may be of broader significance than oral health has been provided by the study of the institutionalized elderly referenced above (11). These indicated that OHIP scores were significantly associated with life satisfaction and, unlike the GOHAI, the association remained clearly significant after controlling for other predictors. This suggests that what could be regarded as an expert-centred measure of subjective oral health may be capturing events which impact on general well-being and quality of life. However, the items comprising the measure do not in and of themselves demonstrate that this is the case.

Oral impacts on daily performances

The OIDP is a distinctive measure in many respects. First, it is one of the few that was developed with a very explicit purpose in mind; that is, to be used in conjunction with normative measures to assess population dental needs in order to facilitate dental service planning (23). Second, it measures what are referred to as the 'ultimate' i.e. behavioural impacts of oral disorders and the extent to which the ability to perform physical, psychological and social performances is compromised. It is based on a modified version of the ICIDH model so that the physical, psychological and social issues it addresses are intended to be equivalent to 'the disability and handicap dimensions' of the model. Perhaps, because it was developed in the early 1990s, descriptions of the development of the OIDP do not include terms, such as health-related quality of life or quality of life. However, the children's version of the measure, developed in 2004 (28) is described as a measure of OH-QoL.

The OIDP originally consisted of nine items selected from the Comparison Table of Disability Indices and other general and oral health status measures. The rationale for selecting the nine items originally comprising the OIDP is not provided so it is uncertain whether the measure achieves content validity. Moreover, since no patients or lay persons appear to have been involved in the selection of the activities to be addressed by the measure the OIDP appears to be the most expertcentred of the measures reviewed.

However, the OIDP is distinct in that it employs a more complex item scoring system than most measures and assesses both frequency and severity of impacts. The item severity score indicates how much trouble the event described by the item caused to their daily living. Assuming that severity can be equated with importance, this item selfweighting approach means that the measure goes some way towards meeting the importance criterion as defined above.

In assessing the construct validity of the OIDP associations were examined with clinical oral health indicators, such as the number of missing teeth. Criterion validity was assessed by means of the associations between OIDP scores and subjects' 'overall perception of trouble from oral conditions'. Since it is unclear what this last variable means and measures, whether or not the OIDP has been validated against proxy quality of life measures is uncertain.

Child oral health quality of life questionnaire – child perceptions questionnaire 11-14 (CPQ11-14)

The Child Oral Health Quality of Life Questionnaire is a battery of measures for children and their parents (24, 29–31). Since all were developed using a similar process, this review is limited to the Child Perceptions Questionnaire for those aged 11–14 years (CPQ11-14) (24). The aim was to produce a measure applicable to children with a wide range of dental, oral and oro-facial disorders, which conformed to contemporary concepts of child health. Since the instrument was intended for use as an outcome measure in clinical trials and evaluation studies it needed to have properties suitable for the assessment of change at the group level.

The instrument was developed to measure 'the oral health-related quality of life of children'. OH-QoL was not specifically defined, although the authors do indicate that measures of this construct 'document the functional and psychosocial outcomes of oral disorders'. Items for the measure were developed by a two stage process. First, a preliminary item pool was developed by a review of existing oral health and child health status measures. Second, the relevance, clarity and comprehensiveness of these items were assessed in a face and content validity study by an expert panel composed of health professionals who treat children with oral and oro-facial disorders and parents of child patients with these conditions. Based on their comments, a modified item pool was developed which was revised further following in-depth interviews with a small number of child patients.

Items for the final questionnaire were selected using an item impact study. As described above, this identifies those items of most importance to the patient population who will be asked to complete the questionnaire. Consequently, the measure meets one of the criteria for a patient/person centred scale. However, since the qualitative component of the study and the extent to which the child patients contributed to the items comprising the questionnaire is not described, it does not meet all those requirements.

The measure was validated using the construct validity by extreme groups approach. Here, the scores of three groups of patients with conditions assumed to differ in terms of the severity of their condition were examined. Further testing of validity was undertaken by examining associations between CPQ11-14 scores, self-ratings of oral health and ratings of the extent to which the condition of the teeth and mouth impacted on life overall. Interestingly, the correlation with self-rated oral health was 0.23 but was stronger for the rating of impact on life overall at 0.40. This last result suggests that the items in the questionnaire address issues and concerns which go beyond oral health and are of sufficient magnitude to have some effect on life as a whole. However, it is important to note

that even though study subjects were recruited from clinical settings where they were being treated for oral disorders, 69% said that the condition of their teeth and mouth had little or no effect on their life overall. This suggests that while oral health may compromise functional and psychosocial status in ways that are deemed to be important, for some individuals the overall quality of life may remain unaffected.

The oral health quality of life inventory

The OH-QoL was developed 'to measure a person's subjective well-being with respect to his/her oral health and functional status (25); that is, 'to evaluate the impact of oral health and functional status on quality of life...and to model the relationship of objective and subjective measures of oral health and functional status and quality of life'. Consequently, the measure draws a distinction between the 'objective', termed self-reported oral health (SROH), and the 'subjective', termed oral health quality of life (OH-QoL). The former is assessed by means of a set of questions concerning symptoms and oral functional problems, while the latter asks about the importance of oral health and functional status to the person and his/her level of satisfaction with their current oral status and functioning. These importance and satisfaction questions replicate the structure of many quality of life questionnaires which measure the subjective appraisal of various aspects of people's lives (32).

Items for the SROH and OH-QoL components of the questionnaire were derived from the literature and expert opinion and covered six domains: taste and salivary function, dental-facial aesthetics, general oral health and functional status, speech and chewing and swallowing. Following preliminary testing these were reduced to 40 SROH and 15 OH-QoL items. In the final questionnaire the OH-QoL items were distributed among the SROH items, with the 'subjective' items following the 'objective' items to which they relate. This means that the importance and satisfaction questions were asked relative to only one-third of the oral symptoms and functional status questions. Scores for the OH-QoL are obtained by multiplying the importance and satisfaction ratings for each item and taking the mean of these products.

The measure was validated by examining correlations between OH-QoL scores, summative rating scales constructed from the SROH items and clinical indicators of oral health. It was also validated by examining correlations with scores on two broader measures; the Quality of Life Inventory (15), a measure of life satisfaction, and the Self-Confidence in Life Test (16). These correlations were significant: r = 0.46 and 0.29, respectively.

The main limitations of this measure are that it is predominantly expert-based and the quality of life component addresses only 15 of the 40 SROH items. Its main strength is that it uses importance and satisfaction questions to indicate the meaning and significance of oral health events to the person. While its characterization of self-reported symptoms and functional limitations as 'objective' can be questioned, it makes an important distinction between health and quality of life. That is, the fact that health may be compromised does not automatically mean that the quality of life is diminished, contrary to the assumption embodied in the concept and measures of OH-QoL.

Defining and measuring oral health-related quality of life

The measures reviewed above are similar in that they all address the functional and psychosocial outcomes of oral disorders and can be readily used in population surveys or clinical trials. All document the frequency of impacts emanating from oral diseases that clinicians, investigators or research subjects have suggested are important. One of their main strengths is that they embody the notion that the patient's perspective has equal legitimacy to that of the clinician and should be taken into account when evaluating the consequences of disease and the outcomes of treatment for that disease. (4).

However, a pertinent questions is, do the measures adequately capture the views and concerns of those completing the questionnaire? As Leplege and Hunt (4) observe, the fact that 'patients are replying to questions designed by experts is not sufficient to claim that scores calculated from these responses reflect the patient's viewpoint'. A further question is – patient views and concerns about what? Do they assess subjective oral health, OH-QoL or quality of life? The reviews of the five measures indicate that there is a degree of uncertainty with respect to both of these issues. None fully comply with the 'patient/person-centred', 'importance' and 'validation' criteria for the development of measures which can be deemed to assess OH-QoL. The answer to the first question requires further qualitative work with sufficiently large samples to ensure that the views of people and patients are being properly represented by existing measures. Qualitative studies by MacEntee and colleagues with elderly subjects have indicated that existing measures capture some of their concerns but do not encompass all of the issues that gave significance to the mouth in the daily lives of their respondents (33, 34). The answer to the second question requires the more precise definition of the main constructs that measures are intended to address.

Perhaps the easiest concept to define is subjective oral health. We would suggest that this refers to the functional and psychosocial impacts of oral diseases and conditions as perceived by the individual. While current measures assess the frequency with which these impacts occur, they fail to establish the meaning and significance of those impacts to the individuals who complete the questionnaires, particularly with respect to their effects on perceptions of quality of life. Consequently, we would define OH-QoL as the impact of oral disorders on aspects of everyday life that are important to patients and persons, with those impacts being of sufficient magnitude, whether in terms of severity, frequency or duration, to affect an individual's perception of their life overall. Based on these definitions, measures of subjective health status offer a description of a person's current status while measures of health-related quality of life also offer a subjective evaluation of that status.

These definitions are distinct from definitions of the quality of life. The WHOQOL Group defined quality of life as 'the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (35). This suggests that quality of life is a complex multidimensional phenomenon that is not captured solely by questions about health. Fitzpatrick et al. (2) think that the use of the term quality of life is 'unhelpful' since it 'misleadingly suggests an abstract or philosophical set of judgments or issues relating to life in the broadest sense of factors outside the person, such as living standards, political or physical environments'. Moreover: 'Because, rightly or wrongly, hardly any of the vast array of so-called quality of life measures used in health settings address matters beyond the health-related, we avoid using this terminology as much as possible' (2). Accordingly, they suggest that 'patient-based outcome measures' rather than 'quality of life measures' be used as a collective term for instruments that assess perceptions of health, its consequences and the benefits derived from therapeutic interventions.

Leplege and Hunt (4) also suggest that the notion of quality of life, even when health-related, should be abandoned altogether and replaced with the more 'easily handled and rigorously defined notion of subjective health status'. Measures of subjective health are valuable in their own right since the outcomes being sought by most of those seeking health care are a reduction in symptoms and improvements in function, irrespective of their impact on overall life quality (20). This is consistent with their view that quality of life is an 'idiosyncratic mystery'. It is also consistent with their view that the proper role of health care is the improvement of health status; that is, health care is concerned with the removal of potential barriers to the quality of life rather than with the quality of life itself.

For those who feel that the quality of life is a legitimate concern of health professionals and the health care system, the problem of how it can be measured remains. Two options mentioned above are the use of individualized measures or the fairly cumbersome approach suggested by Gill and Feinstein (1). Prudkin and Feinstein (20) suggest an alternative that acknowledges that an individual's health status can have a broader impact with respect to how they perceive themselves and their lives and allows this impact to be measured more simply. This entails the use of subjective health status measures along with global ratings of quality of life and health-related quality of life; that is ratings of the extent to which quality of life is compromised by symptoms or functional and psychosocial problems. These ratings incorporate individuals' own beliefs, values and concerns and the relative importance of different life domains. Consequently, they 'allow adequate expression of the way in which individual patients determine their own quality of life' (20). They solve the problem of what existing measures actually measure, provide one way in which data on a unique, highly individualized phenomenon can be grouped for analysis, and provide a way of ascertaining the meaning of scores derived from instruments such as the OHIP, which have no intrinsic meaning. It is also consistent with the WHOQOL Group's approach. They argue that while data on functioning is important, global evaluations are the best indicators of quality of life (35).

This does not obviate the need for measures and scales to be patient- or person-centred and to consist of items concerning symptoms or aspects of functioning that patients or persons consider to be important. This is necessary if subjective health status measures are to be subjective and not reflections of clinicians' or experts' objective definitions and views of what constitute health. This means that the measures currently used in oral health research may need revision and further development in order that these criteria are more fully met. MacEntee suggests (36) that the language, definitions and theoretical model contained within the International Classification of Functioning, Disability and Health (37) may provide a useful departure for the further development of patient-based oral health measures. Of interest is the fact that these definitions and the concepts that comprise the model are wholly concerned with health and functioning. There is no reference to issues, such as health-related quality of life or quality of life. A final question is, if current measures, such as the ones reviewed above, provide useful information about patients' or persons' health status and their perceptions of the outcomes of treatment, does it matter what those measures are called. The answer is yes: there is a compelling scientific and ethical rationale for precision and consistency in the use of language. From a scientific point of view, what is measured by the GOHAI is clearly different from what is measured by the OH-QoL and these differences need to be acknowledged in the way the measures are characterized. From an ethical point of view, precision in the use of language is necessary so that claims about health interventions are not exaggerated. The notion of health-related quality of life implies that an intervention not only reduces the immediate impacts of disease but also improves life overall. This may well be the case. However, this needs to be clearly demonstrated in the measurement approaches we use and not merely assumed by the way in which measures and scales are described.

Conclusion

While the patient-based outcome measures used in oral health research provide valuable information,

the claim that they are measuring quality of life is inappropriate. The claim that they are measuring health-related quality of life is tenuous. The five measures we reviewed only partially fulfil the two main criteria for measures of health-related quality of life; that is, they are patient-centred and incorporate aspects of daily living that patients deem to be important. Further, more attention needs to be paid to the assessment of the broader meaning and significance of the functional and psychosocial impacts they describe. One way is the concurrent use of global ratings which can accommodate individual variations in the meaning and significance of disease-related events.

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