

**Sociodental indicators and a re(de)defined model for oral
health in old age**

by

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ABSTRACT

Objectives: To review and appraise the validity of psychometric instruments used in dentistry, to report on the use of a written vignette and focus groups among older adults, and to evaluate and if necessary refine a model of oral health in old age under the scopes of framework analysis.

Methods: A systematic search was performed to find and compare the psychometric instruments for structure, content and method of validation. In six focus groups, 42 participants (30 women, 12 men), discussed their own experiences of oral health, and how they relate to a vignette and a current model of oral health. Participants focused on the completeness, relevance and interdependency of the model's components.

Results: 16 instruments were identified, and most of them were based conceptually on a negative and functionalist perspective of disability. The validation approach to test these instruments has been focused on how well they reflect their theoretical framework, how clear and relevant is the content of their questions, and how accurately they predict a given criteria. The participants of the focus groups reiterated that not everyone gets limited and impaired when oral health is disturbed. The participants confirmed the relevance of the essential components of the model, and added diet, expectations, economic priorities, and health values and beliefs as new components in a different graphic arrangement.

Conclusions: The validation approach used to validate the psychometric instruments needs a broader scope of attention to evaluate continuously the

content of the questions, the predictive potential of the scores, and their theoretical framework. The graphic changes of the model represent an overlapping and non-hierarchical elliptical rather than a concentric-circular portrayal of oral health as originally presented to remain relevant to older adults.

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LIST OF ABBREVIATIONS

BC	British Columbia
CIHR	Canadian Institutes of Health Research
CODE	Clinical Oral Disorders in Elders
CPITN	Community Periodontal Index of Treatment Need
DBS	Dental Beliefs Survey
DMFT	Decayed, Missing and Filled Teeth
DIDL	Dental Impacts on Daily Living
DIP	Dental Impact Profile
DIS	Dental Indifference Scale
DS-QoL	Dental Health Status Quality of Life Questionnaire
GOHAI	Geriatric (General) Oral Health Assessment Index
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
LORQ	Liverpool Oral Rehabilitation Questionnaire
M	Men
N	Negative
NEUT	Neutral
OHAT	Oral Health Assessment Tool
OHIP	Oral Health Impact Profile
OH-QoL	Oral Health Quality of Life Inventory
OHQoL	Oral Health-Related Quality of Life Measure
OHQoL-UK	Oral Health Quality of Life – United Kingdom
OHRQoL	Oral Health-Related Quality of Life
OHRQL	Oral Health-Related Quality of Life Instrument
OHSI	Oral Health Status Index
OHX	Oral Health Index
OIDP	Oral Impact on Daily Performances
P	Positive
QoL	Quality of Life
SIDD	Socio Impacts of Dental Disease
SDI	Sociodental Indicator
SIP	Sickness Impact Profile
SOHSI	Subjective Oral Health Status Indicators
SROH	Self-Rated Oral Health
VAS	Visual Analog Scale
W	Women
WHO	World Health Organization

PREFACE

The idea for my thesis arose to 'solve' the problem in measurement of oral health-related quality of life - OHRQoL. Puzzled by the meaning of oral health in old age, I came across the term OHRQoL and its measurement through dental psychometrics or sociodental indicators - SDIs. In my hope to find more about the indicators, I became interested in the development of the SDIs and the claim from their developers that the indicators assess the oral health-related aspects of quality of life affected by oral disorders. I quickly realized that there might be a problem in the way the developers conceptualized OHRQoL and during the course of the PhD program I realized that this problem did not need to be solved, but instead it should be understood. My thesis in essence attempts to explain this problem.

With an eye to the objectives of my thesis, I decided to review the existing SDIs in the light of their development, structure, and content. I discovered limitations to the theories or models of oral health that support the questions of the SDIs, which pose threats to the validity of the indicators as subjective measures of OHRQoL. One of the main threats related to the negative theoretical models of ill-health and dysfunction that were used to develop the SDIs. The majority of the negative theoretical models were developed to reflect the personal and subjective meaning of oral health of individuals and possibly populations. They emerged, however, almost exclusively from professional understanding of oral diseases rather than from the advice and opinions of non-experts in general,

and older adults in particular. In 2006, a more positive model of oral health was developed from open-ended individual interviews with a small group of older adults. Consequently, I decided to evaluate this model more broadly in a series of focus groups involving older adults who were asked to assess the relevance of content and graphic representation of the model. However, I was sensitive to the possibility that discussions about the mouth and oral problems could distress some of the participants. Consequently, I developed a short vignette to start the group discussions and to set the stage for evaluating and refining the model of oral health.

The sequence of Chapters in my thesis follows the manuscript-based format suggested by the Faculty of Graduate Studies at University of British Columbia. Chapter 1 provides an overall review of the literature to set the stage for developing my doctoral research. Chapters 2 to 6 are published, in-press, accepted, submitted or draft manuscripts written in the same format. Each chapter is a separate paper with some information recurring from other chapters to provide coherence to the focus of the textual presentation. Chapter 6 closes the thesis and presents a general discussion and conclusion with suggestions for future research. A footnote on the first page of Chapters 2 to 6 states that "a version of this chapter has been published/has been accepted for publication/has been submitted for publication/will be submitted for publication", followed by a list of author(s), title, journal volume, year and pagination (exactly as in the journal), when applicable.

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Lastly, I thank all my friends and collaborators who gave me their time and sympathy in helping me to deal with the struggles regarding grammar and overall cohesiveness of my thesis, especially since I adopted English as my second language only a few years ago.

To all of you,

Thank you!

University of B.C

July 2007

CO-AUTHORSHIP STATEMENT

Dr. Mario Brondani had developed the research design, submitted the research to ethical review, elaborated the interview guides and the written vignette, collected the data, analyzed and interpreted the results and wrote the manuscripts and chapters included in the thesis.

Dr. Michael MacEntee, as my PhD supervisor from faculty of Dentistry, contributed the original design of the research, discussed data collection, analysis and interpretation, and also reviewed in depth each of the manuscripts and chapters.

Dr. Ross Bryant, from Faculty of Dentistry at UBC and member of my thesis committee, contributed to the design of the vignette I used in Chapters 4 and 5, reviewed each of the chapters in depth, and also reviewed the manuscript originating from Chapters 2, 4 and 5.

Dr. Peter Graf, from the Department of Psychology at UBC and member of my thesis committee, reviewed Chapters 1, 2 and 4 in depth, and also reviewed the manuscript originating from Chapter 2.

Dr. André Smith, from the Department of Sociology at University of Victoria and a former member of my thesis committee, reviewed Chapters 1, 4, 5 and 6 in depth and also challenged me with his construct criticism of my methods.

Dr. Bruno Zumbo, from the Department of Education and Counseling, and Special Education at UBC and member of my thesis committee, reviewed

Chapters 3, 5 and 7 in depth, and also reviewed the manuscript originating from Chapter 3.

Dr. Kathryn Hornby, from Woodward Biomedical Library at UBC, advised me in the development of the systematic review presented in Chapter 2.

CHAPTER 1

INTRODUCTION, LITERATURE REVIEW AND OBJECTIVES

1.1 Objective oral health

There is lack of agreement on the definition and measurement of oral health as a phenomenon experienced by individuals, especially in old age. For example, definitions including "the standard of health of the tooth, its supporting structures (periodontal components and alveolar bone) and any other tissue of the mouth"¹ favour a clinical portrayal of the oral cavity that generally implies quantification of oral disorders leading to tooth loss. This clinical definition has supported the measurement of oral health in terms of the presence and absence of disease in teeth, bone and gums² through indices such as the Decayed, Missing, and Filled - DMF index for teeth,³ and the Community Periodontal Index of Treatment Need - CPITN for supporting periodontium.⁴ These two indices portray a detailed and reasonably objective epidemiological assessment of the mouth. As they serve to record the number of teeth with or without pathoses and the status of other oral tissues, they bring focus to the structural and physical consequences of oral disorders.⁵

Although clinical indices are informative, they do not address the psychosocial consequences of oral disorder or the subjective perspectives of oral health as perceived by the patient.^{6,7} For example, they do not reflect the subjective effects of oral disorders on smiling and interacting socially.

