

Measuring Oral Health and Quality of Life



Edited by
Gary D. Slade

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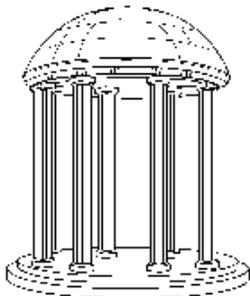
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Gary D. Slade

Proceedings of a conference held June 13-14, 1996, at the University of North Carolina-Chapel Hill, North Carolina. The conference and this publication supported jointly by the Agency for Health Care Policy and Research and the National Institute of Dental Research, NIH Grant #R13 HS09254. Support for attendance by seven individuals was provided by the US Department of Veterans Affairs.

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Published by:
Department of Dental Ecology,
School of Dentistry,
University of North Carolina.
September, 1997.

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Suggested citation style: (Chapter Author(s).. Chapter Title.) In: Slade GD, ed. Measuring Oral Health and Quality of Life. Chapel Hill: University of North Carolina, Dental Ecology 1997.

FOREWORD

This publication contains a selection of papers that were presented at a conference entitled "Assessing oral health outcomes: measuring health status and quality of life". The purpose of the conference, which was held on June 13 and 14, 1996 in Chapel Hill, North Carolina, was to examine methods for measuring oral health related quality of life, with the long-term objective of promoting use of those measures in oral health outcomes research. The specific aims of the conference were:

1. To critically evaluate existing measures of oral health related quality of life - their theoretical framework, method of administration, reliability, validity and potential for use in oral health outcomes assessment;
2. To identify omissions/deficiencies in existing measures and recommend new research directions for their use in future oral health outcomes research; and
3. To disseminate findings through a handbook that describes and critically analyzes existing oral health related quality of life measures

The Chapters that follow address the third aim by presenting background papers and details of eleven instruments that measure oral health related quality of life.

BACKGROUND AND RATIONALE FOR THE CONFERENCE

The conference's aims arose from a concern that there was a significant divide between one group of researchers, predominantly from psychometric and social survey backgrounds, who had developed instruments measuring oral health related quality of life, and another group of researchers, primarily concerned with dental health services and clinical trials, who potentially could use those instruments in the assessment of oral health outcomes. A related problem was recognized more than two decades earlier when Cohen and Jago first advocated the development of "sociodental" indicators to capture non-clinical aspects of oral disease.¹ They argued that sociodental indicators were necessary to broaden the narrow focus that had emerged within oral epidemiology, which emphasized only the clinical parameters of disease, and therefore failed to document the full impact of oral disorders within populations.

Since the initial work of Cohen and Jago, there had been an impressive amount of research undertaken to develop sociodental indicators - although with the passage of time, the term "oral health related quality of life" increasingly was adopted to define these measures of subjective oral health status. This redefinition was consistent with research that had gone ahead within other health-related disciplines that identified "health related quality of life" as a multidimensional construct capturing subjective aspects of health.² The multiple dimensions of health related quality of life range from impairments (which are closely linked to clinically-defined health status) to social function, and more global constructs such as opportunity. The dimensions have been linked in conceptual models in which effects of impairments on disability or reduced opportunity are mediated by intervening personal and environmental factors.^{3,4} Within medicine, these theoretical models have now been adapted to the more practical task of linking general medical status and clinical care to quality of life.⁵

Although dental researchers began to adopt these concepts during the last two decades, resulting in the development of a dozen oral health related quality of life measures, it was clear when planning the conference that those measures had not been widely used to evaluate outcomes from dental care. Instead, most oral health related quality of life measures had been used in survey settings and epidemiological studies. Hence, the priority for this conference was to bring together the two groups of researchers - psychometric/social survey researchers and clinical/health services researchers - so that existing measures could be presented, reviewed and evaluated for use as health outcomes measures.

A planning group was convened and was successful in obtaining funding through the Small Grants Programs of the US Agency for Health Care Policy and Research and the National Institute of Dental Research. The planning group consisted of Drs. Gary Slade (Principal Investigator), Ron Strauss (co-Principal Investigator), Kathryn Atchison, Nancy Kressin, David Locker, and Susan Reisine. In addition to planning the conference format, they worked with an advisory panel to identify the target audience of active researchers, both in oral health related quality of life and oral health outcomes assessment, who were invited to participate in the conference.

FORMAT OF THE CONFERENCE

Some 67 people attended the conference which consisted of four sessions: an opening plenary session which featured four presentations describing the background to quality of life and outcomes assessment; a poster discussion session, where eleven oral health related quality of life measures were reviewed; small group discussions that examined requirements for quality of life assessments in five oral health research settings; and a final plenary session in which reactors discussed directions for future research. The Chapters in this publication arose from the first two sessions and a separate set of papers⁶ will soon be published to summarize the remaining two sessions.

FORMAT OF THIS PUBLICATION

The first three Chapters in this publication provide background material tracing the history of oral health related quality of life measures, concepts of oral health and disease, and challenges and opportunities that exist in measuring quality of life within oral health outcomes research. The three Chapters are based on the oral presentations made by their respective authors at the opening plenary session of the conference. The fourth presenter at that opening session, Dr. Robert Kaplan, reviewed issues in health status measurement within medicine, particularly with reference to the Quality of Well-Being Scale, which has been published elsewhere.⁷

The properties of eleven oral health related quality of life measures were presented during poster discussion sessions, and those results are presented in Chapters 4-15. Specifically, each author was asked to describe:

- Background: a description of why the instrument was developed and what it is intended to measure.
- Development of the instrument: details of methods used to derive the items for the measure, response categories and any procedures for computing scores.

- Evaluation of the instrument: findings concerning the instrument's performance, including its reliability, validity and precision.
- Findings from the use of the instrument: results from the use of the instrument including, if available, response rates and frequency of missing data.
- Alternate forms: a description of any alternate forms of the instrument that have been developed, such as translations, shortened versions of the same instrument, or different coding systems.
- Discussion and evaluation: a critical evaluation of the strengths and weaknesses of the instrument, based on experience with its use.

The sequence of Chapters follows approximately the order in which instruments were originally published. Where possible, authors have provided copies of their instrument or listed questions and described response and coding formats. This has been done with the intention that the measures would be readily accessible for other researchers to review, compare and potentially use in their own work. However, this publication does not attempt to summarize or contrast the various instruments or make recommendations about their use.

Although the absence of a summary may appear to be an omission, particularly for readers who are looking for the "best" instrument for studies of oral health outcomes, it reflects several themes that emerged from the conference. First, many of the instruments are relatively new, some having been used only in one or two population surveys, and hence it is difficult to assess their track record at this early stage. Second, there has been very little comparative research using more than one instrument within a single study, which limits the capacity to compare specific properties of instruments. Third, there was no consensus reached at the conference to declare any specific instrument(s) the most appropriate for a given study design or research setting. Instead, it was recognized that there is a need for these instruments to become more widely understood and utilized, with the hope that findings will soon become available - preferably before another two decades pass - to identify optimal methods for assessing quality of life as an outcome of oral health care. This publication is intended to help in that process of improving the understanding and utilization of these instruments.

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ACKNOWLEDGMENTS

This publication represents the results of a conference which achieved its success only through the willing contributions from many individuals and their organizations. Formal recognition goes to the Agency for Health Care Policy and Research and the National Institute of Dental Research which provided funding for the conference (NIH Grant #R13 HS09254) and to US Department of Veterans Affairs which supported attendance by seven of its employees.

Dr. William Maas of the Agency for Health Care Policy and Research was instrumental in the earliest stages of planning when the conference was first envisaged. He provided both enthusiastic encouragement and practical advice to steer the organizing committee in productive directions. He then continued to work with the organizing committee, serving on the Advisory Panel and acting as a reviewer for Chapters that appear in this publication. Additional encouragement came from Dr. Patricia Bryant from the National Institute of Dental Research and from Dr. Daniel Deykin, Department of Veterans Affairs Health Services Research and Development Service. The conference organizing committee was helped in its work by the wisdom and strategic directions provided by the six members of an Advisory Panel: Drs. Howard Bailit, Lois Cohen, H. Asuman Kiyak, William Maas, Dan Shugars and Alex White.

Inevitably, the success of a conference is dependent upon the willingness of its participants to contribute their own scientific knowledge and to create stimulating, thought provoking discussion. Particular thanks go to the five individuals who served as leaders of small group discussions: Drs. Kathryn Atchison, Ron Ettinger, Bill Hayden, Ceib Phillips and Dan Shugars.

The logistics of planning and conducting a conference demand a large amount of time, patience and skill in arranging travel, accommodation, meeting rooms and meals. Sincere thanks go to Mr. Jim Gray who not only handled these arrangements in an efficient and friendly manner, but who was always willing to take extra care to make the conference truly enjoyable for both participants and organizers.

The preparation of this publication was made possible only through the diligence and commitment of its contributing authors, and thanks goes to each one of them for their hard work and patience in preparing materials. Three members of the conference Advisory Panel very generously served as reviewers, and deserve special recognition: Drs. William Maas, Dan Shugars and Alex White. Mr. Glenn Haugh, UNC Printing Services, provided invaluable advice and assistance in publishing these proceedings.

Finally, I want to pay special tribute to my colleagues in the conference Organizing Committee who individually offered their enthusiasm, expertise and experience, and who collectively worked as a dynamic team in organizing this conference: Ron Strauss, Kathryn Atchison, Nancy Kressin, David Locker, and Susan Reisine. It was truly a pleasure for me to work with them.

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Chapter 1

THE EMERGING FIELD OF ORAL HEALTH- RELATED QUALITY OF LIFE OUTCOMES RESEARCH

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INTRODUCTION

It was about a generation ago, during the Administration of the late President Nixon that this nation was engaged in heated political debates on the viability of a variety of health care programs for the U.S. By the way, this was the last full-blown national debate prior to the one stimulated by the current Clinton Administration. During the late 1960's, it was clear that there were limited data drawn from studies conducted within the confines of the U.S. to base proposals for a unified national health care delivery system. Eyes were focused, consequently, around the world to look for models, or components of model systems which could be effectively and efficiently adapted for application in the U.S. I recall that President Nixon drew on the models, exemplified by Japan, in which about half the population was covered by industry-based insurance reimbursement schemes for service delivered by private practitioners and the rest by a government tax-supported scheme. Senator Ted Kennedy advocated a model closer to the British system, which was exemplified by the government-based National Health Service. While other proposals were raised, databases which would allow for comparisons of health outcomes for these or other systems were sparse.¹

In the U.S. there were some attempts by medical and social researchers, on a collaborative basis, to draw upon cross-national comparative surveys using standardized procedures across countries. While the use of dental services was included in these health care utilization studies coordinated by faculty at Johns Hopkins University, this measure was not of primary interest and, consequently, the results were not analyzed in-depth. Moreover, only the consumer reports were considered, while clinical health outcomes, provider and administrative data were not collected.²

The rationale for embarking on that series of studies, as well as the World Health Organization/U.S. Public Health Services Collaborative Studies of Oral Health Outcomes (ICS-I and II) was based on the "need-to-know" about the effects and efficiencies of alternative health care delivery systems. Fully cognizant that definitive measures of effectiveness and efficiency were not fully developed, the designers of the ICS-I³ and later the ICS-II struggled with the state-of-the-science at those designated periods of history (early 70s, for ICS-I and mid-80s for ICS-II).⁴

INTERNATIONAL COLLABORATIVE STUDY OF DENTAL MANPOWER SYSTEMS IN RELATION TO ORAL HEALTH STATUS (ICS-I)

Conceptually, effectiveness was to be measured by a ratio of services or treatments provided to services or treatment needed. Rather than rely on direct measurement of oral disease(s) alone, the outcome of the delivery system characteristics being studied could reflect the oral health needs of the theoretically-defined potential and actual consumers in the sampling area.

For example, dental caries was recorded in terms of decayed, missing and filled primary and/or permanent teeth. Treatment need was measured, assessing requirements and/or extractions. For other diseases and conditions, much agonizing occurred to clarify and establish indicators of services provided in relationship to services needed.

Questionnaire data to solicit consumer behaviors, attitudes, and perceptions were administered for three age-groups and another set of instruments were designed to solicit conceptually parallel information from providers of care.

Without going into the intricacies of standardization and calibration or all of the analytic techniques, the upshot was that hypotheses related to availability of services and access were not perceived to be significant barriers in most study sites; rather perceived acceptability of the system emerged to be most significant and explained a greater proportion of the variance in utilization of services and, ultimately, in measures of unmet treatment needs (the calculation of service-to-need ratios).

Among the measured oral health data that couldn't be explained in any of the systems studied, was the relative perceived value of a natural dentition. The dramatic comparison of 36 percent of the adult sample in Canterbury, New Zealand as edentulous, compared to one percent or less in Lodz, Poland and Yamanaski, Japan astonished all of us. Fundamental questions about the impact of culture on perception of oral health adequacy were not adequately addressed in ICS-I. It took a national survey in New Zealand and subsequent analyses by Peter Davis, the New Zealand-based sociologist, to discover that the lower the socio-economic status measure, the greater the edentulousness and that the reasons were "culturally-based" and not related to dental indicators per se.⁵

TOWARDS THE FORMULATION OF SOCIO-DENTAL INDICATORS

When public health dentist John Jago of the University of Queensland in Australia began his graduate studies in the socio-dental sciences program at the School of Public Health, Columbia University in New York City, he and our ICS-I medical sociologist consultant, Jack Elinson, began a fortuitous liaison. Jack had organized an important seminar series on socio-medical indicators and invited presenters from different areas of inquiry to present. Marilyn Bergner, for example, presented material on the Sickness Impact Profile⁶ and others on their measures. I was asked to address what didn't quite exist in dental research ... but was clearly needed by the recent ICS-I effort. Mata Nikias had prepared an excellent review paper, "Measurement of Oral Health Status" which was published in *Health Goals and Health Indicators: Policy, Planning and Evaluation* (1977).⁷ That seminal paper and the earlier attempt by John and myself to study existing dental indicators for clues of what they contained and didn't contain about oral health and health consequences (published in 1976) were small starts.⁸ From those humble beginnings, born of a health policy "need-to-know" and interdisciplinary efforts on the part of an international agency, national governments and academicians, work continued to probe for the appropriate outcome measures. At the time, we frankly were embarrassed by the results. All the existing measures were morbidity or pre-morbidity measures, designed and administered by oral epidemiologists. None took into account any dimension of function which would be attributed by samples of the general public.

The World Health Organization oral health staff in developing its series of planning documents for situation audits in developing countries brought a group of researchers together, to re-examine some of these indices to expand them with non-clinical indicators.⁹

Much has occurred since those days in the 1970's and I am personally grateful to those who continued the stream of developing consciousness about the need for better and better outcome measures. Those people are here at this conference. Those who were instrumental in working with the pre-planning for the ICS-I protocol certainly took the inadequacies and proceeded to distinguish determinants from outcomes measures and began to catalogue them and their uses.^{10,11} Others went further to specify and inventory all economic impact measures, the social and psychological consequences of oral health diseases, disorders and treatments.¹² Still others joined the effort and provided a major service in linking what was known in oral health to the health-related quality of life measures for Healthy People 2000.¹³ There

have been significant developments in this country, utilizing oral health measures and health assessments associated with the Rand Health Insurance Experiment.¹⁴ Studies on the elderly have pushed us further to probe for the possibility of changing meanings associated with phases of the life cycle.¹⁵ New international cross-cultural studies of socio-dental indicators, reveal relationships to the multi-dimensionalities of health outcomes and life-style outcomes.¹⁶ And no doubt, managed care is pushing the envelope still further, to help us refine outcomes in order to assign relative values to health treatments of various kinds.¹⁷

TODAY'S ISSUES

While there are many more uses for outcome measures now than originally anticipated – as endpoints or co-endpoints for clinical trials, clinical decision-making and for managed care decisions, one of the most compelling uses as a research administrator is for decisions regarding research priorities and associated resource allocations.

Recently the U.S. Department of Health and Human Services Principal Deputy Assistant Secretary for Health, Dr. Jo Ivey Boufford reflected on the report of the WHO Advisory Committee on Health Research (ACHR). The World Health Organization's Executive Board had reviewed the ACHR Report in January 1996. The Report identified priority areas and gaps in research for health in development. The ACHR strongly criticized the DALY concept – a measure of Daily Aadjusted Life Years developed by the World Bank – as being relatively untested, unreliable and with questionable adequacy to account for multiple pathologies, multisectoral concerns and other factors. The ACHR was urged by the U.S. government to accelerate work in this field and to assess means of estimating disease burdens as a basis for research priority-setting. While the WHO Executive Board considered the DALY concept useful as a starting point for analyses, they did not see it as the sole basis for research priority setting.¹⁸

While international agencies, national governments and state and local authorities “right-size” and streamline for a leaner and, hopefully, not meaner manner of conducting business, criteria for allocating resources for research, for planning programs, implementing or evaluating them, for leveraging scarce resources across organizations...issues of outcome measures become even more critical. What can these measures tell policy-makers about the impact of oral health, specific oral diseases or disorders and the associated services? Should there be quality of life impact

statements required for every clinical trial or demonstration initiative before resource allocations are made? Should there be generic measures of outcome or only component disease or health measures for each of the oral diseases or for dimensions which constitute health? Should outcome measures be devised as clinical or non-clinical or combined to become global patient-based outcomes? Might it be helpful to examine groupings of diseases/conditions whether oral or of a systemic nature (Table Chapter 1.1).

Table Chapter 1.1: Groupings of diseases/conditions*

Inherited Diseases/Conditions
(Craniofacial Anomalies)

Infectious and Re-Emerging Infectious Diseases
(Caries, Periodontal Diseases or HIV-AIDS)

Chronic Disabling Diseases or Disorders
(Sjogrens' Syndrome, TMDs, Osteoporosis)

Neoplastic Diseases
(Oral Cancer, Naso-Pharyngeal Cancers)

* Examples of oral diseases or conditions are noted in parentheses

Would patient-based outcomes be different for these categories of conditions? In this regard, the model developed by Dworkin, LeResche et al¹⁹ for understanding chronic and recurrent pain conditions which taps biological, psychological and social components in the context of the family, the workplace, the health care delivery system and the social welfare system- represents such an effort. Would these or other classifications help us link oral diseases to other health conditions and their outcome assessments?

In any case, there is a real 'need-to-know', not so much different from that which existed in the late 1960s and 70s. I believe we are much further along now, a generation later, but there is much yet left to discover. And once we think we know what research tools to recommend, we will have the added task to convince policy-makers of their utility.

I also believe the current organizers of this conference are doing the right thing. Underlying it all, is the concept of a collaborating team made up of clinical researchers, epidemiologists, psychometricians, health sociologists, economists, social psychologists and others, coming together with relevant

experiences to share. Systematically raising the issues, dividing the labor and assessing the subsequent steps to be taken – surely will give return on this investment of expertise, human and fiscal resources.

It is a worthwhile challenge to find out what meaning is associated with the concept of oral health. It might even move us towards looking at biomedical interventions and assessment of the profound impact that gene therapeutics, tissue engineered new restorative materials, for example, could have upon us all – patients, families, practitioners, administrators and taxpayers. For anyone who wants to wrestle with questions of vaccines for non-life threatening conditions, there are endless possibilities ahead for dental, oral and craniofacial research of the new age. Socio-dental indicators, or as they are now re-incarnated, oral health outcomes measures, are more important to this enterprise than ever before. May we continue this work in the spirit of collaboration – putting our heads together to come up with some reliable, valid and useful outcomes.

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Chapter 2

CONCEPTS OF ORAL HEALTH, DISEASE AND THE QUALITY OF LIFE

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As the paper by Dr Cohen indicates, interest in the development, testing and applications of patient-based assessments of oral health outcomes has grown significantly over the past ten years and, as is evident by this conference, is rapidly becoming a major area of research in dentistry. As a consequence, the development and testing of these measures and, hopefully, their use in health surveys, clinical trials and studies evaluating oral health services is accelerating.

CONCEPTS OF ORAL HEALTH, DISEASE AND QUALITY OF LIFE

The aim of this paper is to briefly review some of the conceptual and theoretical issues involved in this area of research and to attempt to clarify concepts such as disease, oral health and quality of life. This is quite a daunting task and one that ought to give rise to debate and disagreement.¹ There are a number of reasons for this.

First, concepts of health and quality of life are elusive and abstract; while we know intuitively what they mean, they are difficult to define. Second, they refer to multidimensional, complex, and not-well demarcated events. Third, they refer to events which are predominantly subjective in character. Fourth, they are constantly evolving so that what we mean by health today may be different from what we mean by health tomorrow; and finally, what we mean by health and the quality of life may vary according to the social, cultural, political and practical contexts in which the concepts are being operationalized and measured. That is, definitions of health and quality of life necessarily involve personal and social judgements about what is normal or worthwhile and are heavily imbued with values.²

It is also the case that discussions of the concept of health are often complicated by the abundance of terms used to describe health and its constituent domains which are often ambiguous, ill-defined and/or used interchangeably. For example: health, disease, illness, wellness, well-being, psychosocial impact, positive health, functional status, functional efficiency, health-related quality of life, quality of life. Not to mention: impairment, functional limitations, disability, handicap, discomfort, resilience, dissatisfaction, health perceptions, disadvantage, deprivation and, of course, death.

THEORETICAL LITERATURE ON ORAL HEALTH

There is now a substantial literature concerning the concept of health and its application in dentistry in which various theoretical approaches and conceptual frameworks are discussed.^{1,3-9}

Consequently, many of the basic conceptual issues involved in this field will be familiar. For example, the limitations of using clinical disease-based measures to describe and monitor the oral health of populations and individuals, or the effectiveness of health care interventions, has been widely discussed and does not warrant being covered here.

Consequently, this paper will address a question posed by Gift and Atchison¹ at the end of their recent paper on the concept of health-related quality of life and its value in measuring and understanding oral health. That question is: What is oral health? The reason for addressing this question is that a variety of definitions and formulations have begun to appear in the literature, many of which are confused or subject to conceptual flaws.

In pursuing this question, it is also necessary to consider the following; 1) are what is referred to as oral health and general health separate domains?, and 2) are concepts of health and the quality of life one and the same or related but distinct? Since these are conceptual issues, there are no right or wrong answers; there are only answers which reflect different ways of thinking about health and how it is produced.⁷

TWO PARADIGMS OF HEALTH

To place this discussion in context, the development of patient-based measures of health outcomes, in both medicine and dentistry, should be seen as part of a broad paradigm shift in health care in which the medical model has been modified, if not replaced, by the socioenvironmental model of health.¹⁰ The socioenvironmental model, which provides the basis for health promotion theory and practice,¹¹ involves a change in our thinking about what constitutes health and the strategies necessary to produce it.

Traditional ways of thinking derive from the medical model which has the following characteristics. The philosophical roots of the model are to be found in mind-body dualism in which mind and body are separate entities. The model adopts a mechanical metaphor in which the body is seen as being akin to a machine.

It is reductionist in that health and illness are viewed as strictly biological phenomena. High technology and health services are seen as being the key to restoring and improving the health of populations and individuals. As a result, the body is isolated from the person and the patient's subjective experiences of health and illness are ignored.

In the applying this model in dentistry, there has been a tendency for us to treat the oral cavity as if it were an autonomous anatomical structure which happens to be located within the body but is not connected to it or the person in any meaningful way. That is, the mouth as an object of enquiry has usually been isolated from both the body **and** the person.

Over the past 20 years the traditional approach exemplified by the medical model has been increasingly challenged by the socioenvironmental model of health. Here health is defined not in terms of the absence of disease but in terms of optimal functioning and social and psychological well-being.¹² As a result we have moved from a concern with disease to a concern with health; from curing disease to prevention and health promotion, and from an emphasis on health services to an emphasis on the physical and social environments in which we live as major determinants of health status. At the same time the patient has been transformed from a body into a person so that increasing significance is attached to the individual's subjective experiences and interpretations of health and illness.

As Coulter et al⁷ have recently indicated, this represents a move away from an atomistic or reductionist way of thinking to a more holistic perspective on health and illness. In dentistry, this shift has been accompanied by two discoveries; the discovery of the body and the discovery of the person, and these have given rise to a research agenda concerned linking oral conditions to diseases of other body locations and to health outcomes and the quality of life.

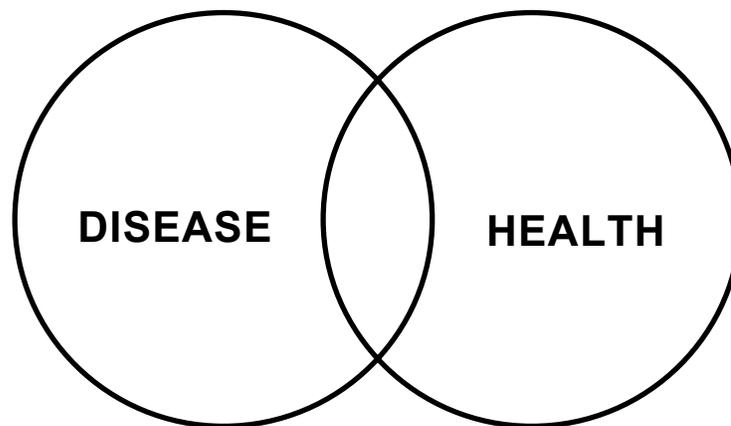
CONCEPTS OF DISEASE AND HEALTH

In addition, in order to take this discussion forward it is necessary to draw a fundamental distinction between disease and health. This was initially articulated in the World Health Organisation's 1948 definition of health. Accordingly, disease can be defined as "pathological processes which (along with injury and developmental anomaly) affect the biological and functional integrity of the body". Defined as such, this is a biological concept which applies to bodies, body parts and systems and tissues. It belongs to the medical paradigm with its focus on etiological agents, physiological parameters and clinical outcomes.¹³

Health, however, can be defined as "an individual's subjective experience of his/her functional, social and psychological well-being". Consequently, it refers to our experience of our bodies and our selves and the consequences of that experience for the conduct of daily life. As such, it is a sociological and psychological concept which applies to people and populations. It belongs to the socioenvironmental paradigm and commits us to the development of ways of measuring perceptions, feelings and behaviours.

Of some theoretical and practical importance is the relationship between disease and health and ill-health.¹¹ As Figure Chapter 2.1 indicates, disease and health are not points on a continuum but independent dimensions of human experience. While they are related in the sense that they often overlap, they are not necessarily co-incident and may be experienced separately.

Figure Chapter 2.1: Relationship between health and disease



That is, disease does not necessarily impinge on health and poor health may not have its origins in pathological conditions. In fact, this model indicates that disease is only one of many threats to health.

OTHER IMPLICATIONS OF THE CONCEPTUAL DISTINCTION

This distinction between disease and health has other important implications. First, it can be used to evaluate current definitions of oral health. Yewe-Dwyer¹⁴ defined oral health in the following way:

Oral health is a state of the mouth and associated structures where disease is contained, future disease is inhibited, the occlusion is sufficient to masticate food and the teeth are of a socially acceptable appearance.

While this definition makes reference to functional and social concerns, and in so doing attempts to cross the divide between medical and socioenvironmental paradigms of health, ultimately it remains largely within the former. That is, health is equated with the absence of disease and the focus remains predominantly on the mouth rather than the person.

This mode of thinking also underlies the OHX, a new index for measuring oral health.¹⁵ Although the authors of the OHX reviewed the literature on health status measurement, and considered concepts such as functional limitation, disability and handicap, the content of the measure indicates that it is largely disease based (Table Chapter 2.1). Apart from three questions on pain, chewing and appearance, the bulk of the index concerns the state of the teeth, periodontal tissues, the mucosa and the occlusion.

