# **Health and Quality of Life Outcomes**

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# Review Assessment of oral health related quality of life P Finbarr Allen\*

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Published: 08 September 2003

Health and Quality of Life Outcomes 2003, 1:40

Received: 14 July 2003 Accepted: 08 September 2003

This article is available from: http://www.hqlo.com/content/1/1/40

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### Abstract

In Dentistry, as in other branches of Medicine, it has been recognised that objective measures of disease provide little insight into the impact of oral disorders on daily living and quality of life. A significant body of development work has been undertaken to provide health status measures for use as outcome measures in dentistry. In descriptive population studies, poor oral health related quality of life is associated with tooth loss. There is a less extensive literature of longitudinal clinical trials, and measurement of change and interpretation of change scores continues to pose a challenge. This paper reviews the literature regarding the development and use of these oral health related QoL measures and includes an appraisal of future research needs in this area.

# Introduction

In an effort to focus on the assessment of health and quality of life issues, the term "health-related quality of life" is now widely used. Regarding the relationship of health and disease to quality of life, there appears to be an association between these domains which is not clearly defined. Locker suggested that health problems may affect quality of life but such a consequence is not inevitable [1]. The implication of this is that people with chronic disabling disorders often perceive their quality of life as better than healthy individuals, i.e., poor health or presence of disease does not inevitably mean poor quality of life. Allison et al attempted to further explain this phenomenon by suggesting that quality of life was a "dynamic construct", and thus likely to be subject to change over time [2]. Individual attitudes are not constant, vary with time and experience, and are modified by phenomena such as coping, expectancy and adaptation. They give as an example an individual who had eating problems due to pain and discomfort, who would have rated this problem as extremely important at one point in time. However, when this problem is diagnosed as oral cancer, and treated with radiotherapy and/or surgery, the same individual may report the original problem as relatively unimportant.

Interest in the outcome of oral health problems has been the subject of significant research activity over the past ten or so years. Oral healthcare researchers and policymakers have recognised that assessment of oral health outcomes is vital to planning oral healthcare programmes. The purpose of this paper is to review the current status of oral health quality of life outcomes in light of more recent developments in the field.

# Models of health and disease

Traditionally, dentists have been trained to recognise and treat disease such as caries, periodontal disease and tumours. Consequently, various indices have been used to describe the prevalence of these diseases in the population. In dentistry, these indices include Helkimo's index of mandibular dysfunction [3] and the Community Periodontal Index of Treatment Needs (CPITN) [4]. However, important as these objective measures are, they only reflect the end-point of the disease processes. They give no indication of the impact of the disease process on function or psychosocial well-being. Furthermore, trends in disease processes are often not related to objective indicators per se. For instance, the prevalence of total tooth loss (edentulousness) varies widely between various communities, from 36% in one study in New Zealand, to 1% in a Japanese population [5]. This strongly suggests that cultural and economic factors influence oral health care outcomes, as originally suggested by Davis [6].

In studies which assessed the association between objective measures of dental disease (such as presence of dental caries or periodontal attachment loss) and patient based opinions of oral status, the relationship was weak and objective measures did not accurately reflect patients' perceptions. [7–9]. This clearly indicated the need to develop a paradigm which encompassed the multi-dimensional nature of health, and all its possible outcomes.

The limitations of the "biomedical" paradigm of health have been recognised, principally that this model only deals with disease. Consequently, any measure of health needs to assess social and emotional aspects of health as well as assessing presence or absence of disease.

In the socio-environmental model of health, each of these separate conceptual domains is recognised. In this model, the complex multi-dimensional nature of health is encompassed, including cultural, environmental and psycho-social influences. Various conceptual frameworks for measuring health have been described, an example of which is that described by Wilson and Cleary [10].

The conceptual framework for measuring oral health status described by Locker [11] shown in Fig. 1 is based on the WHO [12] classification of impairment, disability and handicap, and attempts to capture all possible functional and psycho-social outcomes of oral disorders. By definition, people who lose teeth are impaired (i.e., have lost a body part). Other less well documented consequences of tooth loss include disability (lack of ability to perform tasks of daily living such as speaking and eating) and handicap (e.g., minimising social contact due to embarrassment with complete denture wearing). The publication of this conceptual framework has been pivotal to the development of this research theme in dentistry. Until recently, the psycho-social consequences of oral conditions have received little attention, as they are rarely life threatening. Furthermore, the oral cavity has historically been dissociated from the rest of the body when considering general health status. However, recent research has highlighted that oral disorders have emotional and psycho-social consequences as serious as other disorders. Reisine [13] and Gift et al [14] have indicated that approximately 160 million work hours a year are lost due to oral disorders. Reisine and Weber [15] compared baseline quality of life scores of patients with temporomandibular joint disorders (TMD) against a group of patients with cardiac disorders. They reported that TMD patients were disabled to a greater extent in the areas of sleep and rest, social interaction, intellectual functioning and communication. In the U.K., Cushing et al [16] found that pain, difficulty with eating and communication problems were frequently reported in a study of employed adults.