1.2 Subjective oral health

Subjective oral health may imply, according to Dolan,⁸ “a comfortable and functional dentition which allows individuals to continue in their desired social role”. The subjective characteristics of oral health implied by Dolan go along with the World Health Organization’s⁹ claim that health is more than the absence of disease, and that health has social and psychological dimensions which are not pertinent to a discussion about a pathological disease only.¹⁰ Consequently, there is a need to understand the non-physical impacts of oral disorders that may cause difficulties with social interactions, particularly in old age.¹¹

1.2.1 Measurement of subjective oral health

In order to understand the subjectivity of oral health, Cohen and Jago¹² proposed the development of dental psychometrics called sociodental indicator – SDI.ⁱ An SDI would measure the oral health-related quality of life - OHRQoL consequences of oral disorders in the everyday life.^{13,14} Particularly targeting old age, numerous SDIs have been developed following Cohen and Jago’s suggestion, and most of them are modeled closely on general psychometric questionnaires such as the Sickness Impact Profile,¹⁵ the Health Insurance Study¹⁶, and the Short Term Health Survey 36.¹⁷ Briefly, an SDI is composed of

ⁱ Sociodental indicators, referring to subjective oral health measures, are also known as dental psychometric measures, oral health-related quality of life measures, dental psychometrics, patient-based oral health measures, and subjective oral health measures.

structured questions designed to identify various aspects of oral dysfunction^{18,19,20} influenced by personal and subjective perceptions of health and illness.^{21,22,23,24}

Sociodental indicators have been used to quantify,^{25,26,27,28,29,30,31} report,^{24,31} grade,^{19,32} and qualify a variety of aspects of daily life affected by oral disorders, including a persons' inability to work and restrictions to social activities.³³ However, the questions of existing SDIs tend to focus on the negative consequences of oral disease, and assume that oral disorders are always a burden^{18,34,35} without considering the multiple interpretations that the respondent can make when questioned about dysfunction.^{36,37} This negative focus is emphasized by the absence of questions about the extent or significance of the oral disorder. For example, in the Social Impact of Dental Disease²⁴ indicator, a 'yes' response to the question 'did you experience difficulty opening your mouth wide?' offers no information about the extent of the restriction or about whether the respondent is bothered or concerned by it.

The existing SDIs have emerged to reveal some of the psychosocial aspects of oral disorders; however, they generally fail to capture the multiple facets of dysfunction and the positive contributions to everyday life made by the teeth and mouth.^{38,39} They also fail to assess the effects produced by coping and

adaptive strategies upon disabilityⁱⁱ and by cultural and environmental factors upon oral health and impairment. These failures may be due to the negatively focused theories and modelsⁱⁱⁱ of oral dysfunction that support the content of questions in the existing SDIs.^{40,41,42} These failures also challenge the validity of existing SDIs as measures of the subjective experiences of oral health³⁸ since the indicators do not address questions such as the following:

- Why do some individuals with dental problems do not seek dental care?⁴³
- Why do some individuals perceive their oral health as very good despite the presence of extensive oral disease?²⁶
- Why do some individuals rate their oral health as poor yet express satisfaction with their mouths?^{24,44}

1.3 Theories and models of oral health

The theoretical basis for the questions of the SDIs in current use is mostly Parsons' Sick Role theory,⁴⁵ which presents illness or disease-related symptoms

ⁱⁱ In my thesis, I use *disability* as the umbrella term for any or all of: impairment of body structure or function; limitation in activities; or restriction in participation. Within limitations and restrictions, disability is seen as a gap between individual's capabilities and the demands of the environment in the context of personal values. Impairments can occur at the level of organs, tissues and cells, and at the subcellular level (WHO, 2001).

ⁱⁱⁱ Disagreement exists on the meaning of 'model' and 'framework' when linked to 'concepts' and 'theories'. In my thesis, I use the term original **model**, that proposed by MacEntee, to express specific dimensions and properties of a concept (e.g. conceptual model), such as oral health, and also to describe and explain the relationships between elements or dimensions of the concept (e.g. theoretical framework). Rather than *concepts* or *constructs*, I use the term *components* as referring to the 'words' that form or compose the models to avoid confusion with the 'concept' or 'construct' that models aim to represent.

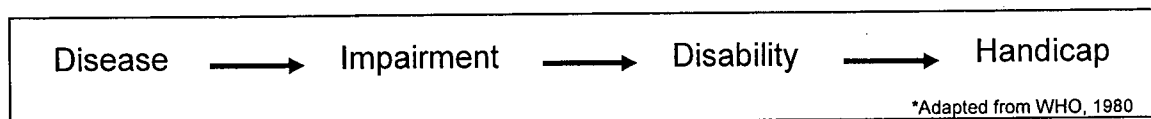
with a social significance beyond a physical or biomedical phenomena.⁴⁶ Parsons challenged the dominant medical understanding of a physiologically sick body. However, he favoured a negative view of the dysfunctional consequences of illness based on the detrimental interference that diseases have on a person's ability to perform regular social roles and relationships. When sick, the individual is exempted from normal tasks and held not responsible for the illness. Exemptions are legitimized as long as care is sought and medical treatment followed⁴⁷ to restore health and to return to normal roles and duties.⁴⁶

Parsons' theory did not accommodate individual variation in interpreting subjectively the severity and meaning of symptoms from a given disease. Since individuals may experience disease-related symptoms differently, they may not always seek medical treatment, which is a request to legitimize the sick role.^{48,49}

In the context of dentistry, the Parsonian functionalist view of oral disorders has led to the measurement of the number of days off work or school due to problems usually involving pain or facial deformities.^{50,51} However, the use of Sick Role theory in dentistry has been questioned because most dental diseases are influenced by conditions for which the individual is held responsible, such as poor oral hygiene or diet. Consequently, dental diseases might not directly legitimise sick role behaviour to individuals.⁵² Furthermore, Parsons' theory seemed irrelevant to most of the chronic oral conditions afflicting older adults.

With a focus on dysfunction and disablement associated with chronic conditions and their consequences, a glossary of disease⁵³ was used to produce the International Classification of Impairments, Disabilities and Handicaps⁵⁴ - ICIDH by the World Health Organization - WHO in 1980 (Figure 1.1). The ICIDH emerged to portray impairments as structural abnormalities from a given disease at the level of the organ or physiological systems. Figure 1.1 illustrates that in the ICIDH, disability is portrayed negatively as a consequence of impairment which limits the functional performance and activity of a person. Handicap then reflects the disadvantage experienced by a disabled person as a result of the meaning given by the social environment to impairment and disability.²³

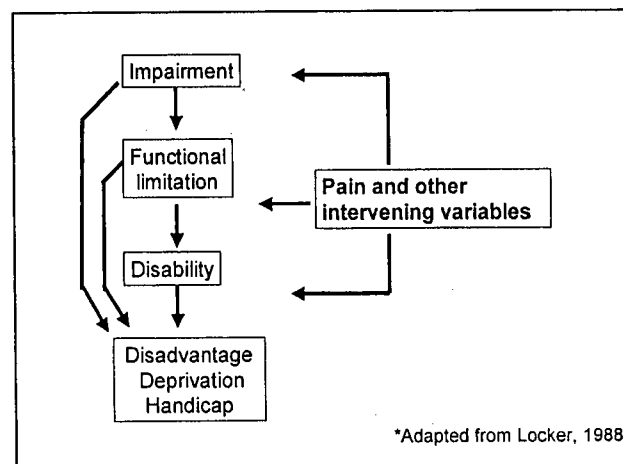
Figure 1.1 - The sequence underlying illness-related phenomena (WHO's 1980)*



The unidirectional arrows in Figure 1.1 represent the linear progression from impairment to handicap after a disease is diagnosed. This progression, although not always leading to handicap, does not accommodate individuals who can minimise, prevent or even reverse disablement, for example, through positive coping and adaptation.