Table Chapter 2.1: Content of the OHX*

<p><u>Standing teeth</u></p> <ul style="list-style-type: none"> - caries - poor restoration - fracture - attrition <p><u>Periodontal status</u></p> <p><u>Occlusion</u></p>	<p><u>Mucosa</u></p> <p><u>Patient assessment</u></p> <ul style="list-style-type: none"> - pain - chewing - appearance
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Source: Burke and Wilson, 1995¹⁵

An alternative definition which more closely reflects contemporary thinking was recently presented by Dolan.¹⁶ She defined oral

health as "a comfortable and functional dentition which allows individuals to continue in their desired social role". In identifying comfort, function and social roles as key components, this definition is located within the realm of health and is person-rather than mouth-centred.

A second implication of these definitions, is that in studying oral diseases and their outcomes there are two levels of analysis.

There is analysis at the level of the body, epitomised by current research investigating the reciprocal relationships between oral diseases and diseases of other body locations; and analysis at the level of the person, epitomised by research which documents the extent to which oral disorders compromise health and well-being. These levels of analysis are frequently confused in the current discourse on oral health.

However, a further implication of these definitions of disease and health is that the idea of oral health itself is problematic since it embodies something of a conceptual anomaly.⁸ One way of illustrating this anomaly is as follows. A question that almost invariably appears in oral health surveys is: How would you rate the health of your teeth and mouth - excellent, very good, good, fair, poor? This is a question which taps general health perceptions and is very useful and analytically quite powerful. I wonder what the response would be to a questionnaire that included the following question: How would you rate the health of your leg?

The point being made here is that we do not conventionally attach the concept of health to any body part other than the oral cavity and, indeed, it seems faintly ludicrous to do so. According to the definitions presented earlier, oral cavities as anatomical structures cannot be healthy or unhealthy only people can. Consequently, the distinction that is often made or implied between general health and oral health is unwarranted; it has no underlying biological or theoretical logic. Rather, it should be seen as nothing more than an organisational distinction that arose through historical accident. Although this is frequently recognised in the literature, and implied by the use of generic conceptual frameworks and measures, it is often the case that the use of language and concepts and the questions we ask about oral and general health frequently implies the opposite; that is, they constitute separate and distinct domains. This is another source of confusion and ambiguity in current discussions of what we mean by oral health.

What then should we do with the concept of oral health given that it is somewhat anomalous and yet so central to our research and practical activities? Perhaps we need do nothing more than to be

clear that, when talking about oral health, our focus is not on the oral cavity itself but on the individual and the way in which oral diseases, disorders and conditions, whether confined to the oral cavity or linked to other medical conditions, threaten health, well-being and the quality of life. In this regard, oral diseases and disorders are no different from diseases and disorders affecting other locations in the body.

As far as the discussion here is concerned, this point of view suggests that the question "What is oral health" can be reduced to "What is health?".

WHAT IS QUALITY OF LIFE?

The next question we might consider is: what is quality of life and is it distinct from health? Quality of life is a term that is frequently used in the medical and social science literature and is one that has been characterised as vague, amorphous and ethereal. The term health-related quality of life was coined to give precision to the rather loose use of the term quality of life in medical contexts.^{2,17} The problem of course lies with the notion of quality of life itself. As Andrews and Withey noted as early as 1976, the measurement of quality of life could involve the measurement of practically anything of interest to anybody.

Anyone who has attempted to review the literature on quality of life will realise that there are many different approaches to this issue, many definitions (some objective and some subjective), and many ways of operationalizing and measuring the concept.¹⁸ The lack of consensus regarding definition and measurement, in spite of fifty years of research and literally thousands of scholarly papers, and the fundamental role of values in determining the quality of life, leads to the inevitable conclusion that the concept has meaning only at a personal level.

A definition of quality of life which adopts this position and is consistent with health promotion theory and practice, was recently developed by the Centre for Health Promotion at the University of Toronto. It states: 'quality of life is concerned with the degree to which a person enjoys the important possibilities of life'.¹⁹ The definition can be simplified to 'How good is your life for you?'. This definition is quite different from what might be called attribute-based or objective approaches which define quality of life in terms of the possession of certain attributes such as adequate income, social support and meaningful work. It is a definition which respects the autonomy of the individual and acknowledges that patients can provide information about what is in their own best interests.

RELATIONSHIP BETWEEN HEALTH AND QUALITY OF LIFE

Also of interest is the relationship between health and quality of life. In some definitions and measures, the two are synonymous, so that measures of quality of life are indistinguishable in terms of their constituent domains from measures of health.

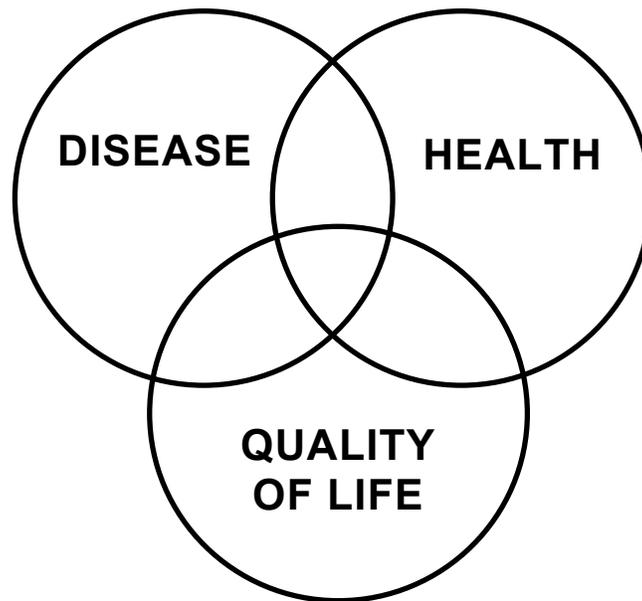
For example, Table Chapter 2.2 shows the content areas from a measure of quality of life recently described by Stewart and King,²⁰ which, given its focus on physical functioning, psychological well-being and pain and discomfort, looks suspiciously like a measure of health status. In addition, a recent review of quality of life measures for use in outcomes research listed generic health status measures such as the Sickness Impact Profile, the Nottingham Health Profile, the Quality of Well-being Scale and the Functional Status Questionnaire as examples of widely-used instruments.

Table Chapter 2.2: Content areas of a quality of life measure*

Physical functioning	Cognitive functioning
Self care	Pain
Usual activities	Energy/fatigue
Social functioning	Self-esteem
Perceived health	

Source: Stewart and King, 1994²⁰

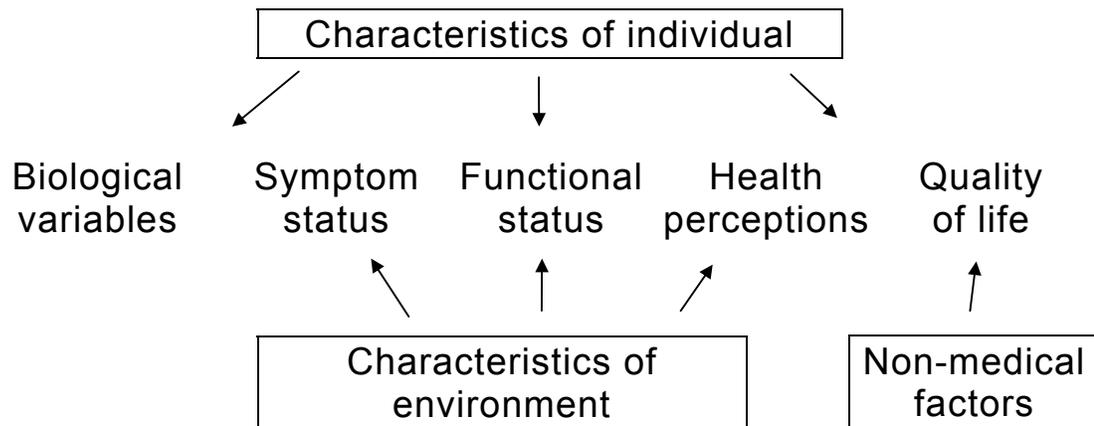
In spite of this, there is increasing recognition that quality of life refers to something much broader than health. There is, then, theoretical and empirical justification for representing the relationship as shown in Figure Chapter 2.2. What this simple model suggests is that while clinical conditions and health problems can impact on quality of life, it is not necessarily the case that they do so. While we often assume that poor health means poor quality of life, many people with chronic disabling disorders rate their quality of life more highly than the healthy.²¹ Some recent studies of the quality of life of elderly people have also indicated that, in talking about quality of life, they mention health but do not consider it the most important factor.

Figure Chapter 2.2: Relationship between health, disease and quality of life

CONCEPTUAL MODELS OF DISEASE AND ITS CONSEQUENCES

This discussion of concepts can be given a degree of coherence by reference to theoretical models of disease and its consequences. Unlike conceptual frameworks, which consist of a list of health domains, these theoretical models link those domains in a causal sequence and identify intervening variables which mediate their relationships. Although there are a number of such models, I would like to confine my comments to one recently specified by Wilson and Cleary (Figure Chapter 2.3).¹³ This model is a useful one in that it encompasses disease, health and the quality of life, makes explicit the main causal relationships between them and allocates a mediating role to personal characteristics and the characteristics of the environment in which an individual lives.

Consequently, like other models of its type, this model links biophysical concerns with social and psychological outcomes and provides a basis for exploring the associations between the two. Another advantage of this model is that by identifying the physical, social and economic environment as an important influence on this causal sequence, it provides a theoretical bridge between biomedical and socioenvironmental concepts of health and modes of thinking. As such, it offers what Engel²² has called a biopsychosocial perspective.

Figure Chapter 2.3: Linkages between clinical variables and quality of life

Source: Wilson and Cleary, 1995¹³

However, in order to be consistent with contemporary thinking, and the definitions and models presented earlier, we need to accept that 1) each of the component parts may be independent of the others; and 2) that the arrows mean "may or may not lead to".

There is evidence from studies in medicine and dentistry of the utility of models such as this. For example, a recent study using the Oral Health Impact Profile found that the psychosocial outcomes of tooth loss were influenced by factors such as poor general health, low socioeconomic status, life stress and age.²³ Further exploration of such models with respect to oral conditions should be regarded as a priority.

CONCLUSION

To conclude, it should be evident from this brief review that confusion remains concerning concepts of disease, oral health, health and the quality of life and the ways in which they are related. The discourse on oral health is also often confused. First, health is often defined in terms of the absence of disease; second; the mouth rather than the person is often the focus of the analysis and, third, ambiguity remains concerning the essential unity of what we call oral health and general health. Consequently, further work to clarify these concepts and their theoretical underpinnings is indicated.

Since some of these conceptual problems can be resolved, and medical and socioenvironmental approaches reconciled, through the use of causal models of disease and its consequences, the exploration of such models with respect to oral disorders is a

priority and essential to furthering our understanding what we call oral health.

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Chapter 3

ORAL HEALTH OUTCOMES RESEARCH – CHALLENGES AND OPPORTUNITIES

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1. Paper prepared while Dr. Gift was at: Oral Health Promotion
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INTRODUCTION

The purpose of this presentation is to consider challenges and opportunities in the field of oral health outcomes research from an oral health-related quality of life perspective. Elsewhere in this volume, the field is well described by Dr. Cohen from a developmental perspective; the conceptual frameworks that have been used to provide structure in the field are clearly articulated by Dr. Locker and elsewhere what has been and can be garnered from general health outcomes research is contributed by Dr. Kaplan.¹ Research in the field has been reported cogently in scientific journals, and substantial review articles have been published.²⁻¹¹

This contribution presents selected observations, both methodological and substantive, about state-of-scientific investigations in oral, dental, and craniofacial health outcomes to illustrate challenges in the research field. Following discussion of observations and challenge, remarks are made about opportunities in the field of oral health outcomes research.

Basic premises for the field of outcomes research have been established from an oral health-related quality perspective: health-related quality of life emphasizes health as opposed to disease; acknowledges that health is multidimensional; and recognizes outcomes of preventive and treatment services, or no treatment at all, as measurable and useful concepts.¹²⁻¹⁴

SUMMARY STATE-OF-THE-RESEARCH FIELD

Observation: Interest in oral health outcomes is not new.² The value of measuring health as opposed to illness, disability, and death became abundantly clear in assessing recruits for military service in World War II. Measures of physical capacity and function, presence of six opposing teeth, and psychological stability were more useful than traditional medical indicators in reflecting suitability for service. Yet, over 50 years have passed and the predominant measurement focus is still disease.

There is no accepted definition of oral health, even though the impact of socioeconomic status on oral diseases and the influence of high levels of oral diseases in reducing opportunities among those with lower socioeconomic status have been observed. Oral health is seldom envisioned as a changing state, altering over time, through the lifespan, or between intermediate and more final stages of treatment. Similarly, there is no clear and comprehensive articulation of how different oral health states contribute to or are

influenced by systemic diseases, functions, or disabilities. The needs to conceptualize and measure oral health and oral health-related quality of life have been identified. Drs. Locker and Cohen have noted that approaches have not been developed fully.^{2-11,15-22}

Challenge: Building on historic developments and current interest in the field, sustained energy needs to be directed to resolutions of definitional, conceptual, and measurement issues. Another 50 years should not pass before appropriate and useful outcome indicators are incorporated into oral health research. Until the multidimensional nature of oral health is understood, at a level beyond the clinical or epidemiological detail of surfaces and pockets, it will be difficult to engage fully in local, state, national and international efforts in preventing diseases, improving health, and reducing health care costs.

Using the historical perspective of Dr. Cohen, it is noteworthy that major policy decisions relative to oral health have been made, not by presentations to decision makers about pocket depth or actual number of surfaces with dental caries, but by articulating impact at the individual or population level. What issues influenced communities to introduce water fluoridation? What issues resulted in use of mouth and head protection in organized football in the 1960s? Who influenced the funding for the National Oral Health Information Clearinghouse? What resulted from the recognition of the importance of number of opposable teeth in army recruits in 1942?

Moving to the present and future, consider issues that influence the US Congress or other governmental bodies. It is most frequently impact on life of individuals or expenditures to provide positive outcomes. Such presentations are difficult to make if concepts and measures regarding oral health outcomes are not improved. Redirecting the oral health profession toward oral health and oral health outcomes is an essential activity. This includes broadening the perspective to more closely reflect health as a state of well-being and ability to function.

Observation: Too often in the literature quality of life appears to be presented as a methodological distinction rather than a concept, e.g., quality of life is represented by self-reported function and perceptions indicators, often to the exclusion of clinical indicators.

Challenge: First, it is important to eliminate the myth that oral health-related quality of life is only a methodological distinction, e.g., the equivalent of patient/individual self report. The value of the field of oral health-related quality of life is not who the respondent or 'measurer' is, but what is being addressed. Quality

of life is represented by those indicators that reflect 'getting on about the business of living'.²³ In general health, the original work resulting in measures of activities of daily living created this focus²⁴, but quality of life has not been addressed well in oral health. As an example in general health, one has to go beyond a repair of a wound due to a fall as the final outcome and consider other potential outcomes. Do shock and disruption of the day's activities affect medication compliance, result in sleep reduction, increase anxiety, reduce food intake, or influence one's ability to return to home alone? The emergency room physician may report satisfactory medical outcomes with the completion of the wound closure, but what is known about health-related quality of life outcomes without knowledge regarding some of the other dimensions? Responses to these questions are not restricted to patient self-report, but may be reflected in clinical indicators, observations by the health care provider or caregiver, records of school or work attendance, or assessment of financial expenditures. Clearly, these indicators go beyond the traditional measures of specific medical outcomes for a single event; they reflect function, resiliency, and co-morbidities, in other words, health-related quality of life. A similar vignette could be prepared for oral health by considering outcomes from a broad perspective.

Challenge: Based on a comprehensive conceptualization of oral health-related quality of life, indicators, observed or reported by a range of sources, need to be developed and used in combination to reflect oral health outcomes from a multidimensional perspective. Much of the research reported in the literature has addressed only selected components (e.g., function, perceptions, illness) of such multidimensional models, too often in isolation from each other. Despite these limitations, information has been gained from oral health-related quality of life studies on components ranging from survival, through impairment, to function and perceptions.

Observation: Both tooth loss and oral cancer have served as examples in examinations of the survival domain of oral health-related quality of life. Tooth loss has been examined in relation to economic, social, physical and psychological costs.^{9,20,25-26} Oral cancer's effect on quality of life has been reported in terms of discomfort and function, morbidity, disfigurement, related economic, social and psychological costs, and years of life lost.^{5,27-28} Treatment for such life-threatening diseases, e.g., surgery for patients with oesophageal cancer, appears to have a mixed impact on quality of life.²⁷ Interestingly, there has been less focus on orofacial trauma, even though the issues of disfigurement, function, and general quality of life may be similarly envisioned at this level.

Challenge: Life-threatening oral conditions require increasing attention across the range of prevention, diagnosis, treatment and recovery with comprehensive indicators of outcomes at each step.

Observation: Clinical and epidemiological indicators of a problem tooth may be precise and many. The presence of discomfort, a toothache, pain, or poor self-esteem (described by the individual as a symptom or a functional barrier), however, affects well-being and influences actions and is not measured by any traditional epidemiologic indicator.^{4,11,17-22} Traditional epidemiological indicators do not represent routine physiological function such as tasting or saliva for digestion or speech. A major shortcoming in traditional oral epidemiologic indicators is the inability to reflect the "capacity of individuals to perform desired roles and activities".²⁹

Combining existing indicators into profiles of oral health status has been the object of several efforts over the past three decades. Together these efforts illustrate the problems in evaluating long-term versus immediate outcomes; defining illness versus function; examining overall oral health versus assessment of single dimensions; and envisioning global oral health status when component conditions are very different, e.g., low caries/high periodontal diseases.^{3-4,7,11,15,17-18,22,30-31}

Challenge: Confidence in and consensus on the use of clinical indicators for oral health outcomes have to be developed. As an example, while number of natural teeth appears to be a relatively clear-cut delineator of function, used alone it conjures up mental images of toothlessness and consequently poor oral health. Number of teeth is used as an indicator of oral health despite the knowledge that many missing teeth are replaced, improving function or appearance. A more meaningful presentation of the assumed intent of such an indicator might be a composite variable reflecting the status of tooth spaces. In addition to evaluations of natural teeth, this would require information on replacements and their quality. Evidence suggests that many parts of this puzzle exist but have not been put together. For example, having few remaining teeth is associated with poorer function than being totally without teeth or wearing full dentures.³² Also, there is evidence that loss of molars reduces chewing performance and efficiency and results in changes in daily activities and poor self assessment of chewing.³²

Data sets including evaluations of natural dentition, treatment needs, and prosthetic presence and status should be examined to develop and test a dentition status indicator reflecting function

and value from a quality of life perspective. The merit of such an approach is the consideration of the mouth as a functional unit.

Observation: Self-reported symptoms, oral health status, and perceived treatment needs are important and measurable dimensions of oral health-related quality of life. The most widely used self-reported conditions are presence or absence of teeth or dentures, presence or absence of a toothache, sore or bleeding gums, loose permanent tooth, pain in tooth when drinking hot or cold liquid, cavity in back tooth, throbbing pain in teeth, cavity in front tooth, tartar or stains on the teeth, broken tooth, sores on tongue or sides of mouth, and crooked teeth.³³⁻³⁴

Special cases of self-evaluation include aesthetics and satisfaction with oral health; evaluation of seriousness of oral health problems in contrast with general health problems (sleeplessness, nausea, headache, overweight, influenza); evaluation of seriousness of specific oral health problems (missing teeth, pain, receding gums, crooked teeth, bleeding gums, mobile teeth, calculus or cavities); evaluation of inconvenience or difficulties with oral problems (loose lower incisors, cavities in back-teeth, gums bleeding with brushing, toothache with hot and cold, tangible calculus, crooked upper incisors, or receding gums); perceived treatment needs; attitudes toward, value of, and responsibility for oral health; and views about inevitability of good or bad teeth.^{3,7,9,11,20,35-37} Other investigations point to the influence perceptions of needs has on treatment decisions of patients and dentists.¹⁶ Analyses suggests that patients and dentists rely on different information in assessing oral health. Both viewpoints need to understand the associations between oral health, general health, and health-related quality of life.

Symptoms are acknowledged and experienced differentially by individuals and influence behaviors differently. Specific symptoms may influence behaviors more than others, e.g., loose incisors and retracted gums cause more concern than cavities, crooked teeth, or bleeding gums.³⁶ Also, a toothache is a driving force in an individual's behavior, whether it is labeled a perceived symptom or pain that affects function. A toothache alters quality of life enough to result in seeking professional care, more than other perceived oral symptoms (sore or bleeding gums, loose permanent tooth, sensitivity to hot or cold, tartar on teeth or crooked teeth).^{6,36,38-40} Results from focus groups suggest that orofacial pain also may alter quality of life more than certain other systemic conditions, e.g., diabetes, high blood pressure, ulcers.

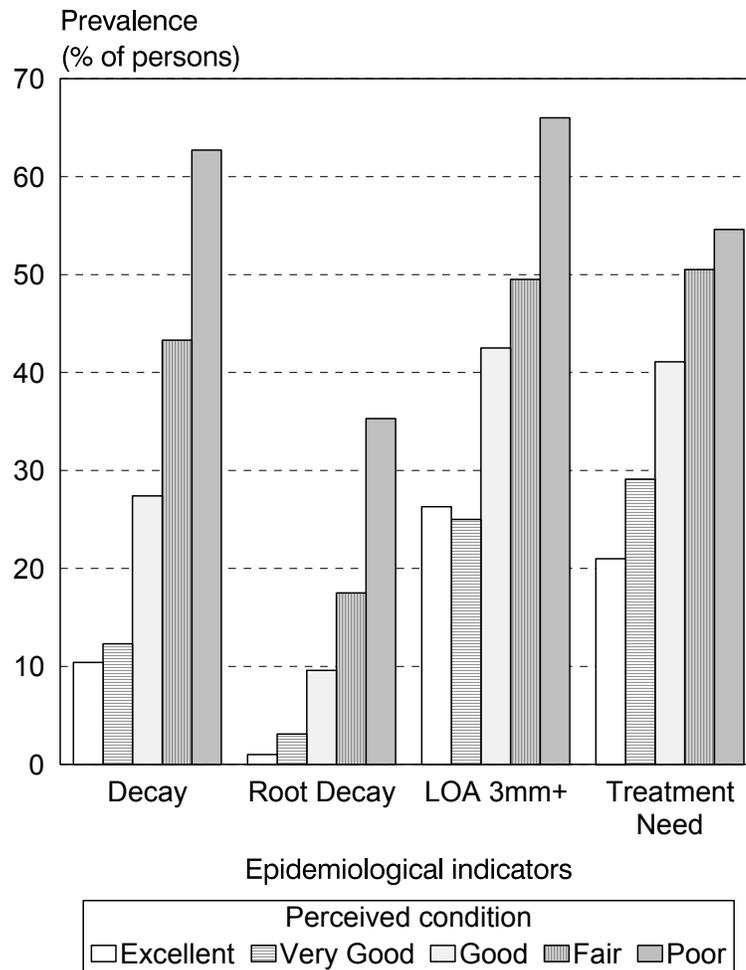
Research to date, using single subjective indicators, profiles, and scales, indicates both commonalities and unique dimensions of

self-reported symptoms, perceptions of oral health, self-assessed oral health status, and clinical oral indicators.^{6,10,15,18,20,22,27,31,33,35} Recent analyses can serve as illustrations.

While the third National Health and Nutrition Examination Survey (NHANES III) was not designed to examine oral health-related quality of life, available data from Phase 1 demonstrate the relations among overall perception of dentition condition, self-reported treatment needs, and clinically-assessed conditions. More positively perceived overall dentition condition is associated with clinical indicators of better oral health. As seen in Figure Chapter 3.1, associations exist between perceived dentition status and number of teeth, prevalence of coronal and root decay, loss of attachment, and recorded treatment need. Perceived overall condition of dentition is negatively associated with perceived treatment needs, but not associated with perceived need for preventive services among individuals whose overall perceptions range from excellent to fair (Figure Chapter 3.2). A strong and direct association of perceived dentition status and perceived general health, as well as an indirect association with trouble seeing and trouble hearing, is observed (Figure Chapter 3.3). While these preliminary results support other findings in the literature, considerably more examination of the data is necessary, and is underway, to consider the influences of age, socioeconomic status, general health, and other factors before reasonable interpretations can be made.

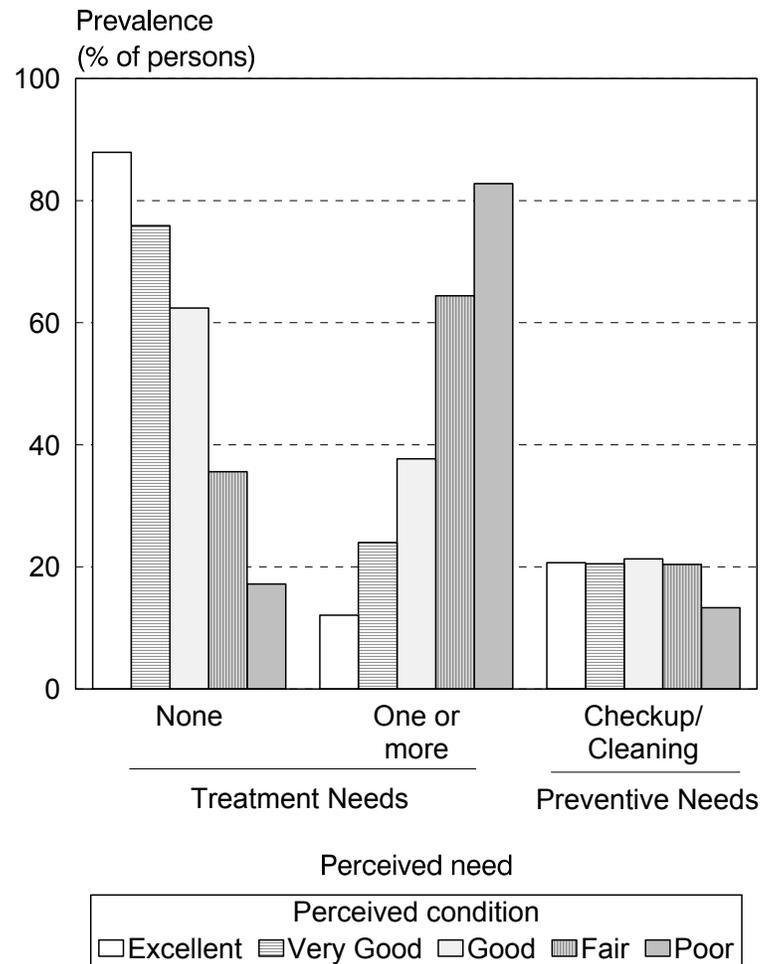
Another example of associations among, as well as independent nature of, perception and clinical indicators is provided in a recent analysis of an early 1980s national data set.³⁴ Using principal components analysis with varimax rotation, structure for four factors (accumulated oral neglect, self-perceived symptoms and problems, reparable oral diseases, and oral health values and priorities) was interpreted. Approximately 50% of the variance was explained by these four factors. Socioeconomic and demographic analyses on factor-based scores indicated that white persons had lower levels of accumulated oral neglect, fewer symptoms, and less reparable oral disease, but similar oral health values, than nonwhites; and level of formal education was associated with each of the four factor-based scores.