# Uses of oral health status measures

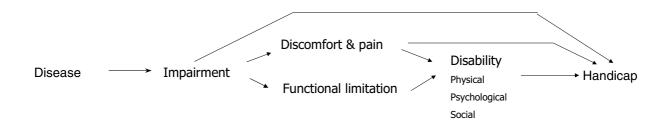
The importance of assessing both patients' perceptions of health and presence or absence of disease lies in the need to have accurate data to promote health, disease prevention programmes [17], and for allocation of health resources [18]. Furthermore, as patients' assessment of their health related quality of life is often markedly different to the opinion of health care professionals [19], patient assessment of health care interventions is warranted. A patient based assessment of health status is, therefore, essential to the measurement of health. Uses of health related quality of life measures have been described by Fitzpatrick et al [18], and are shown in Table 1

Slade and Spencer [20] have also suggested that measures of oral health status may also be used to advocate oral health, especially when attempting to secure public funds for oral health care. The information provided by these measures facilitates an increasing understanding of how individuals perceive oral health needs and what oral health outcomes drive them to seek health care. In a public health context, resources for oral health care are diminishing at the same time as availability of sophisticated treatment options is increasing. For instance, dental implants are now available and are used to anchor prostheses in jaw bone which can be used to replace missing teeth. They are a comparatively expensive treatment option, and demonstrating substantial improvement in oral health related quality of life, as assessed by health status measures, could justify public funding of this type of treatment.

# Methodological issues in oral health status measurement

As research into health related quality of life has grown, so has the use of health status measures. Patient based assessment of the impact of a wide variety of chronic conditions have been reported. The sophistication of measures currently available varies widely, and a number of theoretical issues need to be considered when selecting a health status measure.

In an oral health context, the question of which measure to use has been the subject of intense research effort in recent years. At the present time, both generic and disease specific measures of health status are employed. Generic



### Figure I

Conceptual model for measuring oral health (Locker, 1988). [Reproduced with the permission of the editor of Community Dental Health]

#### Table I: Uses of measures of health related quality of life

• Screening and monitoring for psychosocial problems in individual patient care

- Population surveys of perceived health problems
- Medical audit
- Outcome measures in health services or evaluation research
- Clinical trials
- Cost-utility analysis

#### Table 2: Examples of currently available oral specific health status measures

Authors	Name of Measure	
Cushing et al, 1986	Social Impacts of Dental Disease	
Atchison and Dolan, 1990	Geriatric Oral Health Assessment Index	
Strauss and Hunt, 1993	Dental Impact Profile	
Slade and Spencer, 1994	Oral Health Impact Profile	
Locker and Miller, 1994	Subjective Oral Health Status Indicators	
Leao and Sheiham, 1996	Dental Impact on Daily Living	
Adulyanon and Sheiham, 1997	Oral Impacts on Daily Performances	
McGrath and Bedi, 2000	OH-Qol UK	

measures of health status have a number of important advantages. The psychometric properties of these measures are known, and comparisons can be made between populations with different problems using these scales. However, there is concern that generic health status measures are not sensitive to oral health outcomes [21] and that discriminant validity and responsiveness to change properties of these measures may be poor. Disease specific measures, however, have an advantage over generic measures in that they are more likely to detect subtle changes in specific conditions, thus having better responsiveness. They also contain statements and domains which are only relevant to the clinical condition in question. A further approach suggested by Bowling [22] is to use both an appropriate disease specific measure and a generic measure. The rationale is to have a generic measure with core quality of life statements, and disease specific statements to improve responsiveness. Descriptive population studies have given an indication of discriminant validity properties of many health status measures, but there is a paucity of information regarding responsiveness to change. This is an important gap in our knowledge base, as we clearly need to understand the impact of therapeutic intervention on health related quality of life. Furthermore, a greater understanding of the natural history of oral health related quality of life is needed. For example, are reactions to tooth loss modified by age and should this influence treatment planning for elderly patients?