Nonetheless, the ICIDH has been and continues to be very influential in dentistry and by 1988, David Locker⁵ adapted the WHO's framework to produce a model of oral health (Figure 1.2). Locker's model portrayed *ill*-oral health with unidirectional relationships between oral disease, disability and handicap influenced by pain and several other intervening variables. According to Figure 1.2, an impairment such as tooth loss can lead to a functional limitation in chewing, for example. The same impairment can also lead to physical or psychological pain and discomfort, which can lead to disability and handicap. Disability is portrayed as a limitation or inability to perform physical, psychological or social activities such as speaking publicly. Disability can also lead to handicap due to personal and social influences from the surrounding environment. One example of an oral handicap would include employment difficulties due to poor speech or appearance following loss of teeth.

Figure 1.2 - The model of oral health proposed by David Locker (1988)*



The ICIDH and Locker's model go beyond the structural consequences of illnesses by introducing terms such as disadvantage and handicap. However, they offer little room for the influence of health behaviours and beliefs on functioning and disability. For example, they also overlook the potentially beneficial impact of strategies for coping and adapting to impairments,^{55,56} and do not fully acknowledge the effect of socio-cultural and environmental factors on the perception of health and illness.^{57,58} For instance, total tooth loss may constitute a disability in some Western cultures, but may be perceived as a normal part of life for others⁵⁹ such as for Chinese elders who expect to loose their teeth as they age.⁶⁰

A variety of other models of *ill*-oral health were derived from the ICIDH and Locker's model, including the following in chronological order: Adulyanon and Sheiham²⁹ (Figure 1.3), Gilbert *et al.*¹⁴ (Figure 1.4), Locker and Gibson⁶¹ (Figure 1.5), and Nuttall *et al.*⁶² (Figure 1.6). These four models are most negatively focused as they use components such as 'dissatisfaction with appearance' (Figure 1.3), 'oral pain and discomfort' (Figures 1.4 and 1.6), and 'compromised functioning' (Figure 1.5). The models in Figures 1.4 and 1.5, on the contrary, use one component each with a more neutral or somewhat positive connotation. Although 'self rated oral health' (Figure 1.4) and 'quality of life' (Figure 1.5) hold a more optimistic meaning, the overall portrayal and emphasis in the models is quite negative.

Figure 1.3 - Theoretical framework proposed by Adulyanon and Sheiham (1997)*

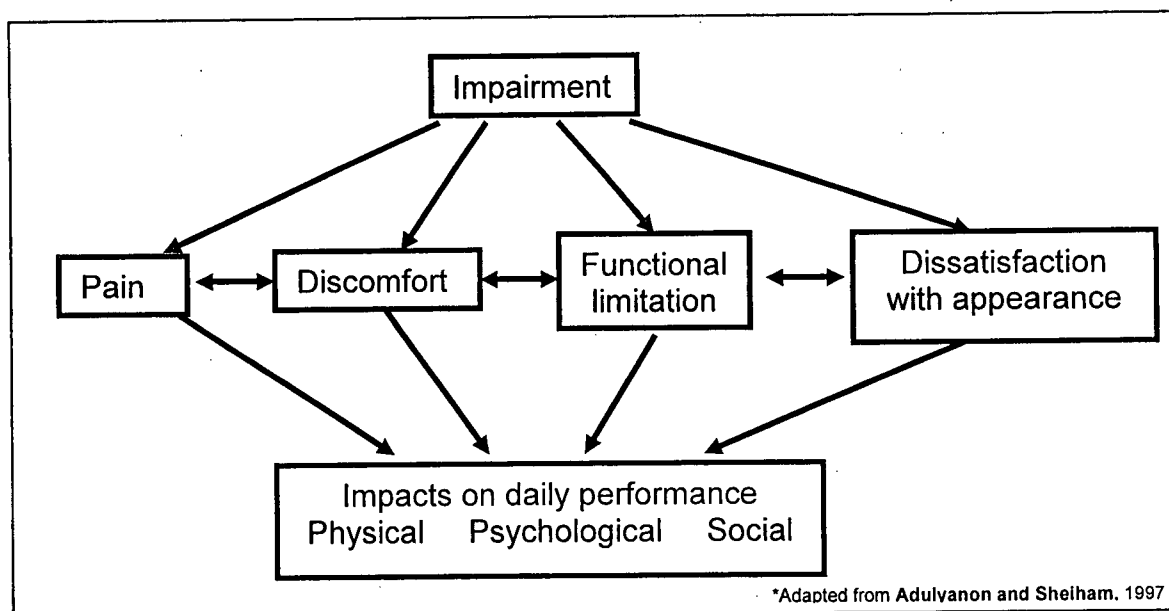


Figure 1.4 - Multidimensional conceptual model of oral health proposed by Gilbert *et al.* (1998)*

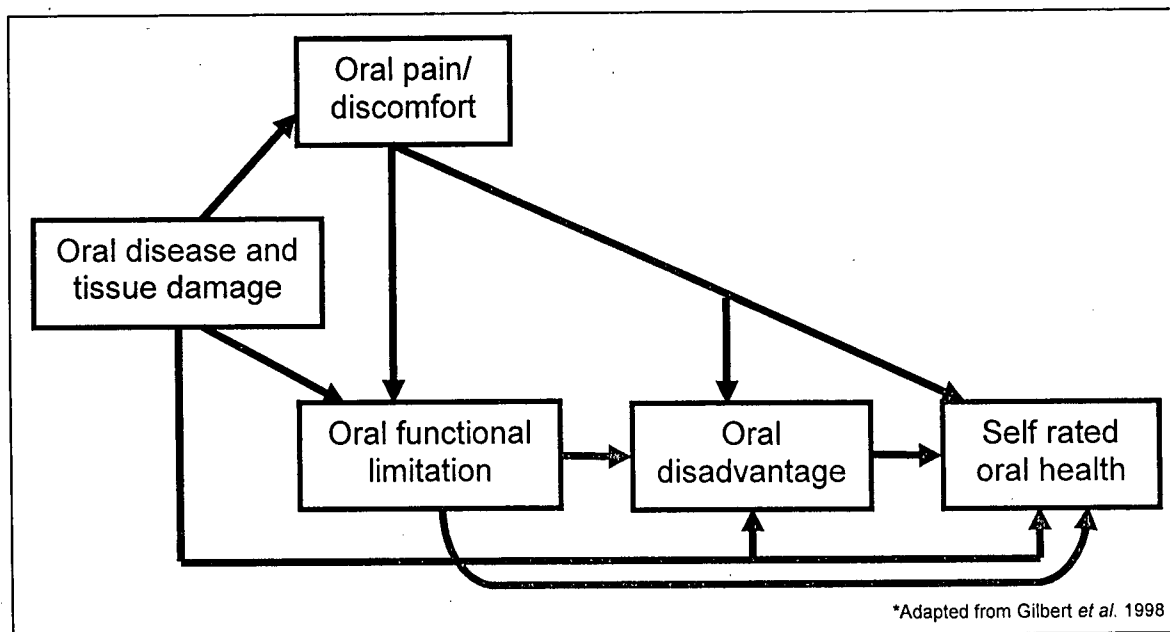
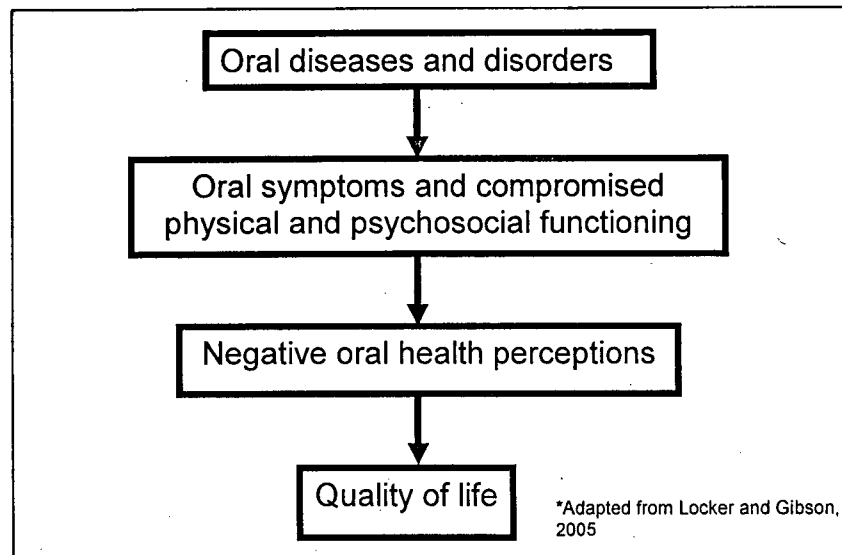
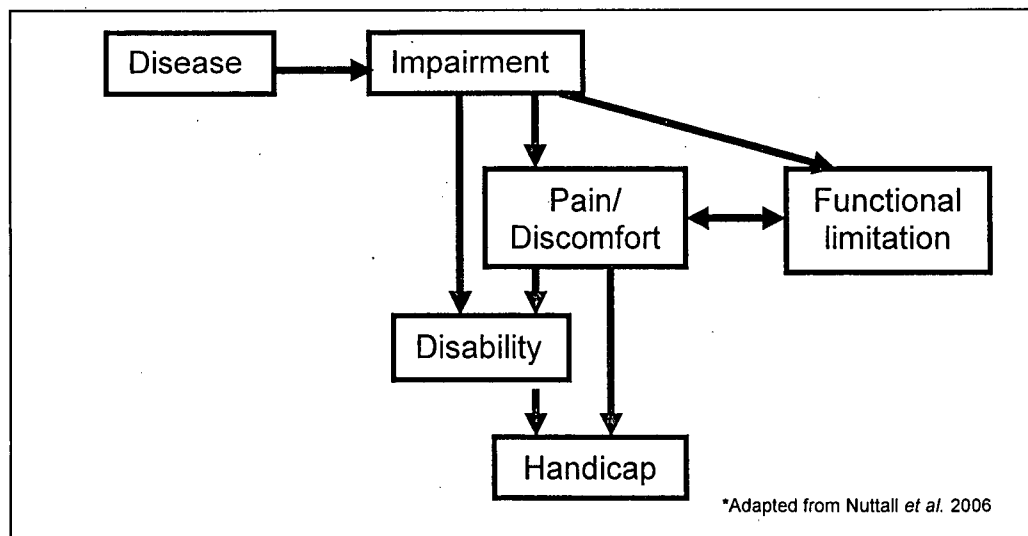