Figure Chapter 3.1: Perceived condition of natural teeth by epidemiological indicators (dentate adults, aged 18-74)



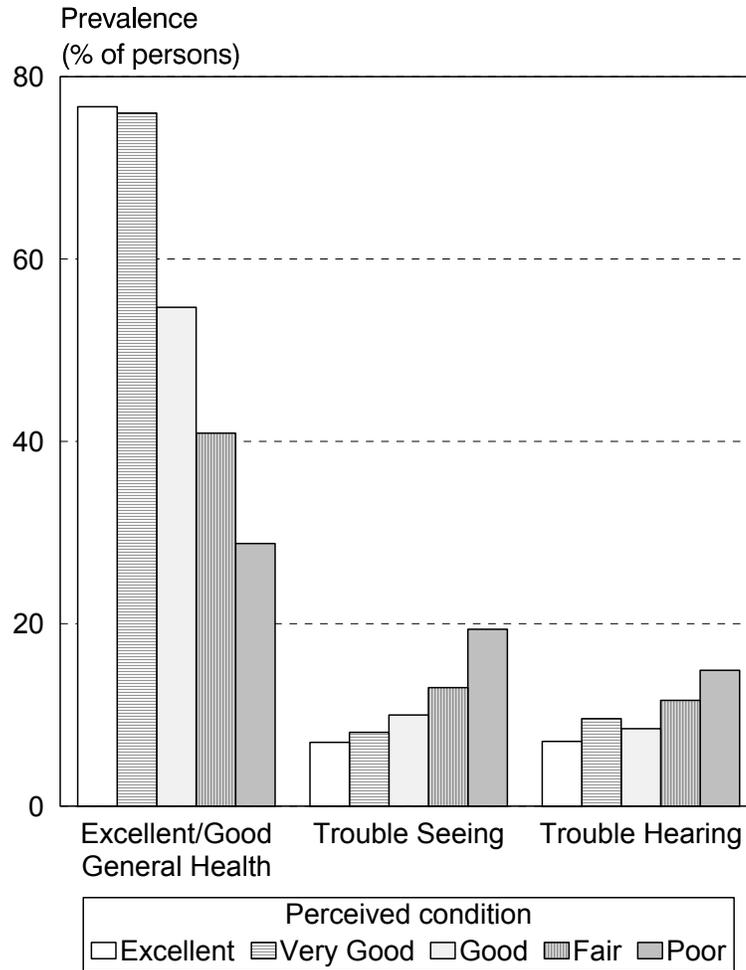
Challenge: It is recognized that perceptions are as important as physical conditions or functional limitations in quality of life. Yet, the impact of most perceived signs and symptoms on individuals' oral health-related quality of life is not well understood. It is important to know more about how individuals value specific components of oral health or overall oral health, the process of valuation, the relation of oral health values to other health and life values, as well as the influence of oral health on oral health norms and behaviors in various cultural and social settings.⁴¹

Figure Chapter 3.2: Perceived condition of natural teeth (dentate adults, aged (18-74) by perceived need for treatment & preventive services



Observation: Whether based on a study designed specifically for examination of quality of life or on secondary data analysis, more research findings relate to function than to other dimensions of oral health-related quality of life.

Figure Chapter 3.3: Perceived condition of natural teeth (dentate adults, aged 18-74) by perceived general health



Oral conditions or pain that hamper daily activities; inability to open the mouth, bite, chew, taste, speak, or swallow; limitations in psychosocial functions, such as personal contacts and role performance; and self-confidence are examples of assessed oral functions. These functions have been examined individually and through profiles and indices, e.g., the Geriatric Oral Health Assessment Index.¹⁵ Indicators of function are often associated with self-ratings of oral health and with selected clinical assessments.^{10,15,16,18,20,34-36} Edentulism and chronic pain are notable areas of investigation for oral function.

Dysfunction (such as oral handicaps; compromised diet; altered meals; unsatisfactory appearance; embarrassment due to dentition; restricted smiling, laughing, or talking due to oral conditions; and discomfort in the mouth) is common among edentulous individuals. These indicators are more highly associated with behaviors, such as visits to a dental office than traditional measures such as denture stability, retention, fit, occlusion, ridge height and whether the denture is worn.²⁶

Chronic and acute pain among the dentate or edentulous are often used to represent reduced oral function. Chronic pain is a major quality of life factor because of its persistence, often causing a great deal of emotional, physical, and economic stress.⁴² Individuals with severe oral pain have a great likelihood of disruption in daily life including missing time from work, staying at home, avoiding friends and family, worrying about oral health, consulting a health care provider, taking medications, and avoiding certain foods.⁴² In the employed adult U.S. population, more hours are missed annually due to dental problems or dental visits by those who reported pain than those without pain.⁴

Function also has been examined beyond the individual level. At the societal level, costs of time lost from work or school due to a dental problem or dental visit have been assessed to reflect the functional component of oral health-related quality of life.^{28,41,43} Lost time due to dental problems or visits is observed more in vulnerable lower socioeconomic populations who are also at higher risk for general quality of life concerns.

Challenge: Most indicators of function are self-reported. It is important to determine if there are other types of measures of function that would be useful. Indicators of function are needed at the individual, family, community, organizational (e.g., HMO), and society levels. Functional outcomes need to be measured at intermediate as well as final stages of treatment.

Observation: Capacity for health is an important dimension of quality of life, but one that appears to have few, if any, current application in the oral health field. Capacity in health is reflected by disadvantage or opportunity.¹⁴ For example, an individual with a congenital heart disease may not be able to obtain health insurance. Disadvantage may come from the illness, its treatment or the environment and is often measured indirectly. Opportunity may reflect resilience, or the ability to cope with or withstand stress. It recognizes that individuals adjust differently to environments such as treatments. How oral conditions and treatments: 1) affect social interactions or caregiver interest and involvement; 2) alter ability to seek and hold employment; and

3) affect ability to taste, chew and retain adequate nutrition despite missing teeth, may be indicative of this component of oral health-related quality of life.^{5,15,44}

Challenge: Opportunity, resilience, and disadvantage need to be conceptualized and operationalized for oral health-related quality of life research.

Observation: As the field of oral health-related quality of life has grown, investigators have: 1) assessed how general health-related quality of life measures relate to existing oral health measures; 2) adapted existing health-related quality of life measures to oral health; or 3) developed new indices to reflect oral health-related quality of life.^{2-11,15-22}

Increasingly, studies have provided evidence of the interrelations of single measures within a specific domain of oral health-related quality of life and among selected domains.^{3-11,15-22,46-48} For example, chewing ability is highly correlated with number of teeth. Various measures of the functional domain are highly intercorrelated, e.g., chewing ability, difficulty in opening the mouth wide, pain in the face, unilateral chewing, and clenching of teeth. Oral sensory perception declines in the presence of complete dentures, affecting food acceptability and dietary intake.⁴⁵ Missing front teeth results in less positive feelings of self esteem, going out less often, covering the mouth with a hand when laughing, not laughing.³² Having fewer functioning teeth and more decayed teeth is correlated with lower perceived oral health status and aesthetic dissatisfaction, altered eating, diminished communication, and pain.

Oral health-related quality of life indicators appear to be independent constructs within the context of general health-related quality of life and psychosocial evaluations. Oral health measures are correlated positively with measures of general health. Little evidence exists to suggest that oral health indicators contribute to evaluations of general health, but self-reported oral symptoms, periodontal breakdowns, and stress-related systemic diseases influence leisure, social and intellectual functioning, social interaction and home tasks.^{6,18,20,33,35,45}

Challenge: The interrelations, redundancies, and gaps in the variety of available oral health measures need to be examined. Analyses need to be continued on large, multidimensional studies, e.g., the Second International Collaborative Study, Boston VA Dental Longitudinal Study, NHANES III, to develop and test indicators of oral health domains and their interrelations. Expansion of data gathering in ongoing studies is needed to

address oral health more comprehensively. New, specifically designed studies need to be initiated. Oral health's association with general health will be understood better with more clearly articulated oral health measures having obvious intent. The comparability of oral health to general health as well as to other specific systems of health, e.g., respiratory or cardiovascular health need to be examined.

Observation: Findings in the field of oral health-related quality of life are generally associated with defined populations. More progress has been made in aging, perhaps because researchers are faced with both a broader range of oral conditions and medical comorbidities.

Challenge: Distinct studies on oral health-related quality of life need to be examined to assess how to apply approaches and findings to different populations. Are there generalized indicators that will be valuable at the population level, for young healthy adults, or for the healthy child population? Can the oral health-related quality of life approach help in understanding variations across the life span and within different sets of cultural norms? Are there specific indicators that are needed for specialized populations? For example, how can consideration of oral health-related quality of life improve research and eventually the care of children with congenital, potentially disabling conditions? Can the consideration of populations along specific dimensions (e.g., Medicaid, poverty, age, gender, ethnicity, type of employee group) make oral health outcomes differentially meaningful?

Observation: In much of the oral epidemiology, health services and sociobehavioral research, a mental set is pervasive that stops short of outcome and impact. Epidemiological indicators are examined within the context of sociodemographics and economics but seldom are the meanings of associations offered. Behaviors and perceptions are contemplated, again without considering outcome. Dental utilization and treatments are studied without considering the impact on either health or cost. Most often each of these dimensions are examined in isolation so the influence of multidimensional factors on oral health outcome cannot be understood.

Challenge: This discussion brings us full circle to the need for: 1) a definition of oral health; 2) a conceptual framework that integrates factors influencing oral health, both with our without treatment; 3) carefully defined operational indicators for concepts; and 4) examination of oral health in a range of populations and patient groups over time. Oral health-related quality of life goes beyond a disease-free mouth and also represents experience of

symptoms, perceived wellbeing and 'getting on with the business of living'. A larger challenge may be to alter the mental set and expectations of researchers, educators and practitioners in the field. If the expectation is to understand and improve outcomes then the importance of outcome needs to be made more obvious to more people. Reducing disease indicators, increasing number of dental visits, or improving self care behaviors are only intermediary in the process leading to final consequences.

WHO CONDUCTS AND USES ORAL HEALTH OUTCOMES RESEARCH?

Who conducts oral health outcomes research from the health-related quality of life perspective? At the present time, the group is relatively small. The opportunity remains to engage more researchers in the oral health field and to reduce isolation by collaborating with researchers in general health, e.g., those studying craniofacial conditions, pediatric asthma, aging. Also, researchers in the field need to collaborate with policymakers, health writers, planners, educators, clinicians and other researchers in envisioning oral health as an important issue with consequences, impacts and outcomes that need to be addressed.

A challenge is to go beyond identifying collaborators and to assess who would benefit from research using this multidimensional, multidisciplinary perspective. Potential benefactors of health-related quality of life approach to oral health outcomes research can be enumerated by examining the range of applications and functions for which relevance exists.⁴ In clinical practice oral health outcomes can be used to select treatments and monitor patient outcomes. In clinical trials and epidemiological research an outcomes approach is useful for identifying determinants of health, investigating the course of illness, and evaluating effectiveness of processes of care and treatments. Health-related quality of life has been used to assess the burden of illness and to establish program and institutional priorities, policies, and funding decisions. Also, health-related quality of life has been useful in tracking levels of health risk factors and use of services in populations. Working with these various functions in mind helps to articulate operational definitions, measures, and indices.

A market analysis is a useful approach in identifying potential users or benefactors of outcomes research. In a market analysis, the end user is the focus. A short list might include the insurance and managed care industries, purchasers of care (government, employers, or individuals), legislators and other policy makers, foundations, educators, researchers in a variety of settings,

community health workers, private practice and public health oral health care professionals, patients, and the public.

There are likely different questions to ask each of these collaborating end users and unique values that oral health-related outcomes research can provide. For example, what do community health planners need to move ahead in promoting oral health, preventing oral diseases, and integrating oral health with general health? For the educator, what is important for assessment and documentation to move forward in evidence based dentistry? For the oral health care provider, what information is needed to improve provider-patient communication or gauge treatment efficacy?

A collaborative assessment (market analysis) is needed with each of these groups to determine: What is being evaluated and what are appropriate outcomes? Why is the information needed? Who will provide the information? Who will benefit from the information? Where and when will the process and outcome occur and where and when will information be obtained? How will the information be used? Until there is an understanding of the issues being addressed and purposes for which outcomes information is needed, the oral health-related quality of life outcomes research field will remain a small focus. Understanding the issues and creating a research initiative that readily moves results into application will enhance development of the field.

FUTURE DIRECTIONS AND OPPORTUNITIES FOR ORAL HEALTH OUTCOMES RESEARCH

The opportunities and future research directions are many. This field offers an exciting opportunity to work across and within disciplines and to integrate oral health with general health and oral health into policy issues relevant to diverse populations over the next few years.

Several significant issues should be re-emphasized for specific consideration in the future:

- Oral health needs to be defined and conceptualized, and appropriate operational measures need to be brought into systematic use. Oral health is multidimensional and usefully is envisioned from a health-related quality of life perspective. Conceptualizing oral health within a health-related quality of life model, combining health status (physical, mental, oral) and multiple domains of health-related quality of life (function, perception, impairment), provides an approach for improving

scientific investigations and ultimately individual health.

Much of the work to date focuses on dental health. Has this limited the range of outcomes based on the multiple roles of oral and craniofacial health? Broadening our perspective beyond dental engages us in outcomes such as taste, bad breath, or oral discomfort or activity limitation resulting from a range of conditions, e.g., aphthous ulcers, orofacial trauma, or poor salivary flow. Similarly, a focus on dental may limit valuable outcome considerations along dimensions such as acute versus chronic episodes, congenital versus acquired conditions, conditions with or without disfigurement, or the impact resulting from duration, intensity, and timing of the disease or condition.

- More needs to be done to conceptualize and measure oral health as a system contributing to total health and within the social complex of the individual or group. How do the range of potential oral health indicators interrelate with each other and with the complex of current health states?

Examining single events and outcomes poorly represent extensive episodes of illness and care, may be misleading, and may result in miscalculations of true outcomes in terms of actual health, treatment needs, or costs. A simple example might be a decision regarding the suitability of different operative procedures. Outcome is not just the successful completion of the cheapest (or the most expensive) treatment at a point in time. What is the projected life of the procedure? How often will it have to be redone? Does one procedure versus another result in more return visits? Does the procedure provide the most satisfactory state of oral health, chewing and comfort, or self perception? Is frequency of use of a procedure or practice profile in utilization review providing the most appropriate information for assessing real cost and improved oral health?⁴⁹ Oral health as a combination of disease state, symptom recognition and perceptions requires an appropriate mix of indicators to measure.

- The many mediating and independent variables influencing oral health outcome need to be thoughtfully considered. Increased attention needs to be given to risks prior to care. Many of the indicators being discussed can be both outcomes and determinants, e.g., an outcome of previous treatment in and of itself becomes a precursor to additional treatment and/or may become a perception that influences future care-seeking behaviors. The values of a specific indicator in representing risk and outcome need to be understood.

Recognizing that clinical or self-reported oral health-related quality of life indicators are both an outcome of one episode of care as well as risk or determinant of future episodes of care encourages the examination of long-term impact at the individual level. For example, it is clear that an extraction of a single tooth has specific outcomes: removal of disease and pain and the creation of a tooth space. This outcome often is altered by placing a prosthesis in the space that may result in positive functional and aesthetic outcomes. What is the impact of a procedure (e.g., extraction) on future treatment needs? Does a procedure have potential for creating a downward cycle in perceived oral health status or morale that is irrevocable? Evidence from focus groups among women with major treatment needs suggests that irreversible treatment early in their lives may have such an effect. Envisioning oral health longitudinally and from a quality of life perspective, provides more opportunity to understand the influence of adaptation, coping, and other psychosocial skills in mediating treatment effects and outcomes.

- An assessment of "outcomes for whom" needs to be conducted to determine the nature and extent of indicators. If the outcome indicators are for health services researchers and epidemiologists, then the choice is self-limiting. If outcome measures are considered as valuable for other audiences, e.g., individual patients, individual non-patient, family member/caregiver, health care providers, administrator of facilities, purchasers of care, purchasers of insurance, managed care actuaries, policy or law makers, the range of indicators becomes more complex.

Indicators of outcomes currently range from counts, to assessed economic value or utility, to comfort, to quality. They range from minute measures, e.g., at a procedure level for one tooth, to a meso level of medical or social impacts of one episode of care for a patient to a macro level of impact of a sealant program for all appropriate children or dental care for all nursing home patients. These simple examples illustrate some possibilities and provide evidence of gaps in reflecting the passage-of-time dimension implicit in outcomes research. Clearly, developing suitable indicators in this multidisciplinary field is a significant challenge.

- Methodological issues to be addressed are numerous:
 - Health-related quality of life outcome studies are complex and time consuming. Yet, particularly in aging populations,

contingencies of passage of time are problematic (e.g., problems of participation in studies due to illness, relocation or death).

- Moving outcomes research to longitudinal approaches is essential, but introduces additional time dimensions. Individuals may not have similar values about their own illness state at different stages. Changes in patients' health and welfare, resulting from intervention(s) or lack of intervention(s), need to be examined to determine the value of treatment.
- Measurement issues, particularly sensitivity, specificity, reliability, and validity, need to be addressed in diverse subpopulations, e.g., different age cohorts, ethnic groups, the disabled, or those who are cognitively impaired.
- Methods from the broader field of health-related quality of life need to be applied in oral health outcomes research.

A quality of life approach begins to help in addressing some challenging research, policy, public health, and health services questions:⁴ What are the effects of orofacial diseases and conditions on systemic health and quality of life? Are the impacts of orofacial diseases different at each life stage? Consideration of oral health-related quality of life strengthens the examination of the process of oral health and oral health care, by more clearly articulating the interactions of risks, mediating factors, diseases and conditions, education, prevention, and treatments with functional oral health and well-being.

The ultimate values of continuing quality of life research are to: 1) provide assessment, beyond the tooth or oral cavity, at the individual level; 2) demonstrate the "burden of illness" due to oral diseases which is useful for advocacy in health policy; 3) serve as criteria to identify priority groups for public health intervention; and 4) establish outcome measures for oral health promotion and disease prevention research that reflect the concept of health. Conceptualizing and measuring oral health leads us closer to examining it as part of general health.⁴

While there are many unresolved issues to be addressed in health-related quality of life, the field has come a long way in conceptualizing and establishing theoretical frameworks and in the development and testing of alternate measures.⁴ Hopefully, research investigators will continue to develop and nurture this area of research.

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Chapter 4

THE SOCIAL IMPACTS OF DENTAL DISEASE

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BACKGROUND

The Social Impacts of Dental Disease (SIDD)¹ measure, developed in the early 1980s, was one of first socio-dental indicators. It was a response to dissatisfaction with the conventional measures of health which failed to incorporate evaluation of the impacts of disease, impairment and health services on people's well-being. The development of the indicator was also influenced by debates of what constituted 'quality of life', because it was an important aim for public policy and prioritizing use of resources.² There was a growing consensus that health extended beyond purely clinical definitions and should include general well-being, freedom from pain and discomfort and effective functioning. Mechanic's³ concept that illness was the inability to cope with symptoms, and the importance of a consensus between the views of the status definers,⁴ influenced the choice of dimensions of the indicator. Wolinsky and Wolinsky⁵ constructed a health status model focusing on the three major aspects of an individual's health status; the physical, the social and the psychological. The physical is measured from the physician's perspective and thus reflects the medical model, the social from society's perspective in terms of task and role performance, whilst the psychological is measured from the individual's perspective of general satisfaction and happiness. Those three perspectives were adopted for constructing SIDD.

DEVELOPMENT OF THE INSTRUMENT

SIDD was developed as a component of a much broader socio-dental model of dental disease and health behavior so that both the clinical and socio-psychological aspects could be considered within an integrated framework.⁶ The model assumes that an individual's present oral health status and treatment needs are influenced by an interplay of three 'dimensions' of background and behavioural factors, namely vulnerability, motivational and preventive dimensions. In this sense, the model is similar to the classes of variables - predisposing, motivational variables, 'blockage' variables and conditioning variables - of the interactional model developed by Antonovsky and Kats.⁷ Vulnerability relates to antecedent or conditioning variables, for example the socio-economic background, dental history and experiences, present home and work circumstances, access to dental services. It represents the degree to which people's life experiences have increased the likelihood of adverse dental health and covers the predisposing variable of Antonovsky and Kats. The motivational dimension relates to beliefs, attitudes, concerns and expectations about dental health and the preventive dimension to

current dental practices, predominantly self-care measures adopted to maintain and promote dental health or to prevent or postpone tooth loss. The model defines dental health status in socio-dental terms; the clinical indicators are largely determined by vulnerability whilst the social elements are more directly linked with the degree of social and psychological impact arising from dental diseases.

The measures of dental impact used represented an initial attempt to incorporate impact measures into measures of oral health. From qualitative interviews, a measure of the social and psychological impact of dental diseases was developed based on five categories of impact: eating restrictions, communication restrictions, pain, discomfort and aesthetic dissatisfaction. Pain and discomfort were distinguished as being different from each other. The score for each individual was constructed from responses to questions relating to those five categories (Table Chapter 4.1). A total impact score is derived by adding the number of categories. A score of 1 is given to the impact category if a positive response has been given to any of the questions in the category. Two total impact scores were used, one including (total score 0-5) and one excluding discomfort (total score 0-4) to see the difference if this relatively common problem was excluded. Symptoms of bad taste and bad breath, though relatively prevalent, were excluded from the total impact score because they had various causes and were not necessarily linked to dental conditions. No attempt was made to measure the severity of an impact. SIDD should therefore be considered as a basic indicator of impact.

Table Chapter 4.1: The Social Impacts of Dental Disease (SIDD)*

Impact Category	Items†
<u>Functional</u> Eating	<ul style="list-style-type: none"> • difficulty chewing • difficulty biting hard • difficulty taking a big bite • having to change types of food eaten
<u>Social Interaction</u> Communication	<ul style="list-style-type: none"> • difficulty or restriction talking • difficulty or restriction smiling • difficulty or restriction laughing • difficulty or restriction kissing
<u>Comfort and Well-being</u> 1. Pain	<ul style="list-style-type: none"> • toothache or pain currently or in previous 12 months
2. Discomfort	<ul style="list-style-type: none"> • sensitivity to cold • food packing • denture discomfort currently or in previous 12 months
<u>Self Image</u> Aesthetics	<ul style="list-style-type: none"> • dissatisfaction with teeth in relation to other features of appearance • dissatisfaction with appearance of dentures

* A score of 1 is given to the impact category if a positive response has been given to any of the items in the category.

Total Impact Score (0-4) = Sum of categories eating, communication, pain and aesthetics

Total Impact Score (0-5, including discomfort) = Sum of categories eating, communication, pain, discomfort and aesthetics.

† Examples of questions used are:

Are there any types of foods you have difficulties chewing? If yes, what food?

Have you had to change the kinds of food you eat because of your teeth or dentures?

Have you any pain from your teeth or gums now or in the past 12 months? If yes, did this trouble interfere with anything you normally do like doing your work, eating normally, sleeping or going out?

Would you say you try to avoid showing too much of your teeth when talking, smiling or laughing?

EVALUATION OF THE INSTRUMENT

The indicator was tested on large randomly selected samples of industrial workers in Warrington, in the North of England and skilled manual workers and their wives in the South of England.⁸ The five impact categories were relatively independent, with two exceptions. There were statistically significant though weak positive correlations between eating problems and discomfort and between dissatisfaction with dental appearance and communication restrictions.^{1,8} Cushing⁸ reported good test-retest reliability.

All the measures of impact related to some aspects of clinical dental caries status. The number of missing teeth was associated with eating problems. Those with eating problems had on average 2.5 more missing teeth than those without difficulties. Missing teeth was also associated with dissatisfaction with aesthetics. Decay was related to pain, discomfort, communication problems and dissatisfaction with aesthetics. DMFT was related to eating problems but not to any other dimensions of impact. Individuals with eating problems had a higher DMFT score (16.4 compared to 13.3).

The number of impacts was related to two new composite indicators of dental health:^{9,10} 'Functioning teeth' - the aggregate number of filled (otherwise sound) and of sound teeth with no decay, and T-Health (short for tissue health) which is intended to represent the total amount of an individual's sound tooth tissue. These indicators are considered to be more reliable indicators of dental health than the DMFT measure and have advantages as a measure of oral health compared to the DMFT. Those people with no impacts at all and no eating, communication or aesthetic impacts had a greater number of functioning teeth. Functioning teeth was also most frequently correlated with self assessed dental status. As such it is a good reflection of both experience of dental health and clinical criteria.

FINDINGS FROM THE USE OF THE INSTRUMENT

Using SIDD as an indicator of oral health status exposed fairly high levels of dental ill-health. Although severity was not assessed, two-thirds of the sample had one or more impacts related to their teeth when discomfort was included. Social and behavioural factors including sex, social class and dental attendance pattern did not markedly affect people's vulnerability to impacts. Discomfort due to either cold stimuli or food packing was the commonest complaint and one which bore no relationship to any of

the clinical measures of oral health. Whilst a number of clinical indicators were related to the experience of dental problems, the traditional measure of DMFT was not a good discriminator of those who did or did not have dental problems. The main findings are summarised in Table Chapter 4.2.

Table Chapter 4.2: Factors associated with each SIDD impact category

Impact Category	Associated factors
Eating problems	<ul style="list-style-type: none"> • partial denture wearing • 35 years or more age group • higher mean DMFT • higher mean number of missing teeth • lower mean number of functional teeth
Communication problems	<ul style="list-style-type: none"> • in-trouble dental attenders • women • male manual workers • higher mean decay score • lower mean number of functional teeth
Pain and discomfort	<ul style="list-style-type: none"> • higher mean decay score
Aesthetics dissatisfaction	<ul style="list-style-type: none"> • 35 years or more age group • higher mean number of missing teeth
Total Impact Score, excluding discomfort	<ul style="list-style-type: none"> • partial denture wearing • lower mean number of functional teeth

Despite the high prevalence of dental impacts, 66 per cent of the sample regarded their dental health as good or very good; 80 per cent considered their gums to be good or very good. Two-thirds of the sample were satisfied with the state of their teeth, whilst one in five had mixed feelings about their teeth. Very few were dissatisfied with them. Most people were consistent in rating their level of satisfaction with teeth and how they rated their dental health. However there were sizable percentages who were inconsistent; 37 per cent of those rating their dental health as not so good or poor were satisfied and 16 per cent of those rating their dental health as very good or good had mixed feelings or were dissatisfied with their teeth (Table Chapter 4.3).

Table Chapter 4.3: Self-assessed dental status and satisfaction with dental status among 339 dentate subjects

<u>Satisfaction</u>	% of persons		<u>Total</u>
	<u>Very good/ good status</u>	<u>Not so good/ poor status</u>	
Satisfied	84	37	69
Mixed feelings/ dissatisfied	16	63	31
Total	100	100	100

There were very significant differences in the prevalence of SIDDs between the consistent perceived good dental health status/satisfaction and inconsistent good dental health status/dissatisfied groups: 34 per cent compared to 67 per cent. Eating problems accounted for most of the difference. The differences were not as great between those who consistently rated their oral health status and satisfaction low and people who rated their status low but were satisfied with dental status; 74 per cent compared to 68 per cent. Eating problems (37 per cent) and impacts from aesthetics (39 per cent) were the most common impacts in the dissatisfied group. This suggests that impacts of dental disease need to be considered in developing a better understanding of how people regard dental health and what actions they may be prepared to take to promote health. Impacts modify people's levels of satisfaction with their dental state.