# Oral specific measures: development and scoring methods

While the use of health status measures to assess health related quality of life is well established in many areas of medicine, their use in dentistry has not been widespread. The need to develop patient based measures of oral health status was first recognised by Cohen and Jago [23], who indicated the lack of data relating to psycho-social impact of oral health problems at that time.

In response to the paper by Cohen and Jago, workers such as Reisine [13], used societal indicators such as work loss due to dental problems to describe the social impact of oral disease. A limitation of this method is, while useful for indicating trends in uptake of health care services, societal indicators give little information on an individual level.

Locker [11] suggested that when assessing health outcomes on an individual level, an individual measure is required. Prior to the publication of the theoretical framework for measuring oral health, Reisine [24] had used the Sickness Impact Profile to measure oral health outcomes. This comprehensive measure had been validated by Bergner and co-workers [25], and had been used widely [26]. However, this measure is a generic measure of health

status, and may not be sensitive to all oral health problems. This was described further by Locker [11], who indicated that while the impact of acute and chronic pain conditions could be detected by this measure, the effects of tooth loss and edentulousness were not.

A number of workers have since developed and employed oral specific health status measures, and a list of these measures is shown in Table 2

Various methods have been used to develop these measures. One approach, used in the General Oral Health Assessment Index [GOHAI] [27] for example, has been to construct scales which provide an index of the impact of oral disorders. The impact of oral disorders on health related quality of life is calculated by assigning an overall score (which is ordinal or interval in nature) to indicate the extent of a range of functional and psycho-social consequences. GOHAI contains 12 statements (e.g. "How often did you feel uncomfortable eating in front of people because of problems with your teeth or dentures") with a Likert response format (i.e. 0 = never, 1 = seldom, 2 =sometimes, 3 = often, 4 = very often, 5 = always). Response codes are summed across the 12 statements to give a 0-60 overall score. A similar approach is employed in the Social Impacts of Dental Disease [16] and the Subjective Oral Health Status Indicators [28].

A further approach has been to evaluate patients' perceptions salience of events, as demonstrated by the Dental Impact Profile [29]. This measure contains 25 statements using the format "do you think your teeth or dentures have a good (positive) effect, a bad (negative) effect or no effect on your eating." The 25 statements are divided into 4 sub-scales (eating, health/well being, social relations, romance), and an overall profile score is calculated as the proportion of positive or negative responses among all items answered.

A final approach has been to place functional disorders and their social consequences in a hierarchy of outcomes. This approach differs from an index in that a respondent can indicate whether a problem is entirely internal (such as some difficulty chewing), or whether this in turn causes interpersonal or social consequences (such as avoiding the company of others). The hierarchy of outcomes is based on the WHO classification of Impairments, Disabilities and Handicaps [12], and Locker's theoretical framework for measuring oral health. Using this method, a "profile" of social impacts can be described. The Oral Health Impact Profile [OHIP] [20], the Dental Impact on Daily Living [DIDL] [30] and the Oral Impacts on Daily Living [OIDP] [31] were developed in this way. Each of these measures attempts to measure both the frequency and severity of oral problems on functional and psychosocial well being.

OHIP is a 49 item measure, with statements divided into seven theoretical domains, namely functional limitation, pain, psychological discomfort, physical disability, psychological disability, social disability and, handicap. An example of an OHIP statement is "Have you had to interrupt meals because of problems with your teeth, mouth or dentures". A Likert response format (0 = never, 1 = Hardly ever, 2 =occasionally, 3 =fairly often, 4 =very often) is used. Frequency of impacts is calculated by summing the reported negative impacts (i.e., fairly often or very often) across the 49 statements. To facilitate assessment of perceived severity of impacts, each statement has a weight derived using the Thurstone's paired comparison technique. Both overall profile scores and individual sub-scale scores may be calculated. A major advantage of this measure is that the statements were derived from a representative patient group, and were not conceived by dental research workers. This increases the possibility of the measure "tapping into" social consequences of oral disorders considered important by patients, and is considered to be the most sophisticated measure of oral health [32].