Figure 1.5 - Locker and Gibson (2005) model of oral health***Figure 1.6 - The oral health model suggested by Nuttall *et al.* (2006)***

Another similarity among the models portrayed by Figures 1.3 to 1.6 is the unidirectional relationships of the components. For example, 'impairment' in Figures 1.3 and 1.6 can cause or lead to 'pain', 'discomfort' and 'functional limitation', while 'discomfort' in Figures 1.3, 1.4 and 1.6 relates directly to 'function limitation'. None of the models have bi-directional arrows to show the possibility of *reversing* the effect of a disablement or a functional limitation, for example. They all assume that, once disabled or functionally limited, people will feel and stay that way as time passes.

In all, Figures 1.3 to 1.6 represent a strongly negative influence of a "causal process that involves specific antecedents and consequences"¹⁴ from the theoretical basis of the ICIDH and Locker's model of oral health. The model proposed by Nuttall *et al.*⁶² in Figure 1.6 appears to have been developed also with advice from lay people. Such advice came in the form of answers lay people gave to an SDI²⁰ focused on disability and dysfunction only. The responses led to the model in Figure 1.6 which shows the influence of Lockers' model, used to developed that SDI, and the negative perspective of the consequences of oral diseases and impairment.⁶³ More importantly, what seemed to have been overlooked by Nuttall *et al.* and all the others is whether or not the ICIDH and Locker's model provided the appropriate basis for portraying the positive and negative psychosocial impacts of oral disorders.⁶⁴

1.4 The International Classification of Functioning, Disability and Health

In an attempt to address the limitations of the ICIDH and to acknowledge current concepts of disability and health, the WHO adopted the International Classification of Functioning, Disability and Health - ICF in 2001^{iv}. As illustrated in Figure 1.7, the ICF portrays disorders and disability dynamically⁶⁵ rather than as a linear progression from normality to handicap and social exclusion.⁶⁶ It acknowledges the influence of anatomical, psychological and environmental factors on health and disease, and on people's functioning, activities and participation^v positively (when facilitated) and negatively (when impeded).⁶⁷ But most significantly, the description accompanying the model in the WHO 2001 report⁶⁵ highlights the possibility that limitations and restrictions may or may not be initiated by a particular health condition, disease or disorder.^{68,69}

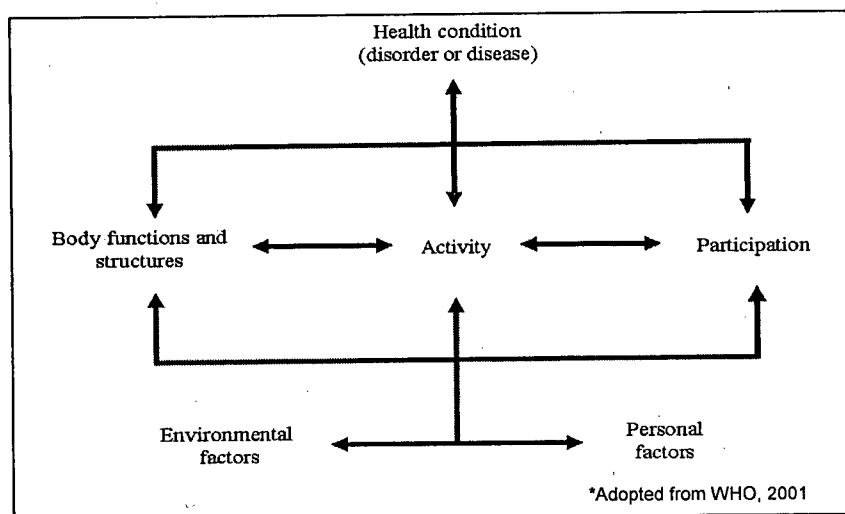
In the context of dentistry, the ICF allows for the possibility that two individuals with a missing front tooth may be equally 'impaired', but 'limited' and 'restricted' differently. One individual may experience limited social participation because of the demands of public appearance, whereas the other may be completely unrestricted since facial deformities from a missing tooth are well

^{iv} A series of three draft reports ascended the ICF: ICIDH-2 Alpha, May 1996; ICIDH-2 Beta-1, April 1997; ICIDH-2 Beta-2, August 1999.

^v Activity (the nature and extent of functioning at a personal level); participation (the extent of a person's involvement in life situations in relation to impairments, activities, health condition and contextual factors); environment (e.g. human organizations, service provision, and the physical, social and attitudinal aspects) (WHO, 2001).

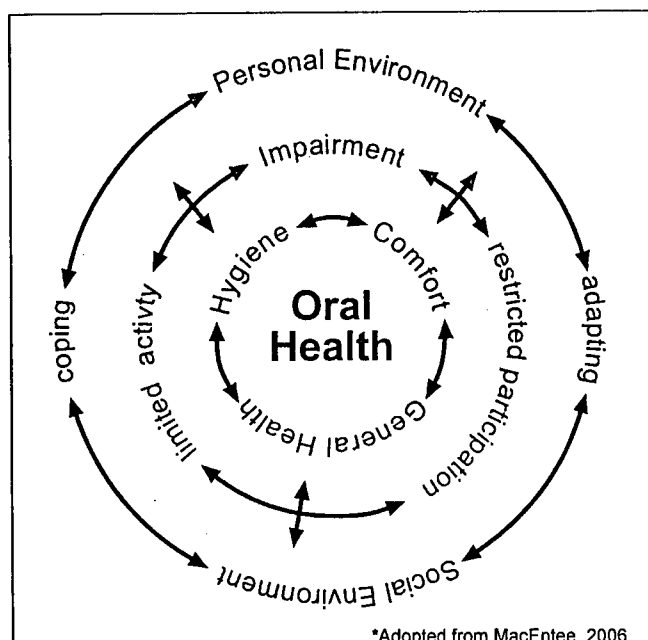
tolerated within his/her communal environment. Overall, a impairment or disability alone may not restrict participation according to the ICF.^{70,71}

Figure 1.7 - The ICF conceptual framework (WHO, 2001)*



The WHO's 2001 framework and its textual classification⁶⁵ has been used to map and assess daily functioning and disability from a biopsychosocial perspective.⁷² It offers a unified and standardised language for describing health and health-related conditions⁶⁵ associated with personal factors, adaptation, health behaviours and beliefs, and socio-cultural environment. In 2006, MacEntee offered a model of oral health which conformed with the theoretical language and general framework of the ICF, and with the empirical findings from a qualitative study using individual interviews with relatively healthy older adults (Figure 1.8).⁶⁴

Figure 1.8 - The existential model of oral health proposed by MacEntee (2006)*



This new model portrays oral health as a dynamic phenomenon which ebbs and flows within the different aspects of function and disablement of the mouth and within a variety of components presented in three concentric circles. The components emerged from an inductive process of analysis with the information gathered from 24 interviewees who were encouraged to freely express their ideas through open-ended questions about oral health.⁷³ The analysis revealed that oral hygiene and comfort with dental appearance had both personal and social significance, while general health had significance mostly at a personal level (inner concentric circle). Hence, the interviewees acknowledged the potential for oral impairments that might or might not restrict participation or limit activity⁶⁴ (middle concentric circle). The results of the analysis supported a

more positive outline for the model from which older adults experience oral health and illness within a variety of personal and social factors as they cope with and adapt to impairments and limitations (external concentric circle).