Dental impacts rarely affected sleep, leisure, social activities, roles and work. SIDDs manifested themselves mainly as discomfort, dissatisfaction with appearance and eating difficulties.⁸ A few people believed their work performance was affected, or were depressed or embarrassed and felt their general health was affected. Fifteen per cent of skilled manual workers and their wives in the North of England and 24 per cent in the South reported an embarrassing experience relating to their teeth.

DISCUSSION AND EVALUATION

A certain level of dental impacts are acceptable as shown by the fact that people rated their oral health as good and had high levels of satisfaction whilst realizing they needed dental treatment. If impacts do not interfere with normal tasks, and they are not considered as serious and the individual does not define themselves as ill, then they are unlikely to seek care. Minor ailments may be considered as normal.^{11,12} The fact that dental impacts are fairly common does not necessarily imply that they are serious. It is therefore important to place dental impacts in perspective in relation to other problems that people experience.

Many people experienced dental impacts whilst rating their oral health good and were highly satisfied with their teeth. Yet they realized their need for dental treatment. Having a dental impact did increase the probability of lower assessment of status and satisfaction suggesting that impacts do modify views of oral health.

Dental diseases are neither life-threatening nor seriously disabling for the majority of people. Yet their consequences, as impacts, are pervasive in subtle aspects of human experience. Impacts may interfere with enjoying life, engaging in satisfying personal relationships and maintaining positive self-image.

The Social Impacts of Dental Disease (SIDDD) represents an initial attempt to measure dental impacts. It is easy to apply. Further development is needed, particularly in relation to weighting the impacts in order to reflect disability and handicap.

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Chapter 5

ORAL HEALTH AND THE SICKNESS IMPACT PROFILE*

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* The authors of the Sickness Impact Profile are: Marilyn Bergner, Betty Gilson, Ruth A. Bobbitt, William Carter, 1976; revised 1985. Current Inquiries concerning the instrument should be directed to Ms. Lyn Paget, Medical Outcomes Trust, 20 Park Plaza, Suite 1014, Boston, MA, 02116; Phone: 617-426-4046.

BACKGROUND

The Sickness Impact Profile (SIP) represents one of the earliest attempts at developing a multidimensional, behaviorally-based measure of health status^{1,2} and provides the conceptual and methodological foundations for the numerous contemporary measures of health status used in health outcomes research today. The SIP is an instrument intended to measure sickness-related changes in functional abilities perceived and reported by health care users.³ The original authors stated that the SIP may be used for: “1) assessing the health of populations; 2) evaluating medical care programs; 3) evaluating treatment programs; 4) planning and program development; 5) assessing individual patient’s status and response to health care.”³ The SIP is a well-established, comprehensive general health status measure that has been translated into several languages (see below), has been used in the context of countless health conditions, treatment, and health care delivery systems, and has evaluated the health status of adults across age groups, social classes, ethnicities and both sexes.

DEVELOPMENT OF THE INSTRUMENT

The development of the SIP began in the early 1970s by culling items from reports of behavior dysfunction from patients, health professionals, care-givers, and healthy individuals.¹ More than 1000 individuals completed forms reporting dysfunction, leading to 1250 statements of health-related behavioral impacts, which ultimately yielded 312 unique statements. These statements were organized into 14 groups or activity subscales. Respondents were asked to check items that described their functional status and were related to their health status. Scale scores and weights were developed by having 25 judges rate items on degree of dysfunction and then having them rank the items in order of relative severity. Agreement among judges was evaluated through correlational analysis and by analyzing the means and standard deviations of scores among judges.

Items lacking consistent agreement among the judges’ ratings or items characterized by too much variability were deleted and the scale was revised to include 235 items. Using the weights created on the basis of judges’ scores, the scale scores of the SIP were calculated by summing the scale values of items checked, divided by the sum of scale values multiplied by 100.

Subsequent field work evaluating the psychometric properties of the scale (see below for more details)⁴ led to the final version of the SIP which now consists of 136 items and 12 subscales, including

sleep and rest, eating, home management, work, recreation and pastimes, body care and movement, ambulation, mobility, emotional behavior, affective behavior, social interaction, and communication. Total and subscale scores vary from 0 to 100. The instrument can be administered by an interviewer or be self-administered and has been used in interview, mail, and telephone surveys.^{4,5} The full scale takes about 30 minutes to complete.

EVALUATION OF THE INSTRUMENT

From its inception, the SIP has been subjected to critical evaluation of reliability and validity. Initially, Bergner, et al^{4,6} evaluated the reliability and validity of their instrument in a sample of patients with three health conditions, hyperthyroidism, rheumatoid arthritis and hip replacements. Test-retest reliability ($r=0.92$) and internal consistency ($r=0.94$) were high. Convergent and discriminant validity using multitrait-multimethod techniques was acceptable; criterion validity using clinical assessments as the criterion was moderate to high.

DeBruin and colleagues⁷ more recently assessed the SIP for validity, reliability and responsiveness in the numerous studies using the SIP since its introduction in the 1970s. The most recent user's manual also provides comprehensive information on the validity, reliability and responsiveness of the SIP.⁸ The consensus in the literature is that the SIP has satisfactory face validity, but a limitation of the SIP in content is the lack of a pain scale. Although no gold standard exists for the measurement of health or functional status, efforts have been made to assess the criterion validity of the SIP, first by comparing SIP scores to clinical judgments,⁶ then by comparing the SIP to clinical tests⁹ and to measures of self-reported health status or functional outcomes in health surveys or clinical trials.¹⁰⁻¹⁶ Most authors conclude that the SIP has good criterion validity particularly when measuring the broader construct of health status or quality of life.

DeBruin and colleagues⁷ indicate that the SIP has good construct and discriminant validity as shown by its ability to differentiate among groups of illnesses and that the subscales of the SIP are correlated with different dimensions of criterion measures. However, few data are available on factor analyses or other methodologies to evaluate the internal structure of the SIP (see below).

The responsiveness of the SIP to temporal changes in health status has not received as much attention as other psychometric properties of the scale. As a result, assessments of the scale's responsiveness are inconclusive with some investigators reporting

good responsiveness¹⁷⁻¹⁹ and others²⁰ finding no clear evidence, or poor responsiveness.²¹ There are no general guidelines or parameters to indicate clinically meaningful changes in the SIP over time.

Deyo's²⁰ assessment indicates that the SIP is acceptable to respondents, although it is perceived as being lengthy. Evidence suggests that the SIP is not sensitive to gender differences,²² but responses may be affected by age, education and employment status^{7,8}.

FINDINGS FROM THE USE OF THE INSTRUMENT

The SIP has been used in the context of many health conditions, including cardiovascular, neurologic, internal, pain and musculoskeletal disorders,⁸ as well as in assessing changes in functional status in the elderly but has not been applied frequently in studies of oral health. Two studies of oral cancer and quality of life and functional status^{23,24} have employed the SIP with good results. The SIP was sensitive to cancer stage, and was responsive to changes over time and to treatment type. A study of patients presenting for temporomandibular disorders (TMD), periodontal disease, denture repair and regular check-ups attempted to assess the utility of using the SIP to assess oral health status.²⁵⁻²⁷ The study showed that the SIP was useful to evaluate functional status where the impacts of conditions are expected to be high, as in TMD, but that that SIP may have more limited application in assessing general oral health status because of lack of sensitivity to oral-functional status.

ALTERNATE FORMS

The Roland Scale²⁸ is a well-known short form of the SIP developed to assess disability associated with low back pain. The scale consists of 24 items from the SIP; scores are calculated by assigning one point for each item checked. The Roland scales has been used subsequently in other spinal and musculoskeletal conditions.^{15,29,30}

The SIP has been translated into many other languages, including French, German, Danish, Dutch, Spanish and Swedish. A Chicano version was developed by the original authors³¹ but Deyo³² found difficulty in applying this version to Mexican-Americans because of cultural differences. DeBruin and co-workers³³ have developed a shortened version of the SIP in Dutch. They conducted a factor analysis to identify underlying dimensions of the SIP using data from several studies including ten diagnostic groups and 2,527

respondents. The analysis described six dimensions based on 68 items. The dimensions are: somatic autonomy (17 items), mobility control (12 items), psychic autonomy and communication (11 items), social behavior (12 items), emotional stability (6 items) and mobility range (10 items). Scores are calculated by adding the number of items checked. Preliminary analysis suggests that this shortened version (SIP68) is robust across diagnostic groups and corresponds well the total SIP. A subsequent study of the SIP68 in sample of arthritis patients (n=51) showed that the shortened version had high test-retest reliability as well as high internal reliability.³⁴

Sullivan and colleagues³⁵ also have worked to shorten the SIP in Swedish to a 64-item core health status questionnaire for use in rheumatoid arthritis patients. Their shortened version demonstrated good internal reliability and discriminant and predictive validity.

DISCUSSION AND EVALUATION

The SIP has been used in many chronic and acute health problems, as well as in numerous populations, to assess health status. Because of its longevity, the psychometric properties of the SIP are well-known and the numerous studies using the SIP provide a wealth of data on comparison groups. Using the SIP in studies of oral health status has the advantages of a well-established instrument and oral health is then placed within the broader conceptual framework of health status. The major limitations of the SIP are the length of the instrument and the apparent lack of sensitivity to oral-facial impacts on functional status.

Recent efforts have been aimed at developing a shorter version of the SIP for general use, but even these measures consist of over 60 items, which is still a rather long scale to complete. The SIP appears even more cumbersome when compared to other well-established general measures of health status such as the SF-36 or the SF-12 which are much shorter and easier to complete. The lengthiness of the SIP might be weighed against the information gained from the scale. However, the SIP may not be sensitive to the more subtle and briefer impacts of oral health problems on general health status. The few available data indicate that the SIP can effectively assess the impacts of more serious oral disorders, but may not be able to assess the effects of minor oral health problems. More information is needed to adequately evaluate the usefulness of the SIP in the context of oral health.

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Chapter 6

DENTAL HEALTH QUESTIONS FROM THE RAND HEALTH INSURANCE STUDY

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BACKGROUND

Health status measurement was advanced in the 1980's with the work of Ware, Brook, Davies-Avery and colleagues^{1,2} as part of the Rand Health Insurance Study (HIS). The HIS was a large-scale social experiment in which families were randomly assigned to one of several insurance plans that differed in patient cost-sharing requirements for dental and medical care. The main purpose of the experiment was to assess the effects of cost-sharing on patient health status, quality of care, utilization, and cost of services. Self-reported measures of physical, mental, and social health, and general health perceptions were developed and evaluated. HIS participants were also asked three dental items intended to quantify the amount of pain, worry, and concern with social interactions (i.e., avoidance of conversation) attributed to problems with teeth or gums. The three impact questions were part of a standard set of questions that appeared repeatedly in the Mental Health Questionnaire of the HIS. They were not specifically constructed to measure the symptoms or adverse consequences of dental disease (or of any other particular condition) but rather were intended to facilitate comparisons of similar kinds of impact among several diseases and conditions. However, all three questions are directly related to major consequences of dental disease: pain, worry, and reduced social interactions.

The three dental items were written to represent factors contributing to the adverse effects of dental disease on individuals. First, depending on the severity of their condition, persons with large carious lesions and periodontal disease are expected to experience increasing levels of pain. In particular, acute pain is expected to be associated with pulpitis and periodontal abscesses, and chronic pain with tooth mobility. Other symptoms associated with oral diseases (e.g., bleeding gums) may also cause worry and anxiety. In addition, loss of multiple teeth may cause discomfort because of difficulty in chewing. Finally, caries and periodontal disease and subsequent loss of teeth may cause concern with appearance, lower self-esteem, and negative effects on social activities and personal interactions.³

Responses to the pain and worry questions range from "not at all" (or equivalent wording) to "a great deal." Responses to the question about conversation avoidance range from "none of the time" to "most of the time" (Table Chapter 6.1). The Rand investigators³ also constructed a composite measure called "any impact." A person was assigned a positive score for "any impact" if he or she gave a response other than "none" to at least one of the three questions. In a subsequent analysis, Gooch and Dolan⁴

constructed a three-item index from the questions used in the RAND study. The index was used as a summary measure of the psychosocial impact of oral conditions on HIS participants.

Table Chapter 6.1: Dental health questions from the Rand Health Insurance Study*

1. DURING THE PAST 3 MONTHS, HOW MUCH PAIN HAVE YOUR GUMS OR TEETH CAUSED YOU?

(Circle one)

A great deal of pain1
 Some pain2
 A little pain3
 No pain at all.....4

2. DURING THE PAST 3 MONTHS, HOW MUCH HAVE YOUR TEETH OR GUMS WORRIED OR CONCERNED YOU?

(Circle one)

A great deal1
 Somewhat2
 A little.....3
 Not at all.....4

3. DURING THE PAST 3 MONTHS, HOW MUCH OF THE TIME HAVE PROBLEMS WITH THE WAY YOUR TEETH OR GUMS LOOK CAUSED YOU TO AVOID CONVERSATION WITH PEOPLE?

(Circle one)

Most of the time1
 Some of the time2
 A little of the time.....3
 None of the time4

* The index score is a simple sum of the three response values, with a possible range of 3 to 12.

DEVELOPMENT OF THE INSTRUMENT

The properties of the index were analyzed using cross-sectional HIS enrollment data collected between November 1975 and January 1977. Except for certain intentional exclusions, the original HIS sample was representative of the United States population

under 62 years of age in the sites studied. The sites were chosen to represent all census regions, to vary by city size, to include rural areas in the North and South, and to vary in the degree of demand on the ambulatory care delivery system. The experiment excluded families with household heads older than 61 years, families with annual incomes over \$56,300 (1984 dollars), those eligible for the Medicare program, the institutionalized, the military and their dependents, and veterans with service-connected disabilities.

Gooch and Dolan⁴ analyzed 1,658 HIS participants who were continuously insured in the experiment for at least three years, resided in five geographic sites (Seattle, Washington; Fitchburg and Franklin County, Massachusetts; Charleston and Georgetown County, South Carolina), were 18-61 years of age, were dentate with at least one natural tooth, and received a dental clinical examination upon enrollment. Depending on the HIS site, a random sample of 50 to 70 percent of participants received a dental examination at enrollment.

Gooch and Dolan investigated the properties of the three-item index, the relationship of the index to sociodemographic variables, dentist-assessed clinical indicators, and the respondent's report of a toothache.⁴ They also examined patterns of association among and between items of the physical, mental, social, and general health indices used in the HIS and the three dental items.⁵

EVALUATION OF THE INSTRUMENT

The distribution of responses for the three dental items was highly skewed, with 72 percent reporting no pain, 61 percent reporting no worry, and 89 percent reporting no conversation avoidance.⁴ Inter-item correlation, item-sum correlation, and Cronbach's alpha coefficient were used to determine whether these three items could be combined into a dental health index. Results of the analysis indicated that a three-item scale of dental impact was statistically appropriate. Items of pain and worry were highly correlated at 0.61. Lower correlations of 0.28 and 0.40, respectively, were observed between the item on conversation avoidance and those of pain and worry. The mean inter-item correlation was 0.43. Item-sum correlations ranged from 0.39 for conversation avoidance to 0.65 for worry. The Cronbach's alpha coefficient for internal consistency and reliability of the three-item scale is 0.69, which is considered acceptable for group comparison.

HIS data were also used in an exploratory analyses to examine the associations of self-reported dental health with other health measures.⁵ Patterns of association among and between items of the physical, mental, social, and general health indices and the three

dental items were tested using principal component analyses. Findings suggest that dental health represents a separate dimension of health that is not fully accounted for by other health measures. However, while dental health may be considered an independent health construct, the dental health index was weakly but statistically significantly associated with the general health perceptions index, and to a lesser extent, to the mental health index and the two physical health indices.

FINDINGS FROM THE USE OF THE INSTRUMENT

Scores for the three-item index ranged from 3 to 12, with 12 indicating no self-reported impact from dental problems. The scale scores, like the scores on the individual items, remained positively skewed with 54 percent of respondents reporting no impact. Seventeen percent of adults had a score of 11, indicating that one of the three questions of pain, worry, or conversation avoidance, "a little" impact was recorded. Finally, 29 percent of respondents had index scores of 10 or less, suggesting that "some" impact had been experienced by the respondent or that there had been "a little" impact in at least two items. The sample mean of the index was 10.9 (sd=1.6).

The index score was notably lower in the presence of a toothache, increasing numbers of decayed teeth, and worsening periodontal health. Weaker, but statistically significant associations were observed for sociodemographic factors. Nonwhites and those persons with lower educational and income levels reported more impact. In regression analysis with the index score as the dependent variable, the respondent's report of a toothache and number of decayed teeth were the most important explanatory factors.

DISCUSSION AND EVALUATION

This research focused on three dental health questions that were asked of participants in the Rand Health Insurance Study. Although it is unlikely that three items will comprehensively assess the psychological and social impact of dental conditions, the questions addressed major consequences of dental disease, namely pain and distress, worry or concern, and reduced social interactions. The finding that self-reported impact of oral disease increases as clinically observed disease levels increases supports the validity of the measure.

A major strength of this research is the richness of the data set available for the sample of HIS participants. Because several

dimensions of a participant's health were evaluated as part of the HIS, we were able to confirm that dental health represents an independent health construct, yet is associated with other health dimensions. This research is limited in that it considered only cross-sectional data, underrepresented aged persons (over 62 years), and used limited measures of self-reported dental health. Improved self-reported measures of oral health, studied in association with other general health measures would allow us to better understand a patient's perceptions of oral health, particularly in relation to other health perceptions. In addition, a valid and reliable multidimensional oral health measure would be valuable as a cost-effective method of epidemiological data collection, as well as a tool for evaluating the effectiveness of oral health interventions.

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Chapter 7

THE GENERAL ORAL HEALTH ASSESSMENT INDEX

(The Geriatric Oral Health Assessment Index)

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BACKGROUND

The Geriatric Oral Health Assessment Index (GOHAI) measures patient-reported oral functional problems in a simple to administer manner. It is also designed to estimate the degree of psychosocial impacts associated with oral diseases, and is being tested as an outcome measure to evaluate the effectiveness of dental treatment. The measure, based on a patient-centered definition of oral health for older adults, includes items regarding freedom from pain and infection, and the patient's ability to continue in his or her desired social roles. This patient-centered definition of health diverges from disease-centered epidemiological measures of health (presence or absence of disease) traditionally used in dentistry.

DEVELOPMENT OF THE INSTRUMENT

Following a review of the literature and consultation with health care providers and patients, a pilot instrument of 36 items was developed. A summary of the development will be presented here.¹ Instrument development was based on previous work in health status measurement, founded in reviews of the literature on oral health and disease impacts and existing questionnaires dealing with oral functional status, patient satisfaction, oral symptoms, and measures of self-esteem and socialization. Ideas for additional items were provided through consultation with health care providers and qualitative research with people attending a senior center in Los Angeles and a Veterans Administration hospital dental clinic.

Items were selected to reflect problems affecting people in three dimensions: 1) physical function, including eating, speech and swallowing; 2) psychosocial function, including worry or concern about oral health, dissatisfaction with appearance, self-consciousness about oral health, and avoidance of social contacts because of oral problems; and 3) pain or discomfort, including the use of medication to relieve pain or discomfort from the mouth.

Instrument Pretest: The GOHAI was initially tested on a convenience sample of 87 older adults. A revised instrument was then administered to a sample of 1911 Medicare recipients in Los Angeles County. Enrollment criteria for the Medicare study were being at least 65 years of age, a Medicare participant, English speaking, having a telephone, and having no terminal or dementing illness. Initial testing of the instrument was conducted on 1755 of these subjects.¹

The original pretest instrument contained 36 items. The respondent was asked to estimate the frequency of problems using a five point Likert scale (always [5] to never [1]). Responses to the original 36 items were evaluated for selection of final instrument. Frequency distributions and correlations between items were evaluated; the scale's internal consistency (Cronbach's alpha) was examined with and without each item. A final instrument, containing 12 items chosen to represent three hypothesized dimensions, exhibited the best distribution of responses and maximized the Cronbach's alpha for the instrument. The items, chosen, which were worded both positively and negatively, are listed in Table Chapter 7.1. A six point Likert scale (always [5], very often [4], often [3], sometimes [2], seldom [1], or never [0]) was chosen for the final Medicare instrument.

Instrument scoring: Before calculating the GOHAI score the responses to nine items, (limit food due to dental problems, trouble biting and chewing, used medication, sensitive to temperature, nervous due to teeth, uncomfortable eating with people, prevented from speaking, worried about teeth, and limited contacts with people) have scoring reversed. This allows final high scores for the GOHAI to represent more positive oral health. For subjects with missing data, if 3 or more items are missing, the subject's data are not used. For subjects with one or two items with missing data, the item mean is substituted for the missing value. The GOHAI score is determined by summing the final score of each of the 12 items. GOHAI scores range from 0 to 60.

EVALUATION OF THE INSTRUMENT

The properties of the measure were evaluated for reliability and validity using the initial sample. Internal consistency, as measured by the Cronbach's alpha, measures the extent to which items in the same scale are interrelated and represents a measure of reliability. Pearson's product-moment correlations were used to measure the inter-item and item-scale correlations. Construct validity was assessed as proposed by investigators in the Rand Health Insurance Experiment,² and involved studies of the association between the GOHAI score and other variables known to be associated with oral health status. Principal components factor analysis of the GOHAI items demonstrated one factor.

FINDINGS FROM THE USE OF THE INSTRUMENT

Initial findings demonstrated acceptable reliability and validity of the instrument, with a Cronbach's alpha of 0.79 and positive associations with a younger age, being male, white, having higher

education, and higher income.¹ Clinical findings included positive associations with a greater number of teeth, not wearing a denture, and having fewer teeth with mobility, root caries, and coronal caries.

Table Chapter 7.1 shows the results of analysis on the Medicare sample. Using the first year of data, GOHAI mean scores and the item mean scores were compared by the individual's dentate status for the 680 subjects with clinical examination data. Results confirmed that people with natural teeth had a higher GOHAI score. Considering individual items, people with natural teeth demonstrated significantly fewer problems with limiting their food choices, trouble biting and chewing or eating without discomfort, and sensitivity to temperature. They also reported fewer psychosocial problems as reflected in limiting contacts with people and uncomfortable eating with people. There was no difference noted between the two groups in feeling happy with their appearance, worrying about their teeth or speaking.

Table Chapter 7.1: Comparison of GOHAI mean scores* (sd) and item means†, by dentition status among subjects participating in the clinical examination for year 1 of the medicare screening and health promotion trial

	Dentate (n=609)	Edentulous (n=71)
GOHAI (mean, sd)	53.1 (7.6)	50.6 (8.9) ‡
*How often did you limit the kinds or amounts of food you eat because of problems with your teeth or dentures?	0.52	0.89 ‡
*How often did you have trouble biting or chewing any kinds of food, such as firm meat or apples?	0.70	1.81 ‡
How often were you able to swallow comfortably?	4.70	4.66
*How often have your teeth or dentures prevented you from speaking the way you wanted?	0.26	0.45
How often were you able to eat anything without feeling discomfort?	3.92	3.23 ‡
*How often did you limit contacts with people because of the condition of your teeth or dentures?	0.08	0.25 ‡
How often were you pleased or happy with the looks of your teeth and gums, or dentures?	3.48	3.54
*How often did you use medication to relieve pain or discomfort from around your mouth?	0.31	0.44
*How often were you worried or concerned about the problems with your teeth, gums or dentures?	0.74	0.80
*How often did you feel nervous or self-conscious because of problems with your teeth, gums or dentures?	0.44	0.69
*How often did you feel uncomfortable eating in front of people because of problems with you teeth or dentures?	0.25	0.52 ‡
*How often were your teeth or gums sensitive to hot, cold or sweets?	0.71	0.30 ‡

* GOHAI mean scores computed after reversal of response categories for questions marked with an asterisk

† Item mean scores for all individual questions computed using 6 response categories coded 0=Never to 5=Always

‡ P < 0.05

Several studies have been conducted since the original study using the GOHAI. The number of response categories on the Likert-type scale chosen in recent studies has not corresponded with the original six categories. Most researchers have chosen five categories although one used three categories (Always, Sometimes, Never). Therefore, a direct comparison of these findings could not be made with the original mean GOHAI score. In order to facilitate

comparison between the original Medicare sample and subsequent studies an analysis was conducted using the entire 1911 Medicare subjects. The data for the 12 items was rescored, then the GOHAI was recalculated. The six response categories were rescored on a 1 to 5 metric (GOHAI range 12-60) and a 1 to 3 metric (GOHAI range 12-36). The rescored is shown in Table Chapter 7.2.

Table Chapter 7.2: Alternative scoring used in studies with the GOHAI

	Always	Very Often	Often	Some-times	Seldom	Never
Original metric	5	4	3	2	1	0
Rescoring (5 categories)	5	4.5	4	3	2	1
Rescoring (3 categories)	3	3	3	2	2	1

Table Chapter 7.3 shows the rescored GOHAI means and standard deviations. In addition, recent uses of the GOHAI have included diverse groups, including samples with older subjects and with mixed ages. Studies have been conducted using the GOHAI as an epidemiologic tool to measure oral problems. It has also been used as an outcome measure in several studies. Most of these studies are still in progress, therefore published data are primarily in abstract form. Table Chapter 7.3 lists other studies utilizing the GOHAI, as well as the type of use, the number of response categories and the size of the sample.

Dolan et al.³ used the GOHAI as both an epidemiologic and an outcome measure in an inhome health promotion study for older adults (Table Chapter 7.3). The purpose of the study was to evaluate the effectiveness of a geriatric nurse practitioner intervention for a sample of 331 seniors, 90% of whom were white. The mean GOHAI score was 53.1 (sd=7.2). As part of a study of the effectiveness of the FDA Guidelines to order dental radiographs for new patients, Marcus, Atchison and Coulter administered the GOHAI to a group of 299 UCLA dental school clinic patients of varying ages.⁴ The patients had a mean age of 38.7 and were of mixed ethnic groups. The mean GOHAI was 47.0 (sd=8.34). The predictors of the GOHAI were determined. Using multiple regression analysis, three variables, pain history, the Oral Health Status Index⁵ (a comprehensive assessment of a patient's clinical oral health), and number of teeth with large caries were significant predictors of the GOHAI score.