DIDL consists of 36 items accumulated into 5 scales, i.e., comfort, appearance, pain, performance and, eating restriction. Impacts for each statement are coded as follows: + 1 = a positive impact, 0 = impacts not considered totally negative, and, - 1 = negative impacts. A weight for each dimension is calculated on an individual basis by dividing the summed responses of that dimension by the total possible scale score. To construct an overall score, scores within each dimension are first calculated by multiplying the summed dimension responses by the dimension weight. Weighted dimension scores are then summed to give a DIDL score.

OIDP attempts to quantify relative frequency of impacts of oral problems on 8 daily tasks, namely: eating and enjoying food, speaking and pronouncing clearly, cleaning teeth, sleeping and relaxing, smiling, laughing and showing teeth without embarrassment, maintaining usual emotional state without being irritable, carrying out major work or social role, and, enjoying contact with other people. Possible responses to the frequency of impact range from 0 (never affected in the past 6 months) to 5 (every or nearly every day for the past 6 months). Respondents are asked to rate the severity of the impact on a scale of 0 ("none") to 5 ("very severe"). An overall score is calculated by multiplying the frequency score by the severity score for each item, and summing these scores.

# Oral specific measures: are they used?

Despite the development of a number of comprehensive, sophisticated measures, the use of patient based assessment of oral health outcomes has not been widespread [32]. Reports of their use have largely been confined to descriptive population studies, particularly of older adults [8,29,33–37]. These studies indicate that oral problems have a significant impact on functional and psycho-social well being. Using multiple logistic regression techniques with social impact summary scores as the dependent variables, periodontal pocketing, missing teeth, retained root fragments, dental caries and problem motivated dental visits were all associated with high levels of dissatisfaction with oral health. In a study reported by Slade et al [34], the social impact of oral conditions in 6 populations aged 65+ years with distinct cultural and economic differences was assessed. These communities were an urban and a rural community in South Australia, a metropolitan and non-metropolitan community in Ontario, Canada, and an Afro-American and Caucasian communities in North Carolina, U.S.A. In addition to describing the impact of oral disease on psycho-social well being, they found that cultural differences had an independent influence on individuals' reactions to oral disease in dentate individuals. No such variation in social impact among strata was found in edentulous subjects. Sheiham et al [37] used the OIDP in the UK National Diet and Nutrition Survey, and reported that tooth loss frequently impacted upon eating and speaking. The extent of impact was related to number of remaining teeth, and 25% of the sample reported that the impact of tooth loss on eating was "severe". This level of disability has a consequence for diet, and can be used to advocate the benefit of good dental health.

There are a number of reasons why these measures have, as yet, not been used by workers not involved in their development. While all of the measures appear to have been well-validated and based on sound theoretical frameworks, some practical issues remain. For instance, which of these measures should be used? Determining which measure to use is unclear, as no substantive work to compare the relative performance of the various measures across a range of clinical situations has been published. This would be useful to clinicians hoping to use these measures to assess outcomes of clinical procedures, as succinct measures such as GOHAI are much easier to use than sophisticated measures such as OHIP. Short versions of health status measures have an inherent appeal in clinical situations, but it is a well known psychometric property that the sensitivity of a measure diminishes as statements are removed [38].

At the present time, measures which use weights to allow the severity of an impact to be described are likely to be better outcome measures. Scoring methods based on ordinal scores are prone to produce skewed results, particularly when the range of possible responses is narrow. However, the contribution of weights to the performance of health status measures has been questioned. Streiner and Norman [38] suggested that weighting of statements does not improve the performance of a measure consisting of more than forty items. Allen and Locker [39] found that the discriminant, predictive and concurrent validity of OHIP was only moderately improved by weights. This finding was consonant with that of Leao and Sheiham [30] for DIDL. As things currently stand, weights increase the complexity of use and interpretation of health status measures. This is likely to act as an impediment to use of these measures in clinical settings. The issues which need to be resolved are whether methods for developing weights appropriate, are ranges of weights wide enough to discriminate, or whether weights are of any benefit at all.

Responsiveness of a measure to change is a complex and controversial issue. As assessment of change is a fundamental requirement of all longitudinal study designs, the issue of ability of health status measures to quantify change is now topical. Locker [32] describes four ways of measuring change, namely: 1) comparison of "before" and "after" measurements; 2) change scores, calculated by subtracting the baseline score from the follow-up score; 3) global transition judgements, and; 4) global transition scales.