MacEntee's graphic portrayal of oral health contrasts with the pragmatic functionalism of Sick Role theory, and offers a more encompassing understanding to personal and social impairment and disorders, and a less pessimistic approach to health and disability.⁶⁴ However, the model presented in Figure 1.8 still focuses on the negativity of impairment, limitations and restriction, a drawback that has been associated also with the ICF.^{69,74} Although the model incorporates empirical information, the interviewees in the qualitative study who identified the model's components did not have opportunity to evaluate and confirm the outcome of the thematic analysis used to develop the graphic outline of the model. Consequently, further evaluation of MacEntee's model is warranted.

The content and graphic portrayal of the ICF, for example, has been evaluated through a variety of different qualitative methods. Stamm *et al.*⁷² interviewed patients about their daily struggles with rheumatoid arthritis and found that 'self-perception', 'attitudes of one self' and 'knowledge about health and disease' were important elements they related to such health condition. These elements are not acknowledged in the content of the ICF when it addresses the effects of rheumatoid arthritis in people's lives. On the contrary, the interviewees from Stamm *et al.* did not confirm that 'carrying out daily routine'

and 'intimate relationship' were important aspects of their lives influenced by rheumatoid arthritis, but yet present in the ICF. Others have criticised the ICF because it fails to present disability also as a phenomenon socially created,^{70,74} or to address the expectations of people who deal and experience health and disability.^{70,75} Other qualitative studies have concluded that the ICF content and graphic representation may not fully accommodate the health values and beliefs of people who experience health and illness.^{72,76,77,78}

Qualitative studies have been also used to appraise the structure and content of other models. For example, in the evaluation of a variety of models for guiding the design of research intervention in nursing, Brathwaite⁷⁹ employed a set of criteria including 'comprehensiveness' of their content, 'congruence' of their structure, 'clarity' of their components, and 'clinical utility' of the models. Likewise, Moody *et al.*⁸⁰ recommended a set of criteria including 'completeness', 'relevance', and 'interdependence' to evaluate quality information models. Completeness relates to whether or not the model includes all the components associated with the concept or construct portrayed by the model, relevance insures that all the components are necessary and important to that concept or construct, and interdependence addresses the way the components relate to one another clearly and appropriately.

I selected Moody's criteria to qualitatively evaluate the model proposed by MacEntee because completeness, relevance and interdependence are directly related to its content and structure. Content and structure are important features

of a model that could assist in planning patient-centred care, evaluating patient outcomes, prioritizing research and treatment options, and supporting the development of an SDI relevant for older adults.^{12,24,26} In order to provide such assistance, MacEntee's model should show a clear structure and portray a content relevant to elders who might benefit from dental services and treatment. Through a qualitative study focused on the model's content and structure, participants can confirm whether or not the components and relationships originally presented by MacEntee are applicable to their oral health experiences.

My thesis has five objectives and four research questions. The first two objectives and research questions relate to a review of the existing sociodental indicators (Chapter 2); and to an evaluation of their validity (Chapter 3). The answers I give to these objectives and research questions justify the development of a more positive model of oral health. Although MacEntee presented a more positive portrayal of oral health in 2006, this model has not been yet evaluated and, if necessary, refined from the perspectives of older adults. I use my third objective to present a series of groups discussions prompted by a written vignette (Chapter 4) as a method to qualitatively evaluate MacEntee's model (forth objective and third research question covered in Chapter 5). In Chapter 6 I present a methodological discussion behind Chapters 4 and 5 (fifth objective). Lastly, my forth research question relates to the future directions of my doctoral study (Chapter 7).

1.5 Research objectives and research questions

My research objectives are to:

1. review existing sociodental indicators in terms of their scope, theoretical and empirical support, content and structure, and internal consistency;
2. appraise the validity of existing indicators as patient-based measures of the full range of experiences and dimensions of oral health;
3. describe an experience of using a written vignette in a series of focus groups to investigate oral health among older adults;
4. evaluate and refine if necessary MacEntee's model of oral health from the opinions and experiences of the participants in the focus groups;
5. explore the methodological perspectives of phenomenology, grounded theory and framework analysis in the context of model evaluation through focus groups and a vignette.

Research questions:

1. *What dental psychometric instruments have been used to measure the psychosocial impact of oral health and disease?*
2. *How have the existing dental indicators been validated?*
3. *To what extent does MacEntee's model of oral health graphically reflect the experiences of older adults and their health values and beliefs?*
4. *Once the model is refined, what type of questions can be developed and added to existing sociodental indicators?*

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CHAPTER 2

A SYSTEMATIC SYNTHESIS OF THE LITERATURE ON SOCIODENTAL INDICATORS

A version of this Chapter has been prepared for publication in the **Social Indicators Research** journal

Brondani MA, Graf P, Bryant RS, MacEntee MI. A Review of the Socio Dental Indicators and Oral Health-Related Quality of Life Measures.

2.1 Background

Interest in describing, defining, and measuring oral health-related quality of life - OHRQoL has been part of oral health care for the past 60 years.¹ In particular, descriptions and models of OHRQoL have emerged for planning patient-centred care, evaluating patient outcomes,² prioritizing research and treatment options,^{3,4} and developing measures of the psychosocial burden of oral disorders in daily life.^{5,6} The extent of such burden allow us to estimate beyond the clinical parameters the health of individuals and populations,⁷ and to assess the quality of healthcare programs.^{8,9}

Aware of the need for subjective psychosocial assessments, Cohen and Jago⁹ advocated the development of a sociodental indicator - SDI as a patient-based measure of the broader psychosocial consequences of oral disorders in daily life. Numerous SDIs were developed to highlight a wide array of behavioural aspects of daily functioning disturbed by oral disorders.^{10,11,12,13,14,15} They are based on models of oral *ill*-health and modeled on more general psychometric questionnaires such as the Sickness Impact Profile,¹⁶ the Health Insurance Study¹⁷, and the Short Term Health Survey 36.¹⁸ Since Cohen and Jago, there have been two major reports on the SDIs, one in 1997¹⁰ and another in 2004.¹⁴ In 1997, Slade gathered researchers worldwide to review 10 of the existing dental indicators in a broadly based description, but did not critically explain the value of the theories supporting the development of the SDIs. In 2004, James *et al.* reviewed seven of the most used SDIs, but without a more elaborated approach

to gather all the existing indicators or to critically appraise the content and structure of the SDIs. Therefore, the goal of this chapter is to perform a synthesis of the literature to reveal how many different indicators exist and to evaluate and compare their theoretical and empirical foundations, content, structure, and internal consistency as presented in their original publication in the light of my first research question: *“what dental psychometric instruments have been used to measure the psychosocial impact of oral health and disease?”*

This review differs from a conventional systematic review in some aspects. Generally, a systematic review formally synthesizes the findings from a range of reports on therapy. Unlike the narrative review (or overview), the systematic review is considered to be primary research with clearly defined research question and sections on materials, methods and results. The method is therefore objective and transparent. The systematic review's research question displays four elements encapsulated in the Patient, Intervention, Comparison and Outcome -PICO acronym. Since I had not used my research question under PICO, but had described the material and methods used, I consider this part of my thesis as a 'synthesis' of the literature rather than a conventional systematic review.