Table Chapter 7.3: Comparison of GOHAI findings in a variety of settings and samples

Author	Sample size	Mean age	No. (range) of response categories	mean	GOHAI range	sd	Refer to reference
<u>USE IN EPIDEMIOLOGIC MEASUREMENT</u>							
Atchison and Dolan	1,755	74	6 (0-5)	52.5	5-60	7.8	#1
rescored	1,911		5 (1-5)	53.8	16-60	6.7	*
rescored	1,911		3 (1-3)	34.3	16-36	2.5	*
Dolan et al	331	81	5 (1-5)	53.1	21-60	7.2	#3
Marcus et al	299	39	5 (1-5)	47.1	14-60	8.3	#4
Atchison and Der-Martirosian	280	39	5 (1-5)	46.8	21-60	8.6	#6
Kressin et al	957	63	3 (1-3)	31.2	17-36	4.4	#7
Calabrese et al - dentist interview	50	81	5 (1-5)	48.2		7.2	#8
physician interview	50	51	5 (1-5)	48.6		9.3	#8
<u>USE AS OUTCOME MEASURE</u>							
Dolan	200		5 (1-5)	52.1	22-60	8.9	#9
Tourville et al control	353	41	5 (1-5)	54.1	12-60	4.9	#10
experimental	406	41	5 (1-5)	53.6	12-60	5.4	#10
Weyant	111	75	5 (1-5)	46.1	30-52	3.7	#11

* Unpublished

The GOHAI was administered to an all-age sample of low income, Hispanic individuals in Los Angeles as part of the UCLA Minority Oral Health Research Center.⁶ Interviews were offered in the subject's choice of Spanish or English by bilingual interviewers. The sample included 280 adult subjects with a mean age of 39 years and was 67% female (Table Chapter 7.3). The GOHAI demonstrated acceptable reliability with a Cronbach's alpha of 0.83. The mean GOHAI score was 44.8. Using Principal components factor analysis, the GOHAI demonstrated 3 factors: a physical health component that included trouble biting and chewing, discomfort eating, swallowing, limitations in food choices, and sensitivity to temperature); social oral health (limitations and discomfort with social contacts, appearance, and speaking problems) and worry about oral health (worry, self-consciousness and use of pain medication). The GOHAI was also offered to a low income sample of African American subjects from South Central

Los Angeles and data analysis is in process. Kressin et al. administered a three category response version of the GOHAI to 957 men who are part of the Veterans Health Study.⁷ Their mean age was 63 and 92% were white. The mean GOHAI was 31.2 and ranged from 17 to 36. Calabrese et al. compared the mean GOHAI score and assessment made by a dentist to that of a physician.⁸ Results indicated good test-retest reliability with agreement of the GOHAI score between the dentist and physician ($r=0.61$, $p=0.002$).

Using the GOHAI as an outcome measure, Dolan et al. have proposed to test the effectiveness of an oral health promotion program for 200 senior residents of an apartment complex in Florida.⁹ Participants were offered subsidized services and two years later, 119 subjects were re-interviewed and examined. The mean GOHAI scores increased 2.3 points over a baseline score of 52.3 ($sd=9.0$). Tourville, et al. used the GOHAI as a self-reported measure of effectiveness of dental care in a large dental plan.¹⁰ The mean GOHAI score for the controls ($n=353$) was 54.1 and for the experimentals ($n=406$) was 53.6. Weyant is currently using the GOHAI in a study of osteoporosis.¹¹ Based on the initial 111 patients with a mean age of 75, the GOHAI scores range from 30-52 and have a mean of 46.1.

ALTERNATE FORMS

The GOHAI has been used with a variety of subjects, using three sets of response categories (three, five, and six categories), as described. The GOHAI has been translated into Spanish and Korean. The variability of the distribution and reliability were acceptable with all three choices of response categories^{1,7,8} and in Spanish and English.

Although all three response categories appear to provide acceptable information, the use of five response categories is advised to allow the researcher or clinician to judge which problem occurs with greater frequency when examining individual items.

DISCUSSION AND EVALUATION

The findings presented begin to give an idea of the type of results one can expect when using the GOHAI in a study. The GOHAI has been utilized in a variety of studies and it appears to provide information to reflect its original intent, that is, it provides summaries of people's self reported oral functional problems. GOHAI scores are related to both clinical measures of oral health and the subject's socioeconomic status. Further, the GOHAI has been tested on a variety of samples of subjects, older and younger,

white, African American and Hispanic. Reliability testing suggests that it is acceptable in all samples tested thus far. Further, Calabrese et al. evaluated the sensitivity, specificity and positive predictive value of using cut points of the GOHAI as a screening tool administered by non-dental personnel.⁸ Finally, preliminary tests of the sensitivity of the GOHAI as an outcome measure indicates that it is useful for evaluating the effectiveness of dental treatment. Inasmuch as the GOHAI appears to have acceptable reliability and validity in all ages, we would recommend that the name of the GOHAI be changed to the **General** Oral Health Assessment Index (GOHAI).

Several questions remain which provide direction for future research. It might be useful to try to expand the original 12 items of the GOHAI to reflect more of the elements of quality of life, opportunity and resilience, as described by Patrick.¹² Further research is also indicated to confirm the GOHAI's preliminary acceptable sensitivity as an outcome measure in evaluating dental treatment for different conditions. Another question which remains is how perceptions of health change as people age. We note that the samples of seniors have relatively high GOHAI scores. Yet, within the Medicare sample,¹ younger people reported fewer oral problems, resulting in higher GOHAI scores. Further, older individuals have greater accumulated clinical oral health problems. Thus, we see a paradox between the problems reported and the clinical history of oral needs. A better understanding of these issues will assist us in gaining knowledge regarding how oral health care improves an individual's quality of life.

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Chapter 8

THE DENTAL IMPACT PROFILE

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BACKGROUND

Research on how teeth and the mouth influence people's daily lives remains limited. This instrument was developed to answer a question; that is "how much do teeth and the mouth matter in people's lives?" If teeth and the mouth are seen as salient factors in life, do different population groups hold different beliefs in this regard? Furthermore, what is the relationship, if any, between culture, ethnicity and the perception of the value and impacts of oral structures?

Research to determine how health problems influence life quality, impairment, disability and function suggest that the presence or absence of health complaints alone is an insufficient explanation for subjective health status evaluation. The concept of sickness impact was based upon the thesis that similar conditions will produce different evaluations in different subjects and that health and social values influence the interpretation of health status.

Generally sickness impact measures do not seek to establish how healthy function of the body or parts of the body may affect the respondent's life, however the Dental Impact Profile seeks to do that for the mouth. It asks the question: how do natural teeth or dentures positively and negatively affect social, psychological and biological functions and life quality?

DEVELOPMENT OF THE INSTRUMENT

Goal. The Dental Impact Profile was constructed to indicate how life quality has been affected, detracted from or enhanced by, oral health and oral structures. It is an entirely self-report instrument that can serve as an indicator of how important or salient teeth are to an individual or a population. It was hypothesized that this measure would be cohort dependent and a reflection of the values and experiences of various cultural, ethnic and racial groups. It can be understood as a measure of cultural influences on the value afforded to teeth or dentures.

Qualitative Interviews. The Dental Impact Profile was developed by questioning and interviewing dentists, social scientists and consumers in a qualitative manner about the ways they held teeth or dentures to matter, or to make a difference in day to day life. The original list of thirty-seven items was then pre-tested among elderly and college age respondents and was revised to twenty-five items. Items that mattered to less than half of the pre-test sample groups were dropped from the scale. Self-administered and interview formats were tested, as were different rating scales, with

participants expressing preference for interviewer administration and a single, three-point response format.

Community-based Pilot Testing. The Dental Impact Profile was pilot tested through community administration to aged persons in nutrition sites and in shopping malls. The impact of teeth or dentures on a person's life was hypothesized to be age dependent and this pilot study was conducted to examine whether two groups of like-age persons (age greater than 60 years) with different social characteristics, shared perceptions about how teeth matter and to document their perceptions. The pilot nutrition site sample included 66 low income respondents drawn from four community-based lunch and recreation centers in Orange and Durham Counties, North Carolina. Trained interviewers were used. The pilot shopping mall sample included 73 respondents, ages 60 years and older who agreed to be interviewed in a semi-public context. Dental student interviewers were utilized in 3 shopping malls in Orange and Durham Counties, North Carolina. The pilot samples allowed for an examination of whether race, age and education influenced Dental Impact Profile responses.

Description of the Dental Impact Profile. Twenty-five Dental Impact Profile (DIP) items have been placed in non-apparent order and respondents are offered three ordinal response choices (good effect, bad effect, no effect) to a query about whether teeth or dentures have had an effect on various aspects of life (Table Chapter 8.1). A response of "good effect" was seen as likely to be most socially acceptable and the potential for response bias in the positive direction exists. While "good effect" and "bad effect" response categories have meaning independently, they may be combined in the estimation of dental impact. Dental impact is noted for an item if teeth are seen to have an effect on that aspect of life, whether that effect is positive or negative. Responses of "no effect" are seen as indication of no dental impact.

Table Chapter 8.1: The Dental Impact Profile

INSTRUCTIONS: As part of this study, I will be asking you to think about how your teeth affect your life. Answer only what you feel and have experienced, not what you think is the right answer. There is no right or wrong answer to these questions.

DO YOU THINK YOUR TEETH OR DENTURES HAVE A GOOD (POSITIVE) EFFECT, A BAD (NEGATIVE) EFFECT OR NO EFFECT ON YOUR: _____	Response codes: 1. Good Effect 2. Bad Effect 3. No Effect
1. feeling comfortable	_____
2. having confidence around others	_____
3. eating	_____
4. tasting	_____
5. living a long life	_____
6. chewing and biting	_____
7. appearance to other people (how you look to others)	_____
8. moods	_____
9. kissing	_____
10. general health	_____
11. attendance at activities	_____
12. success at work	_____
13. appetite	_____
14. smiling and laughing	_____
15. having sex appeal	_____
16. facial appearance (how your face looks to you)	_____
17. social life	_____
18. enjoyment of eating	_____
19. speech	_____
20. breath	_____
21. foods you chose to eat	_____
22. enjoyment of life	_____
23. romantic relationships	_____
24. general happiness	_____
25. weight	_____

Subscale development. Psychometric scale refinement was done in collaboration with sociologist, Cheryl A. Segrist, Ph.D. This work sought to define subscales using pilot data from the community-based sites. Factor analyses were run and four subscales were defined. The four subscales and component items were:

1. Eating Subscale: Eating, Chewing and Biting, Enjoyment of eating, Food choice, Tasting
2. Health/Well-Being Subscale: Feeling comfortable, Enjoyment of life, General happiness, General health, Appetite, Weight, Living a long life
3. Social Relations Subscale: Facial appearance to other people, Facial appearance (to self), Smiling and laughing, Moods, Speech, Breath, Confidence around others, Attendance at activities, Success at work
4. Romance Subscale: Social Life, Romantic relationships, Having sex appeal, Kissing,

Four subscale scores and a total dental impact profile score may be calculated. Though subscales have been defined, most of the use of this instrument has been based on total scores, not on subscales.

Scoring: Scores expressed as percents can be computed for each of the four subscales and for the complete Dental Impact Profile. Impact scores are calculated as the proportion of positive plus negative responses among all items answered in the scale or subscale. The percentage of separate positive or negative effects may be calculated.

EVALUATION OF THE INSTRUMENT

Cronbach alpha coefficients were calculated to estimate the reliability and internal consistency for each subscale and the overall score. These coefficients for the two pilot samples are shown in Table Chapter 8.2. The alpha coefficients for the relationship of the subscale items to the subscale scores varied between 0.68-0.86 suggesting a reliably high degree of internal consistency and correlation of each question or item with the subscale.

Table Chapter 8.2: Internal reliability (Cronbach's alpha) in two study samples

Subscale:	Nutrition site (n=66)	Mall (n=73)
1) Eating	0.68	0.77
2) Health/well-being	0.76	0.87
3) Social Relations	0.86	0.79
4) Romance	0.83	0.74

When the total Dental Impact Profile score for the combined 25 items (from all the 4 subscales) was examined for the relationship between the individual items and the total score the Cronbach alpha was 0.93 in the pilot studies (both samples) and 0.85 in the population-based study. Test-retest reliability has not been studied.

Content validity was considered in the qualitative and pre-test phases of scale development. The format and content of the scale were judged to be satisfactory by interviewers and subjects. The ease with which subjects understood and used this scale offers some evidence of its face validity. The three point response format was chosen over more complex response patterns and this choice was verified in the pre-test phase.

FINDINGS FROM THE USE OF THE INSTRUMENT

In a study of a home dwelling population conducted with Ronald J. Hunt,¹ older adults most commonly saw their teeth or dentures as positively enhancing, as opposed to detracting from, aspects of their daily lives. The dentition was often seen as affecting appearance and eating, with health, romantic and social effects being less common. Health beliefs and values about the impact of teeth were seen as possibly helping to guide how dental services might be marketed and how older patients could be motivated towards improved dental health.

The data for this study were from the Piedmont 65+ Dental Study, which is a dental substudy of the Piedmont Health Study of the Elderly. The parent study was a longitudinal study of the health status of a random stratified cluster sample of over 4,000 people aged 65 and older and living in five contiguous counties in North Carolina. The dental substudy, which also is longitudinal in design, oversampled blacks and dentate people in a stratified design. The final sample included 818 dentate and 200 edentulous

subjects randomly selected (66% response rate) from the parent study.

This investigation of the perceived impact of teeth and dentures used data from 448 dentate and 131 edentulous blacks, 362 dentate and 67 edentulous whites, and 8 dentate and 2 edentulous people who were members of other races who participated in the baseline interviews (N=1018) of the dental substudy.

The participants were interviewed and examined in their homes by one of five trained dentist-interviewers. At the discretion of the interviewer, all the items could be omitted from the interview if the subject was frail or otherwise had difficulty understanding the items. Those subjects (N=110) were excluded from the analyses. In addition, individual items could be scored "no response" or "don't know" if the subject had difficulty with that item. Those responses were excluded from the analyses.

Frequency tables were used to classify the participants according to perceived effect of teeth or dentures on each of the impact items. All proportions were adjusted statistically to reflect the actual distribution in the population sampled.

The items most commonly (in greater than 50% of respondents) affected by teeth or dentures in either good or bad ways were: appearance to others, facial appearance, enjoyment of eating, chewing and biting, eating, and feeling comfortable. Thirty-eight percent of elderly participants held a connection between teeth (or dentures) and general health. On the other hand, more than three fourths of them did not think teeth or dentures had an effect on their : moods, weight, appetite, romantic relationships, success at work, attendance at activities, or kissing.

Table Chapter 8.3 demonstrates the most common good or positive effects found. Teeth or dentures were most commonly seen as enhancing appearance to others and to oneself, eating and its enjoyment, and chewing or biting. Older adults commonly saw their teeth or dentures as enhancing their comfort, their likelihood of living a long life, their confidence, their speech and their enjoyment of life.

Table Chapter 8.3: The "good effects" of teeth or dentures in older adults rank ordered by positive effect

Perceived Effect of Teeth or Dentures on:	N	Percent of People by Type of Effect		
		Good	Bad	None
Appearance to others (how you look to others)	845	46	15	40
Facial appearance (how your face looks to you)	880	44	13	43
Enjoyment of eating	902	43	19	38
Chewing and biting	903	42	30	28
Eating	908	42	25	33
Feeling comfortable	899	38	19	44
Living a long life	761	36	4	60
Having confidence	888	32	10	58
Speech	890	32	12	56
Enjoyment of life	893	31	5	63
General health	866	31	7	62
Smiling and laughing	896	31	11	58
Foods you chose to eat	901	28	21	51
General happiness	891	26	3	71
Social life	883	24	4	73
Having sex appeal	766	21	5	75
Attendance at activities	884	19	2	79
Success at work	698	19	1	80
Kissing	782	18	4	78
Romantic relationships	754	17	3	81
Tasting	885	16	11	74
Appetite	896	14	5	81
Breath	869	14	17	69
Weight	861	9	6	85
Moods	879	9	4	88

It should be noted that on all items, except for one (breath), responses were more positive than negative. Respondents saw teeth and dentures as more likely to enhance their lives than to detract from their lives.

Compared to the largely positive responses, fewer people indicated that their teeth or dentures were having negative impacts. Twelve scale items had negative responses in greater than ten percent of the respondents (Table Chapter 8.4). It is noteworthy that some

items that had a high frequency of positive responses, also had a high frequency of negative responses. Enjoyment of eating, chewing and biting, and eating were items that were among the top five positive and negative responses. This suggests that teeth (or dentures) are perceived as having either a highly positive or a highly negative impact on these eating factors. Between 19 and 30 percent of these older adults indicated that their teeth or dentures had a negative impact on an eating related item, with only 11 percent indicating that their taste had been negatively affected. Facial appearance was negatively affected by teeth or dentures in 13 to 15 percent.

Table Chapter 8.4: The most common "bad effects" of teeth or dentures in older adults rank ordered by negative effect ($\geq 10\%$)

Perceived Effect of Teeth or Dentures on:	N	% of people reporting bad effect
Chewing and biting	903	30
Eating	908	25
Foods you chose to eat	901	21
Enjoyment of eating	902	19
Feeling comfortable	899	19
Breath	869	17
Appearance to others (how you look to others)	845	15
Facial appearance (how your face looks to you)	880	13
Speech	890	12
Smiling and laughing	896	11
Tasting	885	11
Having confidence	888	10

A second study^{2,3} based on this population sample examines racial/ethnic effects. In this study, race and dentate status were related to self-perceived life impacts of teeth and dentures. Dentate African-Americans consistently reported more negative, and fewer positive, life impacts of teeth, than did dentate Caucasians. Large differences by race were found among dentates. Edentulous African-Americans perceived more positive and less negative life effects, than did dentate African-Americans, the reverse of findings among Caucasians. African-Americans more commonly perceived their natural teeth to negatively impact on their lives and were more positive than Caucasians with being edentulous. In 3 separate studies (2 pilot and 1 population-based) overall findings and race-related influences were consistent. Discriminant ability

was apparent in the large and consistent racial differences in the scores.

DISCUSSION AND EVALUATION

The Dental Impact Profile introduces the concept that teeth and dentures have measurable positive and negative life impacts and allows for the study of health values and cultural/ethnic influences. Other measures have focused primarily on how dental problems and the dentition may produce problems in life quality. Such measures seek to clarify how people believe their teeth and dental conditions may result in functional limitations and problems.

The Dental Impact Profile examines both the good and bad effects of teeth to allow scientists to appreciate the balance of factors that affect how persons perceive their dentition. The measure is based upon health beliefs and values as subjectively expressed.

The advantages of the measure are:

1. It is brief and simple
2. It allows for both positive and negative impacts and responses
3. It can be a measure of self-perceived health and healthy function as related to oral status, not only disability
4. It is useful as a measure of cultural or ethnic influences
5. It is particularly useful in older adult populations
6. It is useful in suggesting values of populations and may be helpful in marketing oral health services¹ and in health promotion

The disadvantages of the measure are:

1. It does not measure the disability or dysfunction related to dental conditions
2. It is best administered by an interviewer
3. It may suggest impacts to respondents who had not previously considered them
4. Subscales, while developed, have not been widely used

ACKNOWLEDGMENTS:

Support for this work was from the National Institute of Dental Research, NIDR Grant RO1-08060. Participants in this study were selected from the Duke Established Populations for Epidemiologic Studies of the Elderly, which was performed pursuant to NIA Contract NO1-AG-4-2110.

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Chapter 9

THE ORAL HEALTH IMPACT PROFILE

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BACKGROUND

The Oral Health Impact Profile (OHIP) was developed with the aim of providing a comprehensive measure of self-reported dysfunction, discomfort and disability attributed to oral conditions. These impacts were intended to complement traditional oral epidemiological indicators of clinical disease, thereby providing information about the "burden of illness" within populations and the effectiveness of health services in reducing that burden of illness.¹

The OHIP is concerned with impairment and three functional status dimensions (social, psychological and physical) which represent four of the seven quality of life dimensions proposed by Patrick and Bergner.² Hence, it excludes perceptions of satisfaction with oral health, changes in oral health, prognosis or self-reported diagnoses. Furthermore, the OHIP aims to capture impacts that are related to oral conditions in general, rather than impacts that may be attributed to specific oral disorders or syndromes. All impacts in the OHIP are conceptualized as adverse outcomes, and therefore the instrument does not measure any positive aspects of oral health.

DEVELOPMENT OF THE INSTRUMENT

The development of the OHIP followed approaches that had been used in general health settings to measure the impact of medical care on functional and social well-being.^{3,4} The approach involved identifying a conceptual model that defined relevant dimensions of impact then acquiring a broad range of questions and associated numerical weights which could be combined to create subscale scores reflecting both the frequency of each impact and lay judgments about the severity of the impact. The three steps, which have been described previously,⁵ are summarized below.

Conceptual model. Locker's model of oral health⁶ was used to define seven conceptual dimensions of impact: functional limitation (e.g., difficulty chewing), physical pain (e.g., sensitivity of teeth), psychological discomfort (e.g., self consciousness), physical disability (e.g., changes to diet), psychological disability (e.g., reduced ability to concentrate), social disability (e.g., avoiding social interaction) and handicap (e.g., being unable to work productively). This model is based on the World Health Organization's classification⁷ in which impacts of disease are categorized in a hierarchy ranging from internal symptoms, apparently primarily to the individual (represented in the

dimension of functional limitation), to handicaps that affect social roles, such as work.

Statements about impact. Interviews using open ended questions with a convenience sample of 64 dental patients were conducted to identify statements about adverse impacts of oral conditions. The interviews took place in Adelaide, Australia, among adult patients at public and private dental care settings. Interviews yielded a total of 535 statements which were examined for content resulting in the derivation 46 unique statements that were categorized into the seven conceptual dimensions. Three additional statements from an existing inventory⁴ were adapted for use in the handicap dimension.

Weights. Thurstone's method of paired comparisons⁸ was used to generate weights for statements within each conceptual dimension. Judgments about the perceived unpleasantness of each impact were recorded by 328 people who were members of community groups or university students in Adelaide. All weights were adjusted to positive numbers which ranged from 0.747 to 2.555. Some variation was observed when weights were computed among sub-groups: for example, in the physical pain dimension, wearers of full dentures accorded greater weight to sore spots in the mouth and less to sensitivity of teeth compared with non wearers of dentures. However, a replication of the weighting procedure in Canada found that the ranking of OHIP items made by South Australians were broadly similar to the rankings made by English-speaking people in Ontario and French-speaking people in Quebec.⁹

Structure of the questionnaire. The OHIP questionnaire consists of the 49 statements that have been rephrased as questions, reproduced at the end of this Chapter (Table Chapter 9.2). Respondents are asked to indicate on a five-point Likert scale how frequently they experienced each problem within a reference period, for example 12 months. Response categories for the five-point scale are: "Very often", "Fairly often", "Occasionally", "Hardly ever" and "Never". Respondents may also be offered a "don't know" option for each question. For three questions that ask about denture-related problems (numbers 17, 18 and 30), a response option is provided for non-wearers of dentures to indicate that these questions do not apply to them.

Scoring. For data entry, responses are coded 0 (never or not applicable), 1 (hardly ever), 2 (occasionally), 3 (fairly often) or 4 (very often). "Don't know" responses and blank entries are entered as missing values, which subsequently are recoded with the mean value of all valid responses to the corresponding question.

However, if more than nine responses are left blank or marked "don't know", the questionnaire is discarded. During data processing, coded responses are multiplied by the corresponding weight for each question (Table Chapter 9.2) and the products summed within each dimension to give seven subscale scores, each with a potential range from zero (no impact) to 40 (all impacts reported "very often").

Overall OHIP scores have been computed in two ways. The simplest method is to count, for each subject, the number of impacts reported at a threshold level (for example, "fairly often" or "very often"). In many populations, the distribution of this summary variable may be skewed, with many individuals reporting no impact at this threshold,¹⁰ and this may violate assumptions necessary for some parametric statistical procedures. The second method of computing an overall OHIP score is to standardize subscale scores (subtract the sample mean subscale value from each individual's subscale score and divide the result by the sample standard deviation for that subscale, creating seven "z-scores"), and then sum those standardized scores for each respondent.⁵ Typically, the resulting standardized OHIP score has a better distribution for parametric statistical procedures.¹¹ However, this second method requires more computer programming, and the resulting scores have less intuitive appeal than the simpler count of impacts.

EVALUATION OF THE INSTRUMENT

Reliability of the OHIP was first evaluated among a random sample of 122 people aged 60+ years who were residents of Adelaide.⁵ Cross sectional results were used to generate Cronbach alpha coefficients for internal reliability, which ranged from 0.70 to 0.83 for six subscales, but only 0.37 for handicap. Follow-up administration of the instrument among 46 of those subjects was used to calculate intra-class correlation coefficients of test-retest reliability which ranged from 0.42 to 0.77 for six subscales, but only 0.08 for social disability. In a cross-sectional study of a random sample of people aged 50+ years in Ontario, Canada, Cronbach alpha coefficients for all subscales ranged from 0.80 to 0.90.¹² In another study of older adults in North Carolina, reliability was analyzed separately by race (white and black) and education (<8 years and 8+ years of education) and Cronbach alpha coefficients for the full 49-item questionnaire were 0.96 or more for each group.¹¹

Construct validity was assessed through cross-sectional comparisons of OHIP responses and related, self-reported

measures. In the study of 122 elderly Adelaide residents, OHIP subscale scores were greater ($P < 0.05$) among people who perceived a need for treatment compared with those who did not.¹⁰ There was a similar association between the total number of OHIP items and perceived treatment needs in the Ontario study.¹² In addition, this summary OHIP score had moderately strong, statistically significant correlations with indices of self reported chewing ($\rho = 0.47$), self-reported oral pain ($\rho = 0.41$), other oral symptoms ($\rho = 0.34$), self-reported problems with eating ($\rho = 0.68$) and satisfaction with oral health ($\rho = 0.48$). Relationships between OHIP scores and clinical variables (such as missing teeth, decayed teeth and periodontal destruction) followed hypothesized directions, although as expected, correlation coefficients were only moderately strong.¹³

FINDINGS FROM THE USE OF THE INSTRUMENT

An example of the distribution of OHIP scores is provided in Table Chapter 9.1 which compares mean subscale scores of dentate and edentulous people who took part in a study of older adults in two South Australian cities.¹⁰ Edentulous persons had significantly higher scores for functional limitation and physical disability, although not for other subscales. It should be noted that higher scores for functional limitation, physical pain and physical disability can be expected for denture wearers because each of these subscales has one question that applies only to denture wearers. In this sample, 98 per cent of edentulous people wore dentures, compared with 55 per cent of dentate persons, which would account for some of the differences observed in Table Chapter 9.1.

Coefficients of variation (σ/μ) ranged from 0.63 to 2.46 for dentate people and 1.00 to 3.46 for edentulous (Table Chapter 9.1). In order to detect a difference of 25 per cent in mean scores for a subscale with a coefficient of variation of 1.0, some 251 persons per group would be required to achieve standard type I (0.05) and type II (0.20) errors.

Table Chapter 9.1: Mean OHIP scores among subgroups of South Australians aged 60+ years

Subscale	DENTATE (n=905)			EDENTULOUS (n=312)			P-value
	mean	sd*	cv†	mean	sd	cv	
Functional limitation	7.91	5.15	0.65	8.67	9.33	1.08	0.04
Physical pain	7.84	4.96	0.63	7.85	7.87	1.00	0.98
Psychological discomfort	5.94	6.38	1.07	5.36	11.30	2.11	0.20
Physical disability	3.60	4.33	1.20	5.58	8.26	1.48	0.01
Psychological disability	3.14	4.79	1.53	3.44	8.24	2.40	0.38
Social disability	1.23	3.03	2.46	1.59	5.50	3.46	0.09
Handicap	1.67	3.31	1.98	1.87	5.69	3.04	0.38

* sd=Standard deviation

† cv=coefficient of variation (sd/mean)

Findings from a longitudinal study of 67 elderly South Australians demonstrated general stability in OHIP scores.¹⁴ Subjects were asked to complete one questionnaire per month for a 12 month period. There was a small net increase in the number of items reported per month (baseline=2.10 items, 12-months=2.15, P=0.83). Response patterns for all 12 months revealed that only a small proportion (13.5 per cent) of people displayed an overall trend of increasing or decreasing impacts, although 47.8 per cent had a transient fluctuation of at least two items in at least one month.

In studies of independently living older adults, the self-completed questionnaire has been acceptable to respondents. Response rates for mail questionnaires with up to two reminder notices typically ranged from 71 to 86 per cent, although in a study involving elderly North Carolina blacks, where many survey participants had difficulty reading, the response rate was only 58 per cent.¹¹ While a majority of respondents completed all 49 questions satisfactorily, 43 per cent of respondents in the South Australian study of older adults had at least one blank entry or "don't know" response. In those instances, sample mean values for individual questions were imputed for missing or "don't know" responses when computing subscale scores, although any questionnaire with more than nine such responses was discarded. Some seven per cent of questionnaires were discarded for this reason in the South Australian study of older adults.