All of these methods may be used, but none are universally accepted. Comparing baseline and follow up measurements is straightforward, but positive and negative changes may cancel each other out, thus giving the impression of no change. Change scores, also known as raw gain scores, are difficult to accept because intrinsically they have no meaning. It is, therefore, not possible to describe a change score in either a positive or negative direction as clinically meaningful. A global transition judgement is a patient's overall assessment of how their health status has changed over the study period in question. Changes in health status as measured by a health status measure can be compared with the global transition judgement. Both Locker [32] and Dolan et al [40] have found that changes in global judgements varied over time and were consistent with self-report health status indicators and GOHAI scores. In a sense, this would suggest that discriminant validity properties of global transition judgements may be at least as effective as multi-item oral health quality of life measures. However, it is unlikely that a comprehensive picture of responsiveness to change can be gained from using global measures alone, but further research is required to test this hypothesis.

Global transition scales are derived from a series of global transition statements applied to different dimensions of

health. The scale scores are calculated by summing the response codes, and monitoring changes over the time period of the study. The use of this method has not been widely reported in the literature.

The complexity of measuring change in quality of life has been illustrated by Slade [41]. In a longitudinal observational study, he used OHIP to measure oral health related quality of life at baseline and two-year follow-up visits. He reported that both improvement and deterioration in oral health related quality of life can occur simultaneously. Using three risk predictors (tooth loss, problem based dental visits, financial hardship) to assess effects of various methods of measuring change, high risk and low risk groups were compared. High risk groups had both higher rates of deterioration and improvement in quality of life than low risk groups. The example used to explain this phenomenon was that loss of teeth may increase chewing difficulty, but decrease pain. Tooth loss may, therefore, improve quality of life for some individuals, while decreasing it for others.

# Use of health status measures in clinical settings

There has been a paucity of research using oral health status measures to assess the outcome of clinical intervention. Much of this has focussed on comparing the outcome of tooth replacement of teeth with implant retained restorations and conventional removable dentures [42,43]. A significant barrier to the use of health status measures in clinical settings is the large number of items in many measures currently available. While shorter versions have an intuitive appeal, the reliability of an index tends to decrease as items are omitted [44]. Some efforts have been made to shorten existing measures while retaining such important psychometric properties as reliability and precision. The methods used include internal reliability analysis, factor analysis and regression analysis to identify items that had the strongest associations with the original long versions of the measures [45,46]. The short version of OHIP contains 14 items derived from the 49 - item OHIP, and appears to have good validity and reliability properties [46,47]. In addition, a subset of OHIP items derived using the item impact method has been developed for use as an outcome measure of tooth replacement procedures [47]. The responsiveness of this subset of OHIP items seems to be better than the OHIP-14, and an argument can be made for using an item impact to derive a subset of items for use in specific clinical trial contexts [47].

A potential use of subjective health status measures is to predict treatment need. However, at the present time, so called "predictive validity" of available measures appears to be weak [30,48]. In these studies, associations between professionally assessed treatment need and health status measure summary scores were assessed using sensitivity and specificity statistics. While statistically significant associations between clinical indicators and subjective measures were found, the associations were moderate. These findings were similar to those of Atchison and Dolan [27] and Locker and Slade [9] who reported weak correlation scores between clinical indices (e.g., caries, periodontal pocketing) and summary scores derived from GOHAI and OHIP respectively. Locker and Jokovic [48] suggest that these findings should not be unexpected, as health status measures were not derived specifically as predictive indices. They recommend that health status measures should be used to complement objective needs assessment, and may help identify patients who are likely to benefit most from dental treatment. Reisine and Locker [49] suggest that further research is required to help refine use of health status measures for this purpose.

### **Future developments**

As just described, a substantive body of work has been undertaken in the development of oral specific health status measures. A number of further issues remain to be resolved or clarified. These measures are now being used in adult dental health surveys [50], and the international research community must agree on a strategy which facilitates comparison of data. To this end, it would be helpful if national norms were established for more frequently used measures. Cross cultural relevance of the conseguences of dental disorders must be considered. Allison et al [51] explored this issue and reported that the nature and magnitude of impacts could vary between populations with different cultural backgrounds. Once again, this can be an issue in national population surveys. Further methodological work to assess sensitivity to change properties is required from clinical trials, and clinicians must be encouraged to collect and interpret this data. Finally, models of health are becoming more sophisticated, and it remains to be seen if the conceptual underpinning of existing oral health status measures is now sufficiently robust, or whether new measures, based on more recent models, should be developed.

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