2.2 Methods

2.2.1 Source of the data

In Phase 1 of this review, between 2003 and 2004, I scanned the literature focused on papers about 'measures' of oral health-related problems that disturb daily life.¹⁵ This initial scan revealed 13 different SDIs referenced in 367 publications that I catalogued as my personal library. After reading these papers, I was able to group a set of 28 key words commonly used to classify and reference the 13 sociodental indicators (Table 2.1).

Table 2.1 - Key words gathered from Phase 1

Key words		
A		B
Socio dental; Indicator(s); Patient based measure(s); Questionnaire(s) Self rating(s); Patient derived; Psychometric(s); Subjective measure(s) Self perceived; Self perception Patient rate(d); Measures(s) Assessment(s); Report(s); Impact(s)	AND/OR	Oral health; Oral health related quality of life Dental health; Dental disease; Dental discomfort; Mouth; Dentistry Oral disease(s); Oral dysfunction Oral impairment; Oral discomfort Oral limitation, Outcome Treatment need(s)

In Phase 2, I typed the key words from columns A and B (Table 2.1) combined with the connectors 'and/or' in the major or minor subject headings as offered by the search engines from Table 2.2 till exhaustion. I searched for papers, commentaries, books, book chapters, reports, thesis and dissertations in English, Spanish, Portuguese and Italian published within the earliest and the latest dates of coverage offered by each of the search engines.

Table 2.2 – Searching engines and databases used in Phase 2

Databases	Dates
EBSCO-HOST (including Academic Search Premier, PsycARTICLES, Primary Search, PsycINFO)	1975 to April 1 st 2006
PubMed Central	1970 to April 1 st 2006
Cochrane Database of Systematic Reviews	Issue from the 4 th Quarter of 2005
ProQuest Dissertations and Theses for all dates	1970 to 2006
Conference Papers Index	1970 to 2006
Hispanic American Periodicals Index	1970 to April 1 st 2006
Ovid MEDLINE(R) In-Process	1966 to April 1 st 2006

I found additional 27 papers following a supplemental hand search for SDIs in the lasted editions of 12 journals: *Social Indicators Research*, *Community Dentistry and Oral Epidemiology*, *Journal of Dental Education*, *Canadian Dental Journal*, *Community Dental Health*, *Social Science and Medicine*, *Journal of the*

American Dental Association, Quality of Life Research, Gerodontology, Health and Quality of Life Outcomes, Journal of Public Health Dentistry, and Special Care in Dentistry.

2.2.2 Inclusion and exclusion criteria

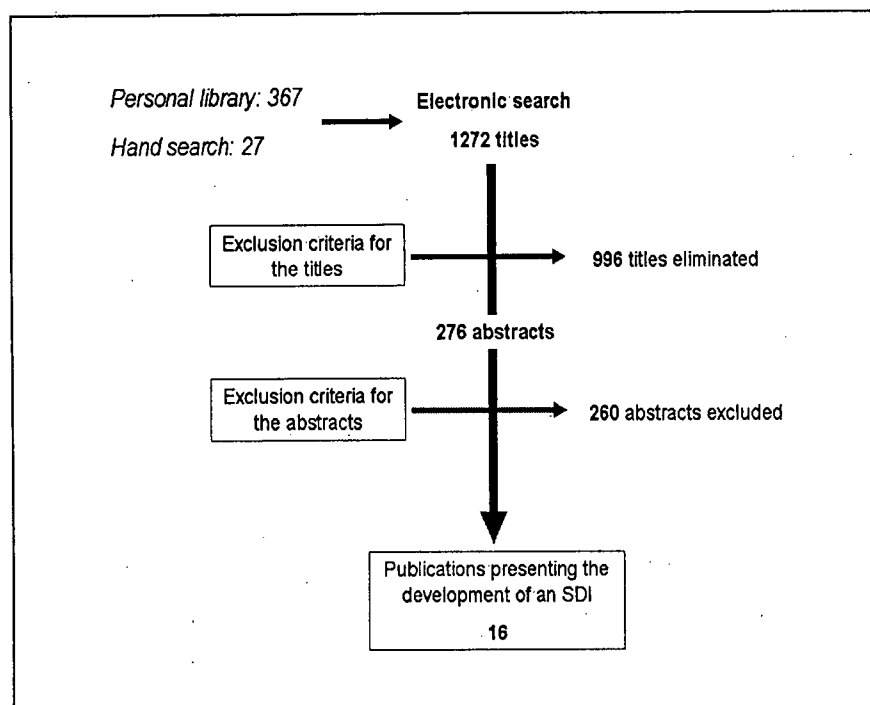
My search from Phase 2 yielded 1272 publication titles (1264 in English, 5 in Portuguese, 2 in Spanish, and 1 in Italian). These titles included the 367 publications from phase 1 and the 27 publications from the hand search. From this large set of 1272 publications, I excluded 451 titles that I judged were clearly **unrelated** to sociodental indicators but surfaced in the search because of the broad range of key-words used. For example, I excluded titles that were addressing objective clinical indices, or reporting on epidemiological studies about prevalence of tooth decay or treatment needs. I also excluded 389 titles that were **duplicated** in different databases and 56 related to instruments assessing the **clinical** rather than the psychosocial consequences of oral disorder, including the Index of Adult Oral Health Status - IAOHS,¹⁹ the Oral Health Assessment Tool - OHAT,²⁰ the Clinical Oral Disorders in Elders - CODE,²¹ the Oral Health Status Index - OHSI,¹⁹ and the Oral Health Index - OHX.²²

After eliminating 896 titles, I obtained and read 376 of the remaining abstracts. I eliminated 100 abstracts focused specifically on **single**

consequences of oral *ill*-health, such as discomfort with the appearance of teeth,²³ orthodontic outcomes,^{24,25} temporomandibular disorders,^{26,27} oro-facial pain,^{28,29} chewing,³⁰ or swallowing problems.³¹ I excluded these abstracts because I was interested in an SDI as described by Cohen and Jago,⁹ that is, an instrument with broader psychosocial focus not restricted to one specific consequence of oral disorders. I also eliminated 12 abstracts that were referring to a sociodental indicator developed exclusively for **children**,³² and 2 others without details on, or reference to, **content** or **structure** of the SDI presented.

Lastly, I eliminated 246 abstracts reporting only on **application of an SDI**, either in an original or translated version, but without information on how the instruments were developed. For example, indicators such as the Oral Health Impact Profile – OHIP, and the Geriatric Oral Health Assessment Index – GOHAI appeared repeatedly in more than 20 publications each with translations into more than 10 different languages. I then obtained the full text for 16 remaining abstracts (references number 33 – 46, 48 and 52). Figure 2.1 shows the elimination and exclusion process applied to the 1272 titles which yielded 16 distinct SDIs.

Figure 2.1 - Inclusion and exclusion criteria applied to titles and abstracts



2.3 Analysis of the 16 SDIs

I analysed the 16 SDIs regarding the: 1) appropriateness of the theoretical and empirical information used to generate the questions, 2) number and connotation (negative, neutral, and/or positive) of the questions, 3) content of each domainⁱ covered, 4) overall purpose of each SDI to measure, assess or

ⁱ A domain is a set of related physiological functions and anatomical structures, social activities or psychological needs such as eating, interacting socially, or portraying emotions.

indicate the psychosocial consequences of oral disease, and finally 5) internal consistency or homogeneity of the questions and domains.

2.4 Results from the 16 SDIs reviewed

Table 2.3 shows the SDIs in chronological order of publication with their acronyms and authors. The first SDI identified by name appeared in 1986, 10 years after Cohen and Jago raised the need for such subjective measures. Five of the SDIs were developed within the last 5 years, and several authors developed more than one indicator. A Sheiham, for example, has helped to develop the Social Indicator of Dental Disease - SIDD, the Dental Impact on Daily Living - DIDL, and the Oral Impact on Daily Performances - ODP.