The number of missing items can be reduced with an interviewer-administered version of the OHIP, although a pilot study revealed other problems with that format, including interviewer burden

(average time for telephone or face-to-face administration was 17 minutes) and lower levels of test-retest reliability.¹⁵

The substantive findings from the OHIP come primarily from epidemiological studies which reveal:

- higher OHIP scores among people who have poorer clinical oral status, as indicated by more missing teeth, more retained root fragments, more untreated decay, deeper periodontal pockets and more periodontal recession^{11,13,16}
- higher OHIP scores among socially and economically disadvantaged groups, and among people who have infrequent or problem-motivated dental visits^{10,13,14,16}
- higher OHIP scores among dental patients with HIV infection compared with general dental patients¹⁷
- overall stability in OHIP scores for a majority of independently-living older adults during two-year follow-up periods¹⁸⁻²⁰
- increases in OHIP scores during a two-year period for dentate people who experienced tooth loss¹⁹ and decreases for edentulous people who received prosthodontic treatment,²¹ although the effects were conditional upon baseline oral status and perceptions of need

ALTERNATE FORMS

A shortened (14-item) version of the OHIP has been developed from analysis of South Australian data.²² Work is underway with French and Spanish forms of the OHIP, although this has revealed some questions and response categories that could not be satisfactorily translated.

DISCUSSION AND EVALUATION

Cross sectional studies that have used the OHIP in various populations reveal levels of dysfunction, discomfort and disability that appear consistent with clinical conditions and access to dental care in those populations. At this descriptive level, the results reveal some subtle differences in the seven conceptual dimensions of impact - for example, edentulous South Australians had higher levels of functional limitation and physical disability than dentate people, while other dimensions did not differ significantly (Table Chapter 9.1). However, there is also a high amount of

correlation among dimensions, so that statistical associations with impact appear fairly consistent using either subscales or summary scores.¹¹ This is consistent with the finding that all 49 items had high loadings on a single factor that accounted for 69 per cent of variation in a principal components factor analysis.²² This in turn suggests that, for descriptive purposes, a single-item global question about oral health related quality of life would capture many of the same associations that are observed with this more detailed OHIP questionnaire.

While these cross sectional findings suggest that the OHIP captures a single dimension of impact, it will be important to examine data from longitudinal studies and clinical trials in order to determine if the conceptual dimensions provide information about subtly different outcomes that are important from a clinical perspective. Other potential uses for the OHIP should be investigated, including its potential to identify groups with a high priority for dental care. Several sub-themes could be investigated: the ability of the OHIP to identify groups that place a high priority on their own treatment needs, or that place a high priority on oral health, or that place a high priority on outcomes of dental care that increase quality of life. In addition, there is scope for additional research to investigate how other aspects of quality of life interact with the dimensions captured in the OHIP. This research needs to take place within a broader agenda of clinical and health services research that examines the impact of dental care on people's well being from a range of perspectives that include clinical outcomes, satisfaction and quality of life.

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Table Chapter 9.2: Questions and weights for the Oral Health Impact Profile

Dimension*	Weight	Question†
FL	1.253	1. Have you had difficulty chewing any foods because of problems with your teeth, mouth or dentures?
FL	1.036	2. Have you had trouble pronouncing any words because of problems with your teeth, mouth or dentures?
FL	0.747	3. Have you noticed a tooth which doesn't look right?
FL	1.059	4. Have you felt that your appearance has been affected because of problems with your teeth, mouth or dentures?
FL	1.154	5. Have you felt that your breath has been stale because of problems with your teeth, mouth or dentures?
FL	0.931	6. Have you felt that your sense of taste has worsened because of problems with your teeth, mouth or dentures?
FL	1.181	7. Have you had food catching in your teeth or dentures?
FL	1.168	8. Have you felt that your digestion has worsened because of problems with your teeth, mouth or dentures?
P1	1.213	9. Have you had painful aching in your mouth?
P1	0.937	10. Have you had a sore jaw?
P1	1.084	11. Have you had headaches because of problems with your teeth, mouth or dentures?
P1	1.053	12. Have you had sensitive teeth, for example, due to hot or cold foods or drinks?
P1	1.361	13. Have you had toothache?
P1	1.088	14. Have you had painful gums?
P1	0.998	15. Have you found it uncomfortable to eat any foods because of problems with your teeth, mouth or dentures?
P1	1.264	16. Have you had sore spots in your mouth?
FL	1.472	17. Have you felt that your dentures have not been fitting properly?
P1	1.002	18. Have you had uncomfortable dentures?
P2	2.006	19. Have you been worried by dental problems?
P2	1.902	20. Have you been self conscious because of your teeth, mouth or dentures?
P2	2.252	21. Have dental problems made you miserable?
P2	1.815	22. Have you felt uncomfortable about the appearance of your teeth, mouth or dentures?
P2	2.025	23. Have you felt tense because of problems with your teeth, mouth or dentures?

Continued

Table Chapter 9.2 continued

Dimen- sion*	Weight	Question†
D1	1.109	24. Has your speech been unclear because of problems with your teeth, mouth or dentures?
D1	1.111	25. Have people misunderstood some of your words because of problems with your teeth, mouth or dentures?
D1	1.051	26. Have you felt that there has been less flavor in your food because of problems with your teeth, mouth or dentures?
D1	1.068	27. Have you been unable to brush your teeth properly because of problems with your teeth, mouth or dentures?
D1	1.266	28. Have you had to avoid eating some foods because of problems with your teeth, mouth or dentures?
D1	1.022	29. Has your diet been unsatisfactory because of problems with your teeth, mouth or dentures?
D1	1.351	30. Have you been unable to eat with your dentures because of problems with them?
D1	1.070	31. Have you avoided smiling because of problems with your teeth, mouth or dentures?
D1	0.952	32. Have you had to interrupt meals because of problems with your teeth, mouth or dentures?
D2	1.950	33. Has your sleep been interrupted because of problems with your teeth, mouth or dentures?
D2	1.393	34. Have you been upset because of problems with your teeth, mouth or dentures?
D2	1.646	35. Have you found it difficult to relax because of problems with your teeth, mouth or dentures?
D2	1.936	36. Have you felt depressed because of problems with your teeth, mouth or dentures?
D2	1.638	37. Has your concentration been affected because of problems with your teeth, mouth or dentures?
D2	1.437	38. Have you been a bit embarrassed because of problems with your teeth, mouth or dentures?
D3	1.572	39. Have you avoided going out because of problems with your teeth, mouth or dentures?
D3	2.555	40. Have you been less tolerant of your partner or family because of problems with your teeth, mouth or dentures?
D3	1.832	41. Have you had trouble getting along with other people because of problems with your teeth, mouth or dentures?
D3	2.236	42. Have you been a bit irritable with other people because of problems with your teeth, mouth or dentures?
D3	1.805	43. Have you had difficulty doing your usual jobs because of problems with your teeth, mouth or dentures?

Continued

Table Chapter 9.2 continued

Dimension*	Weight	Question†
H	2.112	44. Have you felt that your general health has worsened because of problems with your teeth, mouth or dentures?
H	1.420	45. Have you suffered any financial loss because of problems with your teeth, mouth or dentures?
H	1.545	46. Have you been unable to enjoy other people's company as much because of problems with your teeth, mouth or dentures?
H	1.567	47. Have you felt that life in general was less satisfying because of problems with your teeth, mouth or dentures?
H	1.879	48. Have you been totally unable to function because of problems with your teeth, mouth or dentures?
H	1.476	49. Have you been unable to work to your full capacity because of problems with your teeth, mouth or dentures?

* FL=Functional limitation, P1=Physical pain, P2=Psychological discomfort, D1=Physical disability, D2=Psychological disability, D3=Social disability, H=Handicap

† Response categories for all questions are: "Very often", "Fairly often", "Occasionally", "Hardly ever" and "Never". "Don't know" can also be included as a response category. For questions 17, 18 and 30 a "not applicable" response is provided to indicate if dentures are not worn. Instructions to respondents should also indicate the desired time period (e.g., during the last 12 months, during the last month, etc.).

Chapter 10

SUBJECTIVE ORAL HEALTH STATUS INDICATORS

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BACKGROUND

This battery of indicators was developed in Canada to describe the functional, social and psychological outcomes of oral disorders and conditions. It was intended to be used in oral health surveys of older adults in order to supplement the clinical measures routinely employed in such surveys. Subsequently, the indicators, or abbreviated versions of them, have been used in studies of adolescent and adult populations at both a local and provincial level in Canada and a local level in the UK. These subjective oral health status indicators were based on a model of disease and its consequences derived from the WHO's International Classification of Impairments, Disabilities and Handicaps¹ and reflect the key components of that model. This model recognizes the multidimensional nature of oral health and links concepts and the measures derived from them in a linear fashion that moves from a biophysical to a sociomedical and ultimately social level of analysis. In this regard, the indicators facilitate the exploration of the links between oral diseases and their outcomes in terms of health and well-being.

DEVELOPMENT OF THE INSTRUMENT

The indicators, which comprise four indexes and one scale, were developed in an ad hoc fashion over a series of studies of older adult populations. In its initial formulation, the battery consisted of an index of chewing capacity derived from earlier work by Leake,² an oral and facial pain index, an index of other oral symptoms previously used by Locker and Grushka³ and a psychosocial impact scale partially based on questions used in the Rand Health Insurance Experiment. The latter measured the effect of oral conditions on eating and social relationships. These were used in the baseline phase of the Ontario Study of the Oral Health of Older Adults (OSOHOA).⁴

An expanded set of indicators emerged out of that experience and have been used in a three-year follow-up and a seven-year follow-up of the OSOHOA. The indicators now include: a six-item index of chewing capacity, a three-item index of the ability to speak clearly, a nine-item index of oral and facial pain symptoms and a ten-item index of other oral symptoms. The scale of social and psychological impact of oral disorders is assessed by four subscales: a three-item subscale of problems with eating, a four-item subscale concerned with problems in communication/social relations, a six-item subscale of other limitations in daily activities and a two-item subscale of worry and concern about oral health.

The final version of the subjective indicators is given in Table Chapter 10.1.

Table Chapter 10.1: Content and scoring of the 8 subjective oral health status indicators

<u>Index/scale</u>	<u>Items</u>
1. Ability to chew	<p>Are you usually able to:</p> <ul style="list-style-type: none"> chew a piece of fresh carrot? chew boiled vegetables? chew fresh lettuce salad? chew firm meat such as steaks or chops? bite off and chew a piece of whole fresh apple? chew hamburger? <p><i>Response format: Yes/No</i></p>
2. Ability to speak	<p>Thinking about problems with your teeth or mouth...</p> <ul style="list-style-type: none"> do you ever have difficulty pronouncing any words? do you ever have difficulty speaking clearly? do you ever have difficulty making yourself understood? <p><i>Response format: Yes/No</i></p>
3. Oral and facial pain symptoms	<p>In the last four weeks, have you had the following problems?</p> <ul style="list-style-type: none"> toothache pain in teeth with hot/cold foods or fluids pain in teeth with sweet foods pain in jaw joint when opening mouth wide pain in face in front of ear burning sensation in tongue or other parts of mouth shooting pains in face or cheeks pain or discomfort from denture <p><i>Response format: Yes/No</i></p>
4. Other oral symptoms	<p>In the last four weeks have you had the following problems?</p> <ul style="list-style-type: none"> mouth ulcers cold sores bleeding gums bad breath dryness of mouth unpleasant taste changes in ability to taste clicking/grating noise in jaw joint difficulty opening mouth wide <p><i>Response format: Yes/No</i></p>
5. Eating impact scale	<p>Thinking about your dental health over the last year, how often:</p> <ul style="list-style-type: none"> have you been prevented from eating foods you would like to eat? have you found your enjoyment of food is less than it used to be?

did it take you longer to finish a meal than other people?

Response format: all the time (5), very often (4), fairly often (3), sometimes (2), never (1)

Table Chapter 10.1 continued

<u>Index/scale</u>	<u>Items</u>
7. Activities of daily living impact scale	<p>During the past year, how often have pain, discomfort, or other problems with your teeth, mouth or dentures caused you to:</p> <ul style="list-style-type: none"> have difficulty sleeping? stay home more than usual? stay in bed more than usual? take time off work? be unable to do household chores? avoid your usual leisure activities? <p><i>Response format: all the time (5), very often (4), fairly often (3), sometimes (2), never (1)</i></p>
8. Worry/concern impact scale	<p>During the past year, how often have you worried about:</p> <ul style="list-style-type: none"> the appearance of your teeth or mouth? the health of your teeth or mouth? <p><i>Response format: all the time (5), very often (4), fairly often (3), sometimes (2), never (1)</i></p>
Scoring:	<p>1. Count number of 'no' responses. 2-4. Count number of 'yes' responses. 7-8. Count number of 'all the time', 'very often', 'fairly often', 'sometimes' responses, <u>or</u> sum response codes.</p>

EVALUATION OF THE INSTRUMENT

Although the indicators were originally developed and used in studies of older adults, a comprehensive evaluation of their performance was undertaken as part of a study of self-perceived oral health in a randomly selected general population sample aged 18 years and over.⁵ Mail questionnaire data were collected from 553 subjects and 156 completed a second copy of the instrument for test-retest reliability assessment. In this study, the performance of the measures was assessed in terms of their generalizability, efficiency reliability and validity.

The *generalizability* of the indicators across age groups is shown in Table Chapter 10.2. Younger subjects were as, if not more, likely to respond positively to all indicators than older subjects with the exception of the index of chewing capacity. This suggests that the measures are sensitive to the oral health concerns of all adults and not just the elderly.

Table Chapter 10.2: Percent reporting limitations in ability to chew, problems speaking, one or more oral pain symptoms, and one or more other symptoms and percent responding positively* to one or more impact scale items by age group

<u>Index/subscale</u>	<u>Age (years)</u>				<u>P-value</u>
	<u>18-29</u>	<u>30-34</u>	<u>50-64</u>	<u>65+</u>	
Limitation in chewing	0.9	4.8	16.0	33.3	<0.01
Problem speaking	14.8	6.0	9.7	9.6	ns
Pain	43.5	36.7	28.5	28.1	<0.05
Eating	69.6	51.8	50.7	45.6	<0.01
Communication/ social relations	23.5	26.5	23.6	23.7	ns
Activities of daily living	13.9	18.7	20.1	21.1	ns
Concern	65.2	60.2	54.9	48.2	<0.05

* Responding sometimes, fairly often, very often, or all the time

Efficiency was assessed by means of item non-response. The proportion of subjects with one or more missing items was less than 5 percent for six indicators and just over 7 percent for the remaining two.

Data on *reliability* are given in Table Chapter 10.3. Test-retest reliability was assessed using the correlations between the number of items endorsed at each administration of the questionnaire. For six of the eight indicators the coefficients fell between 0.75 and 0.90 and were 0.61 and 0.67 for the other two. Paired t-tests revealed only one difference in the mean number of items endorsed. The mean number of other oral symptoms reported was 1.3 (sd=1.7) at the first administration and 1.1 (sd=1.6) at the second. The internal consistency (Cronbach's alpha) of the four psychosocial impact scales ranged from 0.70 to 0.87.

Table Chapter 10.3: Test-retest and internal consistency reliability

<u>Index/subscale</u>	Test-retest correlation* (Pearson's ρ)	Test-retest paired t-test (P-value)	Internal consistency (Cronbach's α)
Limitation in chewing	0.90	ns	—
Problem speaking	0.76	ns	—
Oral pain	0.77	ns	—
Other oral symptoms	0.75	<0.01	—
Eating	0.78	ns	0.70
Communication/social relations	0.84	ns	0.79
Activities of daily living	0.61	ns	0.87
Worry/concern	0.67	ns	0.82

* All correlation coefficients significant ($P < 0.01$)

In assessing *validity*, associations between the eight measures and three global self-report indicators were examined; namely, self-rating of oral health, self-perceived need for dental treatment and dissatisfaction with oral health. All associations were significant and in the expected direction. Moreover, significant differences were observed for five of the indicators according to dental status (edentulous, dentate with dentures, dentate without dentures). Theoretical propositions derived from the conceptual model were also confirmed using these measures.

This evaluation of reliability and validity was repeated in the UK in a study of two groups of subjects aged 65 years and over, and produced very similar results.⁶ For example, test-retest reliability correlation coefficients ranged between 0.75 and 0.99 for six of the indicators and were 0.56 and 0.58 for the other two. Cronbach's alphas for the psychosocial impact scales ranged between 0.81 and 0.90.

Concurrent validity was also examined using data from the three-year follow-up of the OSOHOA in which the Oral Health Impact Profile was also used.⁷ Correlations between the indicators and OHIP sub-scale and overall scores for 611 subjects aged 53 to 90 years were significant and moderately strong to strong. The correlation between scores on the index of chewing capacity and the overall OHIP score was 0.56. The correlation between a combined psychosocial impact score and the overall OHIP score was 0.68.

Longitudinal data from the OSOHOA were used to assess the sensitivity of the indicators to change over time. There were significant associations between change scores (obtained by

subtracting follow-up from baseline scores) and subjects' global assessments of change in their oral health status. Effect sizes for the indicators ranged from 0.38 to 0.87, which are moderate to strong effects.⁸

FINDINGS FROM THE USE OF THE INSTRUMENT

Response rates in mail surveys using the indicators have ranged from 57.0 per cent⁵ to 77.7 per cent.⁶ They have also been used in personal and telephone interview surveys with response rates above 70%. Data from studies using these indicators suggests that the proportions of subjects experiencing negative impacts on functional and psychosocial well-being as a result of oral disorders is substantial.^{4,5} See also Table Chapter 10.2.

DISCUSSION AND EVALUATION

The main strength of the instrument is that it was based on a coherent conceptual framework and as such is useful in descriptive surveys and more theoretically oriented work which explores the links between distinct dimensions of health. Since the measures constitute a battery of indicators, scores cannot be summated to give an overall oral health status score. However, this approach is consistent with the conceptual framework from which the measures were derived and avoids the theoretical and methodological problems involved in formulating an overall oral health indicator. In addition, the indicators appear to be generally applicable, reliable and valid and sensitive to change over time.

Reasonably good response rates to studies using the indicators and low levels of item non-response, even with self-complete versions of the instrument, suggest that the indicators are acceptable to research subjects and easy to complete.

Because the indicators are relatively succinct and the items comprising the indicators not weighted, the instrument is not likely to be useful as an outcome measure in clinical trials or evaluative studies. Its main value appears to be in describing and monitoring the self-perceived oral health status of adult populations.

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Chapter 11

THE ORAL HEALTH- RELATED QUALITY OF LIFE MEASURE (OHQOL)

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BACKGROUND

In 1991 a group of investigators concerned with health and quality of life in older men selected several questions concerned with the impact of oral health on quality of life to include in surveys on this topic. The theoretical perspective guiding the selection of the particular items was the view that health related quality of life is a broad conception of health, encompassing the traditional definition of health, as well as an individual's subjective evaluation of the impact of health on well being and functioning in everyday life¹.

DEVELOPMENT OF THE INSTRUMENT

Item Selection. The original pool of items from which the OHQOL measure was developed were selected in part from existing instruments which assessed various impacts of oral health on quality of life. Three items were included which concerned the possible effects of oral disease: Have problems with your teeth or gums: 1) affected your daily activities such as work or hobbies?; 2) affected your social activities such as with family, friends, coworkers?; 3) caused you to avoid conversations with people because of how you looked? (this last item is included in the RAND measure of dental health²). Responses for each of these items were scored on a six point scale ranging from "all of the time" to "none of the time". The survey also contained two items assessing oral discomfort (dry mouth and tender or bleeding gums, both scored on a five point scale ranging from "never" to "very often") and two items from the Nutrition Screening Initiative³ assessing eating problems (tooth/mouth problems make it hard to eat; swallowing problems make it hard to eat, with yes/no response format). Dental pain was assessed by asking how much pain or distress the respondents' teeth or gums had caused in the past three months (1=not at all -- 5=a great deal; this item is also included in the RAND measure²).

To examine the possible underlying constructs among the pool of 8 dental items, a factor analysis was conducted, using Promax rotation. A three factor solution was obtained which accounted for 49% of the total variance.⁴ Since the first factor included the three items related to the impact of oral conditions on daily functioning (the working definition of oral health related quality of life), this factor was labeled OHQOL, and the OHQOL scale score was computed by taking the mean of the scores on the 3 items. The second factor was labeled oral discomfort, and the third was labeled eating problems.⁴ Correlations among these factors were negative and relatively low, ranging from -0.24 to 0.02.⁴

Sample. The OHQOL measure was developed with data from the Department of Veterans Affairs Normative Aging Study/Dental Longitudinal Study (NAS/DLS; see Kressin et al⁴ for complete details of the development of the measure). The NAS/DLS is a closed-panel longitudinal study of 2,280 community dwelling initially healthy men recruited through the Boston VA Outpatient Clinic, between 1961 and 1970.⁵ The cohort is primarily white (97%), married, and middle class. The NAS participants are not VA patients; they receive their medical and dental care in the private sector. As part of a mailed questionnaire in 1992, 1,242 participants completed the measures analyzed in this study; these men were aged 47 to 94 years (Mean = 67.3, SD = 7.7).⁴

EVALUATION OF THE OHQOL MEASURE

After the initial factor analyses were conducted to develop the OHQOL scale, the three items comprising the scale were included in another factor analysis which also included the items from the SF-36,⁶ a short measure of health-related quality of life which assesses eight domains: physical functioning, physical role functioning, social role functioning, emotional role functioning, mental health, vitality, pain, and general health perceptions. Results from this factor analysis indicated that the OHQOL items loaded a separate factor, which was the fifth factor extracted, and which contributed 5% of the variance.⁴ These findings suggest that perceptions of the impact of physical health on quality of life are distinct from the perceived impact of oral health on quality of life, supporting the notion that the effects of oral health on quality of life are an important additional dimension.⁴

The internal consistency reliability of the OHQOL scale was also evaluated; its Cronbach's alpha was 0.83, suggesting strong associations among the items.⁴ The correlations between the OHQOL scale and the general life satisfaction, oral discomfort and eating problems scales were also examined. These results indicated that respondents with better oral health related quality of life had fewer eating problems and less oral discomfort; they reported less dental pain and were less likely to have sought treatment for problems during the previous three months.⁴ Correlations between oral health related quality of life and general life satisfaction and self-rated health were small, but in the expected directions.⁴

Having attained preliminary validation of the OHQOL scale, an additional analysis was conducted to further validate the measure by examining its association with problem-based dental care utilization, (e.g., sought treatment for any problems with teeth

and gums in the past three months), controlling for other likely correlates. Results from a preliminary logistic regression model with backward elimination suggested the inclusion of a range of variables including age, self-rated health, presence of a chronic illness or problem, general life satisfaction, and the OHQOL, eating problems, and oral discomfort scales. The final model indicated that dental pain, oral discomfort, and general life satisfaction were associated with increased odds of having sought problem-based treatment, while better OHQOL was associated with a reduced likelihood of seeking treatment.⁴

FINDINGS FROM USE OF THE INSTRUMENT

Since its development, the OHQOL measure has been administered to two additional VA samples. The first of these is the Veterans Health Study (VHS), an ongoing 2 year longitudinal study of health and quality of life in VA ambulatory care patients, begun in 1993.⁷ VHS participants are identified in clinic at 4 sites in the metropolitan Boston area, and are nearly representative of the sampling frame of all users of VA ambulatory care services. These patients are all men, mostly white, married, and have relatively low incomes (52% below \$20,000 per annum). In addition, these veterans have a relatively heavy illness burden, often with multiple disabilities or chronic illnesses. The respondents who completed the OHQOL measure have a mean age of 63 years, and the majority have no more than a high school education. As part of a mailed questionnaire sent between 1993 and 1995, several items concerned with the impact of oral conditions on functioning and well-being were included, which 957 VHS participants completed.

The second VA sample to which the OHQOL measure has been administered is the VA Women's Health Project (WHP), a random sample of women veterans who used VA ambulatory health care services between 1994 and 1995.⁸ Some 911 women completed questionnaires between January and April of 1996; these respondents' average age was 51. These veterans had an average of 14 years of education, 31% were married, 66% of the sample had incomes under \$20,000/year, and 84% of these respondents were white.

Selected findings from these samples, as well as from the original sample in which the OHQOL measure was developed, are shown in Table Chapter 11.1.

Table Chapter 11.1: Summary of results from use of the OHQOL measure

	Normative Aging Study ⁴	Veterans' Health Study ⁹	VA Women's Health Project
<u>Scale scores</u>			
N	1,242	957	911
Mean OHQOL	5.89	4.41	5.46
sd* OHQOL	0.47	1.13	1.10
Cronbach's alpha	0.94	0.83	0.89
<u>Item frequencies (% of persons)</u>			
Affected daily activities...			
All of the time [†]	0.6	7.9	4.2
Most of the time	0.3	1.9	1.9
Good bit of time	0.3	‡	4.4
Some of the time	1.7	7.3	8.4
Little of the time	4.5	12.2	13.7
None of the time	92.7	70.7	67.5
Affected social interactions...			
All of the time	0.6	8.0	3.3
Most of the time	0.1	0.9	1.3
Good bit of time	0.2	‡	2.3
Some of the time	0.7	5.3	4.4
Little of the time	2.5	8.8	8.5
None of the time	95.9	77.0	80.2
Caused avoidance of conversations...			
All of the time	0.7	8.1	3.5
Most of the time	0.8	1.9	2.0
Good bit of time	0.0	‡	1.4
Some of the time	0.6	6.0	4.0
Little of the time	2.7	6.2	5.0
None of the time	95.2	77.9	84.0
<u>Correlations with SF-36 scales:</u>			
Physical Function	0.06	0.06	0.16
Emotional Role Function	0.07	0.13	0.18
Physical Role Function	0.12	0.08	0.18
Social Functioning	0.08	0.15	0.26
Vitality	0.12	0.08	0.19
Pain	0.10	0.13	0.23
Gen. Health Perception	0.12	0.10	0.22
Mental Health	0.15	0.10	0.25

* sd=standard deviation

† Item scoring: all of time=1; most of time=2; good bit of time=3; some of time=4; little of the time=5; none of the time=6. Thus a higher score equals better OHQOL.

‡ response category not included

DISCUSSION AND EVALUATION

The OHQOL measure is a brief global assessment of the impact of oral conditions on individuals' functioning and well being. As such, one of its strengths is its brevity, as it consists of only three items. Thus, the length of the instrument makes it ideal for inclusion in population surveys. In turn, this brevity is a weakness of the instrument, for it cannot assess much detail about specific impacts of oral disease on quality of life.

Results from the use of the OHQOL measure indicate that it is sensitive to differences between samples; sicker, more socioeconomically disadvantaged samples have worse OHQOL scores, and exhibit different patterns of correlations with overall health related quality of life. Overall, the instrument exhibits good psychometric properties, including good internal consistency reliability, and associations in the expected directions with external criteria.

Initial results from the use of the OHQOL measure suggest several issues which need future research. The first issue concerns whether it is appropriate to use the measure as an indicator of perceived need for dental care and as a predictor of dental utilization, and whether it can be used as an assessment of treatment outcomes. The second issue concerns sex differences in the association between OHQOL and health related quality of life; the data presented here suggest that the two are more closely associated in women, but future research needs to confirm this and to explore possible explanations for these associations. Finally, it will be important for future research to develop a better understanding of the influence of intra-individual psychosocial factors (e.g., mental health, attitudes, values, and general dispositions to be positive or negative) on perceptions of the impact of oral conditions on functioning and well being, as assessed by the OHQOL measure and other indices.

ACKNOWLEDGMENTS

Support for this research was provided by the Health Services Research and Development Service, U.S. Department of Veterans Affairs, (HFP #91-012, P.S. Vokonas, P.I., HFP # 92-002, R.I. Garcia, P.I., SDR 91-006, L. Kazis, P.I., and SDR 93-101, K. Skinner, P.I.), by NIDR-VA Interagency Agreement Number Y01-DE-20030, A. Spiro III, P.I., and by NIDR grant R03 DE11035, N. Kressin, P.I.. These results were presented, in part, at the 46th annual scientific meeting of the Gerontological Society of America, New Orleans, Louisiana, and in Kressin, N., Spiro III, A., Bossé, R., Garcia, R., &

Kazis, L. (1996). Assessing oral health related quality of life: Findings from the Normative Aging Study. *Medical Care*, *34*(5), 416-427, and in Kressin, N.R. (1996). Associations among different assessments of oral health outcomes. *Journal of Dental Education*, *60*(6), 502-506. The support of the following colleagues through the provision of data and in various aspects of this work is gratefully acknowledged: Raul Garcia, Catherine Hayes, Judith A. Jones, Lewis Kazis, Yao Meng, Donald Miller, Katherine Skinner, and Avron Spiro III.

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Chapter 12

THE DENTAL IMPACT ON DAILY LIVING

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BACKGROUND

The Dental Impact on Daily Living (DIDL) is a socio-dental measure which assesses five dimensions of quality of life.¹ Those are: Comfort, related to complaints such as bleeding gums and food packing; Appearance, consisting of self-image; Pain; Performance, the ability to carry out daily activities and to interact with people; and Eating restriction, relating to difficulties in biting and chewing. The measure consists of a questionnaire of 36 items, which assesses the oral impacts on daily living, and a scale, which is a graphical representation of a method developed by Leao² to assess the importance respondents attribute to the different dimensions involved.

The aims of DIDL are to obtain score dimensions and also to generate a total single score for all dimensions involved. In addition, DIDL is flexible enough to be geared to the analysis of individual items, dimensions or total score.

DEVELOPMENT OF THE INSTRUMENT

Items in the instrument evolved from open interviews, literature review and items in the 'Social Impact of Dental Disease'.³ After conducting inter-item correlation and item total correlation⁴ the number of items were reduced to 36. In addition, as a result of factor analysis, a fifth dimension was added to the previous four: Eating Restriction .

Scoring of items. Items were summed into a score for each dimension. To compute the score, coded responses within each dimension were summed and divided by the number of items, resulting in a dimension score (For example, Appearance has four questions. The score for this dimension would be the sum of coded responses for all four questions divided by four). Impacts were coded as '+1' for positive impacts, 0 for impacts not totally negatives and '-1' for negative impacts (Table Chapter 12.3).

Weighting of items. Tests conducted on DIDL indicated that it would make no difference either weighting or not weighting items. A correlation between three different versions of the measure was conducted. On the first version items were weighted by loads obtained on a complementary study.² The second version used factor loading obtained from factor analysis. On the third version items received no weight. As Lei and Skinner⁵ found for the 'Social Readjustment Rating Scale' correlation were above 0.95 ($P < 0.001$), indicating that weighting items would only complicate the instrument.

Weighting dimensions. A scale was used together with the questionnaire to obtain a proportional relationship between dimensions (Figure Chapter 12.1). The 'scale' consists, in fact, of a number of identical scales placed side by side in a single frame (see example in Figure). Each scale has sliding arrows that can be moved at will by respondents. The higher the arrow is placed the higher the importance attributed to the corresponding dimension. For each respondent, scale marks for the various dimensions are then added together (denote the value of the resulting sum 'total scale value'). Then, still for each respondent, each of the individual scale markings are divided by their 'total scale value'. As a result, dimension weights are obtained for each respondent (Table Chapter 12.1).

Table Chapter 12.1: Total scale value for the Dental Impact on Daily Living

Example: if a respondent scored '10' to Appearance, '9' to Performance, '9' to Comfort, '10' to Pain and '9' to Eating Restriction (see Figure)

Total scale value = Appearance mark (10) + Performance mark (9) + Comfort mark (9) + Pain mark (10) + Eating Restriction mark (9) = 47.

Weight for dimension (Appearance) = dimension mark / total scale value = $10/47 = 0.213$.

Statistical tests were used to determine whether the weighting of dimensions (as described above) contributed to results in a final score. Two versions were compared: the first version had the weighting attributed and second version did not. A Spearman correlation was calculated between those two versions.⁵ The results suggested that some of those who were classified as unsatisfied (those who had their scores below 0) on version two, had indeed a less severe impact once dimension weights were used on version one. That occurred for 14 out of the 30 people who were classified as unsatisfied (out of a sample of 662 people). We feel that it might be interesting to have that tested on a larger group of unsatisfied people.

Total score. To construct a final score, questions within each category are summed and divided by the number of items, giving a score for each dimension. Before adding the different dimensions, they receive the respective weight attributed on the scale, otherwise it would be assumed that they were equally important. Then the five dimensions are finally added to give a final score.

Total score = (Appearance score x Appearance weight) + (Pain score x Pain weight) + (Comfort score x Comfort weight) + (Performance score x Performance weight) + (Eating Restriction score x Eating Restriction weight).

Respondents were arbitrarily grouped, according to their total scores, as satisfied (from 7 to 10), relatively satisfied (from 6.9 to 0) and unsatisfied (those who had their scores below 0).

EVALUATION OF THE INSTRUMENT

Test-retest reliability and internal consistency were checked for the questionnaire (0.87 and 0.85 respectively) and for the scale (0.78 and 0.59 respectively). For the test-retest reliability 84 interviews were repeated during the main study. That was done after a group of fifty people were interviewed, the next six respondents were recalled on the day following the first interview. Face validity was established during a pilot study. The sample consisted of patients attending the medical service from the Underground transport company and others attending to private medical services. The understanding of the instrument was checked by asking respondents to explain what they understood by each question. After the first 10 people, modifications on some words were done. During the other 49 interviews understanding had improved (they would say in their own words what was being asked). Content validity was established through open interviews and literature review.

Construct validity was established using two tests. Three clinical measures were used for those tests: DMFT, THEALTH (attributes an arbitrary weight to the status of the tooth: sound tooth=4, filled tooth=2, decayed tooth=1 and missing tooth=0) and 'functional measure' (it aggregates the number of filled teeth and the number of sound teeth with no decay, each being given equal value).⁶ Spearman correlation coefficients showed negative correlation with DMFT and positive correlation with THEALTH and functional measure ($P < 0.001$). In addition, scores for dimension distributions, in groups of different oral status, were compared by the Kruskal-Wallis test and found to be significant, showing that depending on their oral status, the distribution between groups differed.

Construct validity of the scale was established in a complementary study where respondents were asked to weight dimensions and also all items in the questionnaire. A comparison of the order in which dimensions were ranked was done and the Wilcoxon signed-rank test was conducted. Overall, the results obtained have shown a close similarity in the comparison between weights being applied

to categories and weights being applied to the corresponding items.

FINDINGS FROM THE USE OF THE INSTRUMENT

The instrument was used in a cross sectional study of a Brazilian convenience sample. Results for this population indicated that at least 50 per cent of the sample had positive impacts when respondents were grouped as satisfied, relatively satisfied and unsatisfied. The dimension that showed a greater number of unsatisfied people, that means, more than half of the answers on that dimension with negative impacts, was Appearance (Table Chapter 12.2).

Table Chapter 12.2: Subjective impacts on the five dimensions and the total score (n=662 persons)

Dimension	% of persons*		
	Satisfied	Relatively Satisfied	Unsatisfied
Appearance	51.3	25.8	22.9
Comfort	50.4	42.7	6.8
Pain	64.8	26.4	8.8
Performance	83.4	13.9	2.7
Eating restriction	82.5	14.3	3.2
Total score	54.7	42.9	2.4

* Satisfied: scores from 7 to 10
 Relatively satisfied: scores from 6.9 to 0
 Unsatisfied: scores from less than 0 to -10

Social impacts had a significant (although weak) correlation with clinical status.⁷ No significant difference was found between males and females in their distribution of impacts for all dimensions. For the Appearance, Performance and Eating Restriction categories and also for the total score of the questionnaire, a difference was observed between social classes ($P < 0.001$). Low social class and the high DMFT group had a higher number of negative impacts ($P < 0.001$). On the other hand, comfort and Pain presented a significant difference on the distribution of DMFT groups. Regression analysis was conducted using the total score of the questionnaire as the dependent variable. Social class, gender and clinical variables were the independent variables analyzed. The model yielded an R-square of 0.24 and the significant predictors were decayed, missing and filled teeth and pocket depth ($P < 0.001$).

DISCUSSION AND EVALUATION

One aspect to be highlighted in DIDL is the degree of flexibility offered in terms of aggregating and disaggregating data (either individual items, dimension scores or total score). Although criticized, a total score reproduces the total impact subjects are experiencing, and since dimensions sometimes may not impact separately, it appears important to have this view of the individual as a whole. Results from this study appear to show that dimensions tend to differ in importance for an individual and also that weights that quantify this difference should be considered before obtaining a total score. Another point to be stressed is that in the total score generated by DIDL, weights attributed to dimensions (by each respondent) are personal. That is, the importance attributed to a dimension by a given individual is directly associated with his or her own impacts on that dimension. For example: in a group of 100 subjects, 10 of whom come from a different culture or have more impacts on appearance, the weights attributed by those ten individuals to that dimension, in particular, should, most likely, differ substantially from those weights chosen by the majority of subjects. The more personal weights used in DIDL would highlight that difference.

There is clearly room for improving DIDL. DIDL involves a quite large number of items in its current form. Nevertheless, that is not an easy task to accomplish, since a smaller number of items could have impact on reliability. In conjunction an 'ideal' number of response options for items (from three to five) should be investigated.

The measure is presently being tested for sensitivity. For the portion of the sample so far analyzed, there has been an increase on positive impacts after dental treatment. Complete results for sensitivity should be available by the end of the year. In addition a subjective set of questions were conducted to improve the construct validation of DIDL.

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Table Chapter 12.3: Dental Impact on Daily Living questionnaire*Instructions*

The interviewer uses a questionnaire, a scale and separate sheets to record answers from respondents. Before interviewing people, the questionnaire and the scale should be shown to the respondents. Confidentiality of the information and the existence of no right or wrong answers should be stressed.

Respondents should be told that questions from five different dimensions are going to be asked of them. In addition, it should also be mentioned that respondents are to be asked about the degree of importance they attribute to each dimension. Each dimension should be introduced in turn:

- Dental Appearance: Consists of the appearance of the mouth,
- Mouth Comfort: Is related to not having complaints of discomfort and/or unpleasant status caused by any problem in the mouth (i.e. Bleeding gums, packing food). It should be stressed that Mouth Comfort is not the same as Pain.
- Oral Pain: It should be introduced by means of its negation - not feeling pain from the teeth and mouth,
- Performance: It is related to the degree to which oral status may affect the ability to carry out daily functions and interactions with people,
- Eating Restriction: It is related to not having difficulties to eat, caused by poor biting and/or chewing.

After administering the questionnaire the scale should be introduced. Dimensions should be once again explained and respondents asked to record on the scale the relative importance they attribute to each dimension (in relation to others).

There are five scales, one for each dimension. All the scales range from 0 to 10 (0 being the lowest value, meaning totally unimportant and 10 being the highest value, meaning extremely important). One should then ask the questions 'Would you please mark, using the arrows and changing their position as much as you like, how important each dimension is to you in comparison with the others?' It should be explained that dimensions could be marked more important, equally important or less important than others. It should also be suggested that 'You can start marking the dimension/s that is/are more important. After that, mark the values for the dimensions which are less important. You can change marking as much as you want'.

Table Chapter 12.3 continued*Questionnaire:*

Questions about your teeth will be asked. There is no right or wrong answer. Feel free to ask anything you do not understand.

Question (and dimension)	Response	(code)
1. How satisfied have you been, on the whole, with your teeth in the last three months? (dimension: Appearance)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)
2. Have your teeth worried you with any problem in the last three months? (caused concern) (dimension: Comfort)	- always	(-1)
	- frequently	(-1)
	- sometimes	(0)
	- rarely	(0)
	- never	(+1)
3. How satisfied have you been with the appearance of your teeth in the last three months? (dimension: Appearance)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)
4. How satisfied have you been with the colour of your teeth in the last three months? (dimension: Appearance)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)
5. How satisfied have you been with the position of your teeth (if they are crooked or not) in the last three months? (dimension: Appearance)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)
6. Some people when not satisfied with their teeth avoid showing them when they smile. Have you tried to avoid showing your teeth when smiling or laughing in the last three months? (dimension: Performance)	- always avoided	(-1)
	- frequently avoided	(-1)
	- sometimes avoided	(0)
	- rarely avoided	(0)
	- never avoided	(+1)
7. How satisfied have you been in showing your teeth when you smiled in the last three months? (dimension: Performance)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)

Table Chapter 12.3 continued

Question (and dimension)	Response	
8. Sometimes, when people eat, they get food stuck between their teeth. Have you had any problems with food getting stuck between your teeth in the last three months? (dimension: Comfort)	- always	(-1)
	- frequently	(-1)
	- sometimes	(0)
	- rarely	(0)
	- never	(+1)
9. Sometimes people have bad breath. Have you had any bad breath caused by any problems in your mouth, during the last three months? (dimension: Comfort)	- always	(-1)
	- frequently	(-1)
	- sometimes	(0)
	- rarely	(0)
10. Have you had to change the food you eat for a long period of time (more than three months) because of anything the matter with your teeth? (dimension: Eating Restriction)	- yes	(-1)
	- no	(+1)
11. Have you had to change the way you prepare your food for a long period of time (more than three months) because of anything the matter with your teeth? (dimension: Eating Restriction)	- yes	(-1)
	- no	(+1)
12. How well have you been able to chew your food, without having any difficulties caused by your teeth in the last three months? (dimension: Eating Restriction)	- very well	(+1)
	- well	(+1)
	- more or less	(0)
	- badly	(-1)
	- very badly	(-1)
13. How satisfied are you with your chewing? (dimension: Eating Restriction)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)
14. How well have you been able to bite your food, without having any difficulties caused by your teeth, in the last three months? (dimension: Eating Restriction)	- very well	(+1)
	- well	(+1)
	- more or less	(0)
	- badly	(-1)
	- very badly	(-1)
15. How satisfied are you with your biting? (dimension: Eating Restriction)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)

Table Chapter 12.3 continued

Question (and dimension)	Response	
16. Have you had any loose teeth in the last three months? (dimension: Comfort)	- yes	(-1)
	- no	(+1)
17. Have you had any spontaneous toothache (toothache without any specific cause) in the last three months? (dimension: Pain)	- yes	(-1)
	- no	(+1)
18. Have you had any toothache when you ate or drank anything cold/hot or sweet in the last three months? (dimension: Pain)	- yes	(-1)
	- no	(+1)
19. Have you had to change your food since this pain began? (dimension: Pain)	- always	(-1)
	- frequently	(-1)
	- sometimes	(0)
	- rarely	(0)
	- never	(+1)
20. Have you had any pain in your jaw joint in the last three months? (dimension: Pain)	- every day	(-1)
	- once a week	(-1)
	- less than once a week	(0)
	- just in some movements	(0)
	- none	(+1)
21. How much did the appearance of your teeth affect your working capacity during the last three months? (dimension: Performance)	- helped a lot	(+1)
	- helped	(+1)
	- was indifferent	(+1)
	- disturbed	(-1)
	- disturbed a lot	(-1)
22. If you had toothache or any jaw joint pain, how much did this pain affect your working capacity during the last three months? (dimension: Performance)	- extremely	(-1)
	- very much	(-1)
	- moderately	(0)
	- little	(0)
	- none	(+1)
23. How much did the function of your teeth (like, eating, talking) affect your working capacity during the last three months? (dimension: Performance)	- helped a lot	(+1)
	- helped	(+1)
	- was indifferent	(+1)
	- disturbed	(-1)
	- disturbed a lot	(-1)

Table Chapter 12.3 continued

Question (and dimension)	Response
24. How much did the appearance of your teeth affect your contact with people (for example, going out with friends) during the last three months? (dimension: Performance)	- helped a lot (+1)
	- helped (+1)
	- was indifferent (+1)
	- disturbed (-1)
	- disturbed a lot (-1)
25. If you had toothache or any jaw joint pain, how much did this pain affect your contact with people (for example, going out with friends) during the last three months? (dimension: Performance)	-extremely (-1)
	- very much (-1)
	- moderately (0)
	- little (0)
	- none (+1)
26. How much did the function of your teeth (like eating, talking) affect your contact with people (for example, going out with friends) during the last three months? (dimension: Performance)	- helped a lot (+1)
	- helped (+1)
	- was indifferent (+1)
	- disturbed (-1)
	- disturbed a lot (-1)
27. How much did the appearance of your teeth affect your romantic life during the last three months? (dimension: Performance)	- helped a lot (+1)
	- helped (+1)
	- was indifferent (+1)
	- disturbed (-1)
	- disturbed a lot (-1)
28. If you had toothache or any jaw joint pain, how much did this pain affect your romantic life during the last three months? (dimension: Performance)	- extremely (-1)
	- very much (-1)
	- moderately (0)
	- little (0)
	- none (+1)
29. How much did the function of your teeth (like eating, talking) affect your romantic life during the last three months? (dimension: Performance)	- helped a lot (+1)
	- helped (+1)
	- was indifferent (+1)
	- disturbed (-1)
	- disturbed a lot (-1)
30. If you had any toothache or any jaw joint pain in the last three months, how much has this pain affected your sleep? (dimension: Performance)	- extremely (-1)
	- very much (-1)
	- moderately (0)
	- little (0)
	- none (+1)

Table Chapter 12.3 continued

Question (and dimension)	Response	
31. If you had any toothache or any jaw joint pain in the last three months, how much stress has this pain caused you? (dimension: Performance)	- extreme	(-1)
	- very much	(-1)
	- moderate	(0)
	- little	(0)
	- none	(+1)
32. Have your teeth helped you to feel confident during the last three months? (dimension: Performance)	- helped a lot	(+1)
	- helped	(+1)
	- was indifferent	(+1)
	- disturbed/ affected	(-1)
	- disturbed/ affected a lot	(-1)
33. Have your teeth caused any embarrassment in the last three months? (dimension: Performance)	- extremely	(-1)
	- very much	(-1)
	- moderately	(0)
	- little	(0)
	- none	(+1)
34. How satisfied have you been, on the whole, with your gums in the last three months? (dimension: Comfort)	- very satisfied	(+1)
	- satisfied	(+1)
	- more or less	(0)
	- unsatisfied	(-1)
	- very unsatisfied	(-1)
35. Have your gums bled in the last three months? (dimension: Comfort)	- yes	(-1)
	- no	(+1)
36. Have you felt any sensitivity when you ate or drank anything cold or acidic because your gums retracted in the last three months? (dimension: Comfort)	- yes	(-1)
	- no	(+1)

Figure Chapter 12.1: Scale for Dental Impact on Daily Performance

Chapter 13

ORAL HEALTH QUALITY OF LIFE INVENTORY (OH-QoL)

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Supported by: NIH-NIDR 1 P50 DE 10756

BACKGROUND

The Oral Health Quality of life Inventory (OH-QoL) is a 15-item dental-specific measure that assesses a person's satisfaction with his or her oral health and functional status, as well as the importance he or she attributes to oral health and functional status. We developed the OH-QoL to measure a person's subjective well-being with respect to his or her oral health and functional status. The OH-QoL was developed for the Oral Health Quality of life subproject of our National Institute of Health funded Research Center on Oral Health in Aging. The specific aims of the Oral Health Quality of life subproject are 1) to evaluate the impact of oral health and functional status on quality of life and 2) to model the relationship of "objective" and "subjective" measures of oral health and functional status to assessments of overall quality of life. Inclusion of the "subjective well-being" dimension of quality of life assessment complements traditional "objective functional status" measures, such as the Sickness Impact Profile¹, which assess self-reported symptom frequency and functional impacts; thus, reestablishing the role of the personal or "humanistic" element into the quality of life equation.^{2,3,4}

DEVELOPMENT OF THE INSTRUMENT

OH-QoL and the Oral Health Quality of Life Interview. The 15-item OH-QoL, reproduced at the end of this Chapter (Table Chapter 13.4), is part of a larger home-based interview, the Oral Health Quality of Life Interview (OHQOLI)*. In addition to the OH-QoL, OHQOLI includes self-report assessments of oral health and functional status (SROH), a Nutrition Quality of Life Index (NutQoL), and an interview version of the Quality of Life Inventory (QOLI™).^{3,4} The SROH items are "objective functional status" measures of oral health and functional status. These self-report measures ask about the frequency of oral health problems and their impact on a person's ability to function in daily life. Figure Chapter 13.1 displays sample SROH and OH-QoL items for dental-facial pain.

* A copy of the complete OHQOLI interview is available in English and Spanish by request. Send all requests to John E. Cornell, GRECC/ALMMVH (182), 7400 Merton Minter Blvd., San Antonio, TX 78249.

Figure Chapter 13.1: Sample Oral Pain Items from the SROH and OH-QoL Sections of the OHQOLI

SROH Pain-Related Symptom Item	SROH Pain-Related Functional Status Item	QH-QoL Pain-Related Item
My mouth hurts: 1. Never 2. Hardly Ever 3. Sometimes 4. Fairly Often 5. Always 6. DK/REF	Pain in my mouth keeps me from eating the foods I like: 1. Never 2. Hardly Ever 3. Sometimes 4. Fairly Often 5. Always 6. DK/REF	How Important is it to you to be able to bite and chew foods without pain? 1. Not at all Important 2. Somewhat Important 3. Very Important How happy are you with your being able to bite and chew foods without pain? 1. Unhappy 2. Somewhat Unhappy 3. Somewhat Happy 4. Happy

NutQoL items measure the importance and satisfaction attributable to dietary habits like the daily consumption of fresh fruit and vegetables, taking daily vitamin supplements, and eating low fat meals. The QOLI™ measures a person's assessment of importance and satisfaction within 16 key areas of life: e.g., health, self-esteem, goals and values, money, and leisure activities.^{3,4} OH-QoL items ask about the importance of oral health and functional status to the person, and it assesses his or her level of satisfaction with current oral health and functional status. Construction of OH-QoL items followed the response format developed for the QOLI™.^{3,4}

Item Generation for the SROH and OH-QoL. A synthesis of the literature and expert judgment produced an initial pool of 50 items measuring self-reported oral health and functional status (SROH), 22 items measuring oral health quality of life (OH-QoL), and 11 items measuring nutrition quality of life (NutQoL). We wrote OH-QoL and SROH items for each of 6 dental-specific domains: 1) taste and salivary function, 2) dental-facial aesthetics, 3) general oral health and functional status, 4) dental-facial pain, 5) speech, 6) chewing and swallowing.

Initial Screening for SROH and OH-QoL Items. The initial items were administered to a systematic sample of $N = 63$ adult patients scheduled for dental diagnostic screening at the University of Texas Health Science Center Dental Clinic. Half the sample were Mexican Americans. Examination of item means and standard deviations flagged items that had little variability or were prone to floor and ceiling effects. Three OH-QoL items were dropped after examination of item means and standard deviations. In addition, item-total correlations (r_{iT}) and the impact removing an item would have on the instrument's internal consistency (coefficient alpha, α) revealed weak associations for some potential OH-QoL items with a total OH-QoL score derived from the sum of the importance \times satisfaction product for the 19 remaining candidate items. Four items had weak associations ($r_{iT} < .30$) with the total score. Removal of these OH-QoL items yielded an $\alpha = 0.91$ for the measure, and the correlation of the revised OH-QoL with the QOLI™ was $r = 0.65$.

Scoring the OH-QoL. OH-QoL items are rated on two dimensions: Importance and Satisfaction. Before scoring, the OH-QoL importance responses are recoded as 0 = not at all important, 1 = somewhat important, and 2 = very important. Satisfaction responses are recoded as -2 = unhappy, -1 = somewhat unhappy, +1 = somewhat happy, +2 = happy. An OH-QoL score for a given item is the product of importance \times satisfaction. The overall OH-QoL score is the mean value of the answered OH-QoL items; thus, yielding an almost interval level measure that ranges from a -4 to +4. One OH-QoL item is only asked of denture-wearers. Consequently, this item is scored only for denture-wearers. No overall OH-QoL score is computed, however, if 2 or more of the relevant items are assigned missing values.

EVALUATION OF THE INSTRUMENT

The final OHQOLI interview has 40 SROH items, 15 OH-QoL items, and 9 NutQoL items. The OH-QoL items are distributed among the related SROH items. Thus, the subjective well-being items appear immediately following the related objective functional status items in the questionnaire. The overall format of the OHQOLI is designed for interviewer administration. Several questions were added to smooth out transitions and trigger skip patterns in the interview. There are a total of 66 items among the SROH, OH-QoL, and NutQoL components of the OHQOLI. The measures were administered, along with the QOLI™^{3,4} and Frisch's Self-Confidence in Life Test (SILT™)^{5,6}, to another systematic sample of $N = 100$ adult patients scheduled for dental diagnostic screening at the University of Texas Health Science

Center Dental Clinic. The patients were between 20 and 84 years of age. Forty-two percent were male. Mexican Americans comprised 29% of the sample.

Complete data was available on $N = 98$ patients. The OH-QoL had an internal consistency of $\alpha = 0.84$. It had significant correlations of $r = 0.46$ and $r = 0.29$ with the QOLI™ and SILT™, respectively. The OH-QoL also correlated with a series of simple summative rating scales constructed from the 40 SROH items. These summative scales measure problems with salivary function, taste, dental-facial aesthetics, oral-facial pain, speech, chewing and swallowing and global oral health. The correlations of the OH-QoL with these scales ranged from $r = -0.23$ with self-reported speech problems to $r = -0.53$ with self-reported chewing and swallowing problems. All correlations were significant at the $P < 0.05$ level or less.

FINDINGS FROM THE USE OF THE INSTRUMENT

We recently presented a paper that examined the influence of age, gender, and ethnicity on the OH-QoL. Data were from the first $N = 290$ participants in the cross-sectional phase of the Oral Health: San Antonio Longitudinal Study of Aging (OH: SALSA).

The OH: SALSA is a comprehensive population based epidemiological survey of oral health and oral functional status. Participants represent a stratified random sample of Mexican American (MA) and European Americans (EA) from three socioeconomically distinct neighborhoods in San Antonio, Texas. Our sample is further stratified into 6 age-decade strata ranging from 35-44 to 75+ years. The survey participants are members of two cohorts involved in the San Antonio Heart Study and the San Antonio Longitudinal Study of Aging.

For these analyses, the sample was stratified by age (less than 65 years vs. 65 years or older), ethnic group (MA vs. EA), and gender. An ANOVA on the overall OH-QoL score revealed that MAs rated their overall OH-QoL as worse relative to EAs ($P \leq 0.002$). ANOVAs on the summative oral health and functional status scales derived from the SROH showed that MAs reported greater dissatisfaction with dental-facial aesthetics ($P \leq 0.001$) and their overall oral health ($P \leq 0.001$) than EAs. These results suggest that important ethnic group differences may exist in subjective assessments of oral quality of life, and that these differences are associated with dissatisfaction with dental-facial aesthetics and overall oral health.

ALTERNATE FORMS

Our OH: SALSA survey involved Spanish-speaking (MA-Spa) and English-speaking MAs (MA-Eng), as well as English-speaking EAs (EA-Eng). A translation/backtranslation process, followed by an expert review of the translations and back-translations, produced a Spanish-version of our entire OHQOLI instrument.⁷ Valid use of the OH-QoL with MA-Spa and MA-Eng subjects, however, depended on a clear demonstration of its cross-cultural equivalence and psychometric integrity for each distinct linguistic and cultural subgroup involved in our epidemiological survey.^{7,8}

Data on $N = 605$ OH: SALSA participants were used to evaluate differential validity of the OH-QoL. All participants completed the OHQOLI and a 4-hour comprehensive oral health and functional status evaluation. The NIDR Diagnostic Criteria and Procedures for Oral Health Surveys provided a standardized protocol for our clinical assessment of oral health and functional status.⁹ Criterion measures were derived from the SROH and the periodontal section of the NIDR protocol.

Participant Characteristics and Quality of Life. Demographic data are displayed in Table Chapter 13.1, along with summary data on the OH-QoL and the interview adaptation of the QOLI™. One-way ANOVAs and contingency table Chi-square tests were used to evaluate group differences on these measures. The three ethnic/language groups do not differ with respect to age, gender, or denture status. Response rates for the OH-QoL and QOLI™ are near 100% for each ethnic/language group. Mean values for the OH-QoL and QOLI™ are relatively high, given a maximum possible score of +4.00, across all 3 ethnic/language groups. EA-Eng do have significantly higher OH-QoL scores than either MA-Eng or MA-Spa subjects. EA-Eng score significantly lower, however, on the QOLI™ than either MA-Spa or MA-Eng subjects. Hispanics in the national norming sample for the QOLI™ also had significantly higher scores than either European Americans or African Americans.³

Consistency in Psychometric Properties. Internal consistency coefficients for the OH-QoL are $\alpha = 0.79$ for EA English-speakers, $\alpha = 0.71$ for MA English-speakers, and $\alpha = 0.81$ for MA Spanish-speakers (Table Chapter 13.1). Except for MA-Spa subjects, the internal consistency coefficients remain within this range when the data is further stratified by denture-wearers and non-denture-wearers. Internal consistency for MA-Spa is only $\alpha = 0.59$. Complete data was only available on $N = 25$ MA-Spa subjects.

Table Chapter 13.1: Summary statistics for demographic characteristics and quality of life measures

	Ethnic group/language used			P-value
	EA-Eng: European American/ English (N = 281)	MA-Eng: Mexican American/ English (N = 256)	MA-Spa: Mexican American/ Spanish (N = 66)	
Age (mean \pm sd*)	62.4 (\pm 11.7)	61.3 (\pm 10.3)	64.5 (\pm 8.8)	0.099
Age range	36-81	36-78	39-78	
% Female	54.1%	53.5%	68.2%	0.085
% with Dentures	36.4%	43.4%	45.2%	0.211
OH-QoL	98.5%	100.0%	99.6%	1.000
QOLI	98.5%	100.0%	100.0%	1.000
OH-QoL (mean \pm sd)	3.13 (\pm 0.99)	3.05 (\pm 0.99)	2.70 (\pm 1.33)	0.013
QOLI (mean \pm sd)	3.00 (\pm 0.86)	3.18 (\pm 0.93)	3.31 (\pm 0.74)	0.009
Internal consistency	0.79	0.71	0.81	
Correlation with QOLI	0.45 [†]	0.20 [†]	0.25 [†]	

* sd=standard deviation; † P<0.001

Correlation of the OH-QoL with the QOLI™ are significant within all three ethnic/language groups (Table Chapter 13.1). The OH-QoL correlation with the QOLI™ is significantly higher for EA-Eng compared with MA-Eng subjects ($P \leq 0.0006$). No significant differences are observed for the correlation of OH-QoL with QOLI™ between either EA-Eng or MA-Eng and MA-Spa subjects.

Self-Reported Oral Health and Functional Status. Eleven scales were formed from the 40 SROH items. Eight scales are measures of oral health or functional status problems common to denture-wearers and non-denture-wearers: 1) salivary function, 2) taste, 3) sensory problems, 4) dissatisfaction with dental-facial aesthetics, 5) halitosis, 6) bleeding gums, 7) oral facial pain, and 8) chewing and swallowing difficulties. Another scale measures social problems with dentures, and is, therefore, applicable only for denture-wearers. Another set of items measure self-reported oral hygiene behavior, and a final scale is comprised of items that measure an individual's assessment of his or her overall oral health and functional status.

Correlations of the OH-QoL with 10 of the self-report measures are displayed by ethnic/language group in Table Chapter 13.2. The magnitude and significance level for the self-report indices are similar to those reported in the earlier studies. They also show remarkable consistency across the three ethnic/language groups. For example, the correlations of denture problems and OH-QoL range from $r = -0.43$ to $r = -0.47$. The correlations of self-reported dissatisfaction with dental-facial aesthetics and OH-QoL range from $r = -0.54$ to $r = -0.59$. Although not all sets of correlations are consistent in magnitude, the bulk of the evidence suggests that OH-QoL scores do behave as expected with respect to the other self-report measures within each ethnic/language group.

Table Chapter 13.2: Correlation of OH-QoL Score with Self-Report Oral Health Measures

Measure	Ethnic group/language used		
	EA-Eng: European American/ English (<i>N</i> = 281-283)	MA-Eng: Mexican American/ English (<i>N</i> = 254-256)	MA-Spa: Mexican American/ Spanish (<i>N</i> = 54-66)
Salivary Function	-0.40§	-0.35§	-0.41‡
Taste	-0.24§	-0.27§	-0.43‡
Sensory Problems	-0.40§	-0.35§	-0.31*
Dental-Facial Aesthetics	-0.54§	-0.55§	-0.59§
Halitosis	-0.30§	-0.24§	-0.43‡
Bleeding Gums	-0.29§	-0.20†	-0.24
Pain	-0.52§	-0.39§	-0.41‡
Chewing and Swallowing	-0.34§	-0.34§	-0.54§
Global Oral Health	0.58§	0.47§	0.62§
Denture Problems	-0.45§ (<i>N</i> = 81)	-0.47§ (<i>N</i> = 87)	-0.43* (<i>N</i> = 26)

* $P < 0.05$; † $P < 0.01$; ‡ $P < 0.001$, § $P < 0.0001$

Clinical Measures of Oral Health and Functional Status. Clinical measures were derived from the periodontal section of the NIDR Diagnostic Criteria and Procedures for Oral Health Surveys.⁹ Some measures are rather simple: e.g., the number of teeth, percent teeth with plaque, and percent teeth with calculus. Other indices were derived as weighted averages taken across the number of

units at risk (teeth or sites probed). The weights were chosen to reflect the degree of severity.¹⁰ Validity coefficients for the OH-QoL with the nine periodontal measures and a summary score derived from the prosthesis assessment section of the clinical evaluation are displayed in Table Chapter 13.3.

Table Chapter 13.3: Correlation of OH-QoL Score with Clinical Oral Health Measures

Measure	Ethnic group/language used		
	EA-Eng: European American/ English (N = 258-264)	MA-Eng: Mexican American/ English (N = 226-234)	MA-Spa: Mexican American/ Spanish (N = 57-60)
Number of Teeth	0.25§	0.23‡	0.23
% Teeth with Plaque	-0.23‡	-0.19†	-0.25
Gingival Inflammation Index	-0.18†	-0.32§	-0.15
% Gingival Bleeding	-0.17†	-0.38§	-0.07
% Teeth with Calculus	-0.18†	-0.35§	-0.31*
Mobility Index	-0.18†	-0.26§	-0.38†
Recession Index	-0.17†	-0.10	-0.34*
Pocket Depth Index	0.04	-0.19†	-0.24
Loss of Attachment Index	-0.16*	-0.13	-0.33*
Prosthesis Assessment Score	-0.15 (N = 53)	-0.11 (N = 55)	-0.15 (N = 16)

* P < 0.05; † P < 0.01; ‡ P < 0.001, § P < 0.0001

DISCUSSION AND EVALUATION

The OH-QoL is designed to assess the “subjective well-being” aspects of a person’s evaluation of his or her oral health and functional status. It emphasizes the person’s assessment of the importance of oral health and functional status in his or her life, as well as his or her satisfaction with current oral health and functional status. Our data suggest that the OH-QoL has reasonable internal consistency and validity. The data also suggest that OH-QoL scores measure the same construct among MA-Eng and MA-Spa subjects as it does for EA-Eng subjects. Correlations of the OH-QoL score with self-reported and clinically assessed oral health and oral function support its validity. Some weaknesses do appear, however, with respect to some psychometric properties and the correlation of the Spanish language version of the OH-QoL and clinical measures periodontal status. On balance, however, the data tend to support the use of our Spanish-language version of the OH-QoL with this population.

One disadvantage of the OH-QoL is that the items are scattered throughout the larger OHQOLI interview. It is not known how well it would perform outside this context. Similar quality of life measures, such as the QOLI™, provide extensive definitions for each area of life the individual is asked to assess. This reduces the ambiguity inherent in such constructs as community, health, love relationships, etc. The distribution of OH-QoL items within the OHQOLI interview provide a context for the OH-QoL items. This context implicitly reduces some of the ambiguity that may accompany oral health related constructs.

The purpose of the OH-QoL is to expand our definition of oral health quality of life to include the “subjective well-being” or personal dimension.² As such, it is intended to complement “objective functional status” measures of oral health and functional status, such as the Oral Health Impact Profile¹¹ and the Geriatric Oral Health Assessment Index,¹² which focus on the psychosocial and functional sequelae of problems with oral health or oral function. Taken together the “subjective well-being” and “objective functional status” may provide increased power to model the relationship between oral health and a person’s overall quality of life.

Assessment of the subjective dimensions of importance and satisfaction with respect to oral health and function may also help explain some clinical phenomena. It may help explain continued patient dissatisfaction with dental care when objective clinical indicators suggest that optimal oral health and function have been

restored. Patient compliance with oral hygiene and treatment may also be influenced by the subjective dimension. Although designed primarily as a research instrument, the OH-QoL, or some revision of it, could provide clinicians information that can pinpoint psychological areas that need to be addressed in order to increase patient acceptance of dental treatment and his or her compliance with oral hygiene and treatment related activities.

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Table Chapter 13.4: Oral Health Quality of Life (OH-QoL) inventory

Instructions: The following statements are about your oral health, speech and eating habits. For each statement, please give the answer that comes closest to saying what is true for you. There are no right or wrong answers; so, please tell us what is true for you.

- 1 a. How important is it for your mouth to feel moist:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with how moist your mouth feels:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 2 a. How important is it to you not to have to stop what you are doing to get a drink of water because your mouth is dry:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with the number of times you have to stop what you are doing to get a drink of water because your mouth is dry:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 3 a. How important is your being able to taste your food:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with your being able to taste your food:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 4 a. How important to you is your sense of smell:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with your sense of smell:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |

continued

Table Chapter 13.4 continued

- 5 a. How important is it to you how your teeth or dentures look:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with how your teeth or dentures look:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 6 a. Do you have and wear dentures or partial dentures?
- | | |
|---|----------------------|
| 1 | Yes? <u>or</u> |
| 2 | No? ----> SKIP TO 7a |
- b. How important is it to you that your dentures don't slip or make noise:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- c. How happy are you with how often your dentures slip or make noise:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 7 a. How important is the health of your mouth to you:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with the health of your mouth?
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 8 a. How important is how your breath smells:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with the way your breath smells:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |

continued

Table Chapter 13.4 continued

- 9 a. How important is it to you to drink hot and cold liquids without pain:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with drinking hot and cold liquids without pain:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 10a. How important is it to you to speak clearly:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with your ability to speak clearly:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 11a. How important is it to you to be able to bite or chew hard foods such as nuts, apples, dried fruit, crunchy breads or rolls:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with your being able to bite or chew hard foods such as nuts, apples, dried fruit, crunchy breads or rolls:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
- 12a. How important is it to you to be able to bite and chew food without pain:
- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |
- b. How happy are you with your being able to bite and chew foods without pain:
- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |

continued

Table Chapter 13.4 continued

13a. How important is it to you to eat all your food without it sticking in your mouth (under your dentures; in your cheeks; on your tongue):

- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>Or</u> |
| 3 | Very Important? |

b. How happy are you with your being able to eat all your food without it sticking in your mouth (under your dentures; in your cheeks; on your tongue):

- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |

14a. How important is it for you to swallow your food without choking or it getting caught in your throat:

- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |

b. How happy are you with your being able to swallow your food without choking or it getting caught in your throat:

- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |

15a. How important is it to you to chew any food you want:

- | | |
|---|-------------------------------|
| 1 | Not at all Important? |
| 2 | Somewhat Important? <u>or</u> |
| 3 | Very Important? |

b. How happy are you with your ability to chew any food you want:

- | | |
|---|---------------------------|
| 1 | Unhappy? |
| 2 | Somewhat Unhappy? |
| 3 | Somewhat Happy? <u>or</u> |
| 4 | Happy? |
-

Chapter 14

ORAL IMPACTS ON DAILY PERFORMANCES

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BACKGROUND

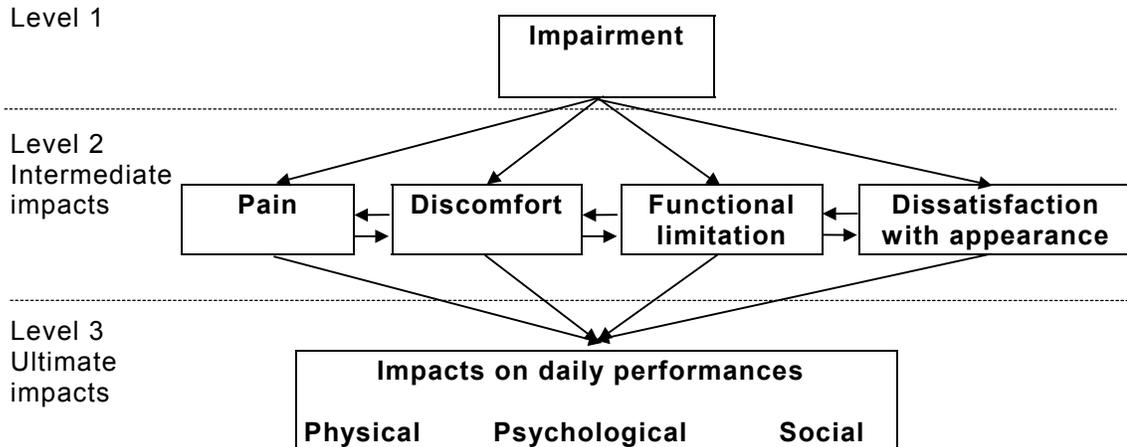
The Oral Impacts on Daily Performances¹ (OIDP) aims to provide an alternative sociodental indicator which focuses on measuring the serious oral impacts on the person's ability to perform daily activities. The approach should provide advantages, not only in terms of being easier to measure the behavioral impacts on performances than the feeling-state dimensions, but also in being short. That will be achieved by measuring the serious consequences of outcomes.

DEVELOPMENT OF THE INSTRUMENT

Theoretical Framework. The theoretical framework of OIDP is presented in Figure Chapter 14.1. It was modified from the World Health Organization's (WHO) International Classification of Impairments, Disabilities and Handicaps² amended for dentistry by Locker.³ The main modification was that different levels of consequence variables were established. The first level refers to the oral status, including oral impairments, which most clinical indices attempt to measure. The second level, "the intermediate impacts", includes the possible earliest negative impacts caused by oral health status: pain, discomfort or functional limitation. Dissatisfaction with appearance was added in this level since studies indicated that it was a major dimension of oral health outcomes.⁴⁻⁶ In addition, functional limitation may cause pain, discomfort or dissatisfaction with appearance and vice versa. The third level, or the "ultimate impacts" represents impacts on ability to perform daily activities which consists of physical, psychological and social performances. Any of the dimensions in the second level may impact on performance ability. This third level is equivalent to disability and handicap dimensions in the WHO² model .

Figure Chapter 14.1: Theoretical framework of consequences of oral impacts

(Modified from the WHO's International Classification of Impairments, Disabilities and Handicaps²)



The OIDP focuses on measuring the Level Three consequences which provides four main advantages. First, this approach makes the measure concise and yet covers the main consequences. Other concise indicators concentrate on some of the intermediate impacts in Level Two such as pain or chewing ability. OIDP, on the other hand, encompasses all of the consequences of the Level Two impacts in performing daily activities. Second, it helps to avoid, or at least reduce, overscoring from repeat scoring of the same impacts at each of the three levels. Third, only the significant impacts are recorded, by eliminating minor niggling conditions which do not lead to impacts on daily performances. Lastly, it is less difficult to measure the behavioral impacts, in terms of performance of daily activities (e.g., eating, speaking), than the feeling-state dimension (e.g., discomfort, worry). The reliability and validity of behaviorally-based measures are easier to establish.⁷

Contents. The nine physical, psychological and social performances were developed from the Comparison Table of Disability Indices⁸ and from various other sociomedical and sociodental indicators, to achieve content validity.^{5,6,9-15} After the analysis of internal consistency and item-total score correlation, one of the performance measures, 'Doing light physical activities', was considered to be redundant and excluded, so the final version of OIDP consists of eight daily performances (Table Chapter 14.1).

Table Chapter 14.1: Performances assessed in the Oral Impacts on Daily Performances

- a. Eating and enjoying food
 - b. Speaking and pronouncing clearly
 - c. Cleaning teeth
 - d. Sleeping and relaxing
 - e. Smiling, laughing and showing teeth without embarrassment
 - f. Maintain usual emotional state without being irritable
 - g. Carrying out major work or social role
 - h. Enjoying contact with people
-

The Oral Impacts on Daily Performances index attempts to use the logical approach of impact quantification by assessing both frequency and severity. A complementary objective is that the severity score weights the relative importance of respondents' perceived impacts within different performances.

Frequency score. The criteria used for the description of both frequency (periodic pattern) and a spell period are modified from the questionnaire of the National Survey of Health and Development (Table Chapter 14.2).¹⁶ The respondent is asked to describe the frequency of impact by the pattern of occurrence. The basic guideline for the border line cases in differentiating between "regular" and "spell" pattern, is that the spell pattern is used for the case of less frequency of impacts than once a month. For example, a person who twice experienced impacts on eating during the past six months for 5 days in total should receiving a score of 2 according to a period/spell basis, rather than score of 1 according to a regular/periodic basis.

Table Chapter 14.2: Criteria of frequency score of affected performances over past six months

Frequency (for people affected on a regular or periodic basis)	Duration (for people affected for a period/spell)	Score
Never affected in past 6 months	0 days	0
Less than once a month	Up to 5 days in total	1
Once or twice a month	Up to 15 days in total	2
Once or twice a week	Up to 30 days in total	3
3-4 times a week	Up to 3 months in total	4
Every or nearly every day	Over 3 months in total	5

The time frame for the OIDP was set at the past 6 months period as that has often been used in chronic pain studies and considered to be appropriate for the commonly occurring oral conditions. In case of blank or "don't know" response, the mean score of sample in that item is assigned. Respondents with more than two missing scores are abandoned.

Severity score. The perceived severity of impacts in the OIDP was derived by asking respondents to rate the score, ranging from 0 to 5, as an indication of how much trouble it caused to their daily living. Five represents "very severe" and 0 represents "none". Fractional responses, such as 2.5, were not permitted.

Scoring method. The score representing the total impact on each performance was calculated by multiplying the frequency with the severity score. The total score was the sum of all the performance scores for an individual. Then the sum was divided by the maximum possible score (8 performances \times 5 frequency score \times 5 severity score = 200) and multiplying by 100 to give a percentage score (Table Chapter 14.3).

Table Chapter 14.3: Scoring method for Oral Impact on Daily Performances

OIDP score =

$$\begin{aligned} & [(\text{frequency score}^* \text{ of "Eating"} \times \text{severity score}^* \text{ of "Eating"}) + \\ & (\text{frequency of "Speaking"} \times \text{severity of "Speaking"}) + \\ & (\text{frequency of "Cleaning teeth"} \times \text{severity of "Cleaning teeth"}) + \\ & (\text{frequency of "Sleeping"} \times \text{severity of "Sleeping"}) + \\ & (\text{frequency of "Smiling"} \times \text{severity of "Smiling"}) + \\ & (\text{frequency of "Emotional stability"} \times \text{severity of "Emotional stability"}) + \\ & (\text{frequency of "Major role"} \times \text{severity of "Major role"}) + \\ & (\text{frequency of "Contact with people"} \times \text{severity of "Contact with people"})] \end{aligned}$$

$\times 100 / 200^\dagger$

* Scores range from 0 to 5

† maximum possible score [Sum of 8 performances score \times 5 frequency score \times 5 severity score] = 200

EVALUATION OF THE INSTRUMENT

The proposed questionnaire was pilot tested and then tested on 501 villagers aged 35-44 years in 16 villages in Thailand selected by cluster random sampling.¹ Some 73.6 % of all subjects had at least one daily performance affected by an oral impact during the past 6

months. Mean number of performances affected in the total sample was 1.9 (SD. 1.8) and in affected persons, 2.6 (SD 1.6).

The inter-item Pearson correlation coefficients among the scores of eight performances ranged from 0.03 to 0.54, with a mean of 0.19 and variance of 2.16. Test- retest reliability was studied in 47 subjects during the time interval of 3 weeks. The Kappa for frequency scoring ranged from 0.95 to 1.0 while Kappa for severity scores ranged from 0.57 to 1.0. Reliability coefficient of item scores ranged from 0.91 to 1.0. The Cronbach alpha of the scale (internal consistency among items of questions) was 0.65. The standard item alpha, in which all items variances were standardized, was 0.67.

To investigate whether the multiplication of frequency score and severity score added more details of impact than using only frequency or severity, three multiple regression models were applied in prediction of two major variables; DMFT and number of sextants with deep periodontal pockets. The three approaches were, all subsets regression, the stepwise method to select the best predictor among the three kinds of scores, and the hierarchical regression. For all three approaches, the OIDP score was a better predictor than either frequency or severity score separately. All subset regression model with OIDP showed the lowest mean square residuals. In the stepwise method, only OIDP was included in the equation to predict both dependent variables. However, the improvement, by multiplying frequency and severity score, was not statistically significant ($P>0.01$).

For construct validity test, the OIDP scores of a subgroup with better oral condition, in terms of number of functional teeth, decayed teeth, missing teeth, and sextants with deep periodontal pockets, were much lower than those with poorer oral conditions (Table Chapter 14.4).¹ In criterion validity test, subjects were grouped into 3 groups according to their overall perception of trouble from oral problems; those who reported little, fair or very much trouble from oral conditions. OIDP scores for the three groups increased from a mean score of 3.8 in the group with "little trouble" to 10.7 and 18.4 in "fair trouble" and "very much trouble" groups; percentage increases of 184% and 384%, respectively (Table Chapter 14.4) . All the above differences in scores were strongly statistical significant ($P<0.001$).

The final version of the Oral Impacts on Daily Performances is shown in Table Chapter 14.5

Table Chapter 14.4: Comparison of OIDP scores between groups with different oral conditions and overall perceptions

<u>Subgroups</u>	<u>n</u>	<u>OIDP score</u>		<u>difference</u>	<u>% increase</u>	<u>P-value</u>
		<u>mean (sd*)</u>	<u>score (se†)</u>	<u>score‡</u>		
<u>Construct validity test</u>						
Number of functional teeth						
32 teeth	131	4.1 (6.6)	7.1 (1.2)	174.9	<0.001§	
26 teeth or less	80	11.1 (10.1)				
Number of decayed teeth						
none	282	5.9 (8.0)	4.3 (1.1)	72.6	<0.001§	
3 teeth or more	73	10.2 (9.3)				
Number of missing teeth						
none	217	5.1 (6.8)	6.6 (1.8)	129.4	<0.001§	
5 teeth or more	43	11.7 (11.6)				
Number of sextants with deep periodontal pockets						
none	394	6.4 (7.7)	6.2 (1.5)	96.9	<0.001§	
2 sextants or more	55	12.6 (10.9)				
<u>Criterion validity test</u>						
Overall perception of trouble from oral problems						
1) little	55	3.8 (5.5)	1)&2) 7.0 (1.7)	184.2	<0.001#	
2) fair	125	10.7 (7.8)	2)&3) 7.6 (0.8)	71.0		
3) very much	320	18.4 (11.2)	1)&3) 14.6 (1.5)	384.2		
* sd=standard deviation						
† se=standard error						
‡ percent increase of mean OIDP score from the baseline score of healthier subgroup						
§ Mann-Whitney test						
# Kruskal-Wallis test						

Table Chapter 14.5: The final version of the Oral Impacts on Daily Performances

1) In the past 6 months, have problems with mouth, teeth, or dentures caused you any difficulty in (performance*)?

If yes,

2a) Have you had this difficulty in (performance) on a regular/periodic basis or for a period/spell?

-If ability restricted on "a regular/periodic basis",

2b). During the past six months how often have you had this difficulty?

-or, if ability restricted "on a period/spell"

2c). For how much of the past 6 months have you had this difficulty?

Responses and scores for answers to 2b and 2c are in Table Chapter 14.2

3) And using a scale from 0 to 5, where 0 is no effect and 5 is a very severe effect, which number would you say reflects what the difficulty in (performance). had on your daily life?

* Individual performances are listed in Table Chapter 14.1

ALTERNATE FORMS

In comparison to using solely frequency or severity score, OIDP score was a better predictor for DMFT and number of sextants with deep periodontal pockets. Therefore, the multiplication score would still be presented in the final version of OIDP. However, since the improvement of OIDP compared to either frequency or severity score used alone was not statistically significant in the prediction test, using one of them to improve simplicity and efficiency can be considered. As frequency and severity scores had similar predictive powers, frequency should be a better representative single choice because of its better reproducibility.

Causal relationship of impacts. To increase the usefulness of the OIDP for assessing specific treatment needs, additional questions have been asked about the perceived causal symptoms and impairments of any impact on performance. Respondents who perceived any impact were asked whether the major cause of their problems was from pain, discomfort, limitation in function, dissatisfaction with appearance or other problems. Then they were asked to specify the oral impairments, such as toothache, loose tooth, gum abscess or bad breath, which they perceived caused their problems. The methods and results have been described elsewhere.^{1,17}

DISCUSSION AND EVALUATION

OIDP was satisfactory as regards construct and criterion validity. The scores discriminated clearly between groups of relatively healthy and those with poor oral status, as well as between people who had different perceptions of overall oral impacts. Longitudinal studies of OIDP are required and should include the sensitivity of change, as well as testing on a wider range of populations with different age ranges, disease prevalences and cultures.

OIDP was applied successfully in the integration of perceived impact into normative (professional judged) dental treatment need in a group of Thais.^{1,17} By adjusting different cut-off points, OIDP demonstrated usefulness as an indicator in dental treatment need planning in populations. OIDP is being used to assess outcomes of treatment in a study in England.¹⁸

The Oral Impacts on Daily Performances measure has acceptable psychometric properties, as well as a sound theoretical basis. A distinguishing feature is that it provides a significant endpoint outcomes scale for oral conditions within a concise, reliable and valid measurement.

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