Table 2.3 - The 16 SDIs according to their names, acronyms and data of publication

Sociodental indicators		
Name	Acronym	Origin
Social Impacts of Dental Disease	SIDD	Cushing, Sheiham and Maizels, 1986 ³³
Rand Dental questionnaire	Not specified	Dolan and Gooch, 1989 ³⁴
Geriatric Oral Health Assessment Index	GOHAI	Atchison and Dolan, 1990 ³⁵
Oral Health-related Quality of Life Measure	OHQoL	Dolan, Gooch and Bourque, 1991 ³⁶
Dental Impact Profile	DIP	Strauss and Hunt, 1993 ³⁷
Oral Health Impact Profile	OHIP	Slade and Spencer, 1994 ³⁸
Subjective Oral Health Status Indicators	SOHSI	Locker and Miller, 1994 ³⁹
Dental Impact on Daily Living	DIDL	Leao and Sheiham, 1996 ⁴⁰
Oral Impact on Daily Performances	OIDP	Adulyanon and Sheiham, 1997 ⁴¹
Oral Health Quality of Life Inventory	OH-QoL	Cornell <i>et al.</i> , 1997 ⁴²
Oral Health-Related QoL-Instrument	OHRQL	Gadbury-Amyot <i>et al.</i> , 1999 ⁴³
Oral Health Questionnaire	Not specified	Locker, 2001 ⁴⁴
Oral Health Quality of life United Kingdom	OHQoL-UK	McGrath and Bedi, 2001 ⁴⁵
DENTAL	DENTAL	Bush <i>et al.</i> , 2003 ⁴⁶
Self-Rated Oral Health	SROH	Gilbert <i>et al.</i> , 2003 ⁴⁷
Liverpool Oral Rehabilitation Questionnaire	LORQ	Pace-Balzan <i>et al.</i> , 2004 ⁴⁸

2.4.1 Theoretical and empirical foundations of the SDI's questions

Table 2.4 shows that questions from 15 of the indicators were based on models of ill-health such as the International Classification of Impairments, Disabilities and Handicaps - ICDH,^{49,50} on general psychometric measures such

as the Sickness Impact Profile - SIP,¹⁶ or, more fundamentally, on Sick Role theory.⁵¹ More than two-thirds of the SDIs were developed using the ICIDH, the SIP and Sick Role theory, alone or combined, but without inputs or advice from prospective respondents or lay people. Six of the indicators including the SIDD, the GOHAI, the OHIP, the DIP, the DIDL and the OHQoL-UK were also developed in combination with empirical information gathered through interviews or focus-group discussions with healthcare professionals or with patients who were receiving dental treatment. The publication presenting the OH-QoL and the Oral Health Questionnaire did not inform whether or not empirical data was also used to develop the questions for those SDIs.

Table 2.4 - Theoretical and empirical foundation, orientation and number of questions of the 16 SDIs found on the review of published literature between 1970 and 2006

<i>Indicators</i>	<i>Theoretical Origins</i>	<i>Empirical Foundation</i>	<i>Orientation of Questionsⁱⁱ</i>	<i>Number of Questions</i>
SIDD	SIP ⁱⁱⁱ	Yes	N	14
Rand Dental questionnaire	SIP	No	N	3
GOHAI	ICIDH & SIP	Yes	N & P	12
OHQoL	ICIDH & SIP ^{iv}	No	N	3
DIP	SIP	Yes	N & Neut & P	25
OHIP	ICIDH ^v	Yes	N	49
SOHSI	Existing SDIs	No	N & Neu	34
DIDL	SIP	Yes	N & Neut & P	36
OIDP	ICIDH	No	N	8
OH-QoI	SIP	Unclear	N & P	31
OHRQL	Multiple ^{vi}	No	N	36
Oral Health Questionnaire	ICIDH	Unclear	N & Neu & P	70
OHQoL-UK	ICIDH2	Yes	N & P	32
DENTAL	Not specified	No	N	6
SROH	ICIDH	No	N & P	3
LORQ	Existing SDIs	No	N	40

ii N – negative, Neu – neutral, P – positive.

iii Sickness Impact Profile

iv Also developed for other measures including the Rand Questionnaire.

v International Classification of Impairments, Disabilities and Handicaps

vi Health-related Models; Natural History of Disease Model, and SIP.

2.4.2 Orientation and number of questions presented in the SDIs

Table 2.4 shows that eight indicators combine both positive and negative oriented questions, and the other eight, only questions with a negative orientation such as "have you been *unable* to work to your full capacity because of problems with your teeth, mouth and dentures?"³⁸ and "have your teeth caused *embarrassment* in the last three months?"^{40,52} It is clear from Table 2.4 that there is no SDI with all its questions positively oriented. The number of questions varies from 3 to more than 60, and five indicators have less than 10 questions each, whereas seven have at least 30 questions.

2.4.3 Purpose of the indicators

Table 2.5 presents the purpose or objective of each SDI as phrased by their developers. Typically, the SDIs were designed with the purpose of measuring, assessing, indicating, estimating, determining, qualifying or describing the negative consequences of oral disorders in everyday life.^{53,54} As a result, they only **measure dysfunction** (the OHIP) and **assess symptoms** (the OHRQL) and **problems** (the LORQ) with questions such as "how often were you worried or concerned about the problems with your teeth, gums or dentures?"³⁵ There is no SDI developed with the exclusive purpose of assessing or indicating the positive contribution that teeth and the mouth can make to everyday life.

The SDIs are used to estimate the health of individuals and populations,⁷ to prioritize research and treatment options,^{3,4} and to assess the quality of healthcare programs.^{8,9} However, only the GOHAI aims specifically “to evaluate the effectiveness of [dental] treatment”. Lastly, the OHQoL, the DIP, the OH-QoL and the Oral Health questionnaire are the only SDIs that claim to focus on oral health rather than oral disease alone.

Table 2.5 - The purpose of the 16 SDIs as stated by their developers

<i>Indicator</i>	<i>Purpose^{vii}</i>
SIDD	To measure dental impacts of oral diseases [that] interfere with enjoying life, engaging in satisfying personal relationships and maintaining positive well-being.
Rand Dental questionnaire	To quantify the amount of pain, worry, and concern with social interactions attributed to problems with teeth and gums. It does not measure the symptoms or adverse consequences of dental disease.
GOHAI	To measure patient reported oral functional problems, to estimate the degree of psychosocial [oral] oral impacts, and to evaluate the effectiveness of treatment.
OHQoL	To measure the impacts of oral health on well being and functioning in everyday life, e.g. daily work and hobbies, social activities with families and friends, and avoiding conversation by the way teeth or dentures look.
DIP	To indicate how life quality has been affected, detracted from or enhanced by, oral health and oral structures ... [e.g.] how important or salient teeth are to an individual or a population.
OHIP	To measure [the] self-reported dysfunction, discomfort and disability attributed to oral conditions, complementing epidemiological indicators of clinical disease.
SOHSI	To describe the functional, social and psychological outcomes of oral disorders and conditions to supplement clinical measures.
DIDL	To assess five dimensions of comfort, appearance, pain, performance, eating restrictions quality of life ... in order to obtain score dimensions and to generate a total single score for all dimensions involved.
OIDP	To provide an alternative sociodental indicator which focuses on measuring the seriousness of oral impacts on the person's abilities to perform daily activities.
OH-QoI	To assess people's subjective well-being ... [e.g.] the satisfaction with their oral health and functional status, as well as the importance they attribute to oral health and functional status.
OHRQL	To assess the domains of symptom status [such as] the presence of oral pain, discomfort; functional status [such as] the ability to perform specific oral functions; and oral health perceptions [about] oral conditions.
Oral Health Questionnaire	To assess self-perceived oral health status using measures of function, pain, and other symptoms and the impact of oral conditions on daily life. To focus on oral health other than oral disease.
OHQoL-UK	To measure both the effect and impact of oral health on quality of life, incorporating an individualized weighting system.
DENTAL	To determine whether older adults have undetectable dental conditions [which] compromises their overall health and decreasing their quality of life.
SROH	To measure oral health by self reported questions on oral, dental and periodontal health.
LORQ	To better assess the issues and problems related to patients undergoing oral rehabilitation.

vii From the original references with emphasis in bold added.

2.4.4 Domains of oral health in the indicators

Table 2.6 presents how 12 domains in no particular order of importance are covered by the 16 SDIs, and shows in brackets some examples of the different aspects of life covered by each domain. The physical or psychosocial domains are addressed usually in one or more questions. For example, 'physical pain' is represented in the DIDP by a question about the frequency of spontaneous toothache,⁴⁰ whereas 'handicap' is addressed in the OHIP by several questions about unemployment and about restriction and limitation with social activities.³⁸ The number of questions usually increases if the indicator was developed to address a higher number of domains. For instance, the OHIP covers nine domains using 49 questions, whereas the OHQoL covers three domains using a total of three questions.

Some domains are described clearly (e.g. in the OHIP and the DIDL), whereas others are simply mentioned (e.g. in the DIP). Some indicators have questions that encompass more than one domain. For example, the question from the Rand Dental questionnaire that asks if the respondent "avoids conversation due to the way teeth look like", covers domains such as 'function limitation' and 'social disability' simultaneously. Although the list of 12 domains in Table 2.6 is not exhaustive, there is no indicator that covers all of the domains.

Table 2.6 - Domains of oral health-related quality of life in the SDIs

<div>INDICATORS</div> <div>DOMAINS^{viii}</div>	SIDD	OHIP	GOHAI	OHQOL	OIDP	DIDL	DIP	OHQoL	OH-QoL	RAND Dental	OHQ ^{ix}	OHQoL-UK	SOHSI	LORQ	SROH	DENTAL
Functional limitation (chewing, pronouncing words, eating, swallowing, bad breath, taste, food catching, problems with digestion)	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓	✓	✓
Physical pain (toothache, sensitive teeth, painful gums, pain opening mouth wide, uncomfortable denture)	✓	✓	✓	✓		✓			✓	✓	✓		✓	✓		✓
Use of pain medication			✓													
Psychological discomfort (worry, miserable, tense, uncomfortable)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Physical disability (unclear speech, misunderstood, unable to brush and eat, avoid smiling, interrupted meals)	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓		✓
Psychological disability (problems sleeping, upset, difficult to relax, depressed, embarrassed)		✓		✓	✓	✓					✓	✓	✓	✓		
Social disability (avoid go out, irritable, problem to get along with people and to do usual jobs)		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		
Handicap (worse general health, unable to enjoy people's company, life less satisfying, unable to function)		✓				✓		✓	✓		✓	✓	✓		✓	
Ageing (direct effect in living longer)							✓									
Sexual function (romantic relationship, sex appeal, kissing)	✓					✓	✓					✓				
Confidence/personality (emotion, mood, self-consciousness)	✓	✓	✓		✓	✓	✓					✓		✓		
Financial (out-of-pocket expenses, financial burden/loss)		✓									✓	✓				
Quality of life overall (well being)							✓									

viii

Some domains may overlap and share the same content on questions.

ix

Oral Health Questionnaire.

2.4.5 Values of internal consistency on the SDIs

Typically, the internal consistency of an indicator is tested by the Cronbach Alpha coefficient to determine the response agreement or homogeneity between questions, *i.e.* how closely related are responses to similar questions.⁵⁵ Generally, the coefficient runs from '0' (none) to '1' (maximum consistency or homogeneity) usually with a cut-off at 0.6 or 0.7 to identify an acceptable value.⁵⁶ When negative, the coefficient indicates that the questions are redundant (*e.g.* the OIDP had two questions eliminated due to negative alphas), or that a shortened version of an extensive SDI has acceptable psychometric properties.⁵⁷ For example, the original version of the OHIP with 49 questions was reduced to a version with 14 questions by selecting the two questions with the highest internal consistency within each of seven domains.⁵⁸

Internal consistency has been used also to compare the homogeneity of different indicators (*e.g.* the OHIP and the LORQ) that address the same domains with similar questions.⁵⁹ Lastly, a test for internal consistency indicates how well a translated version of an indicator remains consistent and homogeneous with the original SDI.⁶⁰

The middle column in Table 2.7 shows an acceptable overall internal consistency for each indicator, when reported. However, when the internal consistency is analysed for each domain, as for the LORQ, the Rand Dental questionnaire, the OHIP, and the OHQoL-UK, there are coefficients below acceptable values (Table 2.7, right column). Indicators such as the SIDD, the

Oral Health Questionnaire and the DENTAL had not been evaluated for internal consistency, overall or per domain, in the publications in which they were originally presented.

Table 2.7 - Cronbach's Alpha coefficient values for the internal consistency of the 16 SDIs

<i>Indicator</i>	<i>Internal Consistency Measured with Cronbach's Alpha Coefficient^x</i>	
	<i>Overall</i>	<i>By Domain</i>
SIDD	not reported	not reported
Rand Dental questionnaire	0.69	0.28 to 0.61
GOHAI	0.79	0.79 to 0.83
OHQoL	0.83	not reported
DIP	0.85	0.68 to 0.86
OHIP	not reported	0.37 to 0.83
SOHSI	0.78	0.70 to 0.87
DIDL	0.85	not reported
OIDP	0.67	0.65
OH-QoI	0.91	not reported
OHRQL	not reported	0.74 to 0.89
Oral Health Questionnaire	not reported	not reported
OHQoL-UK	0.94	0.44 to 0.75
DENTAL	not reported	not reported
SROH	0.90	not reported
LORQ ^{xi}	0.88	0.21 to 0.87

^x From 0 to 1. Numbers refer to the values presented in the original publication. When employed in more than one study, the indicators present different Cronbach Alpha values.

^{xi} LORQ with 25 questions.

2.5 Discussion

There are several researchers involved with the development of more than one indicator (Table 2.3). Although this might imply that different indicators were constructed, the reality is that many of the SDIs present similar foundation and connotation of the questions since they were developed from similar theories of dysfunction as interpreted by their authors. For example, Dolan was involved with three different groups of researchers to develop the GOHAI, the OHQoL and the Rand Dental questionnaire. As a result, the three indicators present the same negative connotation in their questions that ask for how frequently oral problems prompt people to avoid conversations. Likewise, Sheiham is associated with the developers of the SIDD, the OIDP and the DIDL. The authors of the OIDP reported that existing SDIs, including the GOHAI, concentrate on pain, discomfort and functional limitation, whereas the OIDP measures broader consequences of oral disorder.⁴¹ However, both indicators share the same negative content in their questions. More importantly, there is no consensus on how to select an appropriate SDI for a given study or survey, and since the SDIs are very similar it appears that each developer has produced a new instrument without regard for the instruments already in existence.¹⁰

The theories of disability and dysfunction supporting most of the SDIs offer a perspective on oral impairment and disability that is largely negative, which overlooks the positive perspective projected by many disabled people.^{61,63} The influence of negative theories, like the Sick Role theory, and models, like to

ICIDH, certainly conflict with recent empirical evidence on how elders cope and adapt positively⁶² to oral impairment.⁶³ Most of the indicators were developed from theory alone, as interpreted by experts who were knowledgeable about the potentially negative impact from disease they regularly encounter in their patients. As a result, the indicators focus largely on the impact of disability and dysfunction as the main consequences of oral disorders, and do not address the significance of adaptive strategies and social and cultural contexts in which disability and dysfunction occur.^{64,69}

Indicators such as the OHIP, GOHAI and the OHQoL-UK were developed from a combination of theory and empirical information from health professionals or patients undergoing treatment. However, these three indicators have potential limitations because the information provided by health professionals and patients was mostly focused on oral dysfunction, impairment and disability. Consequently, 'patients' would not necessarily reflect views of oral health seen by healthy elders who are likely to have a more positive, or at least different, perspective on health and illness, as discussed by MacEntee *et al.*⁶¹ and Hunt.⁶⁵ The majority of the population likely to be the focus of larger surveys and studies feels healthy, and yet they were not to a significant extent consulted for their inputs on the development of SDIs.⁶⁵ Patients under treatment and with clinical problems are a poor source of information for developing psychometric instruments, and this has been a recognized concern because it limits the application of the health indicators in general.^{66,67,68}

None of the SDIs present their questions entirely positively oriented to measure the psychosocial burden of oral disorders as there is an assumption that 'burden' is a common occurrence and always a disturbance. The absence of all positively oriented questions would not be a surprise if the SDIs were called measures of *ill*-health, or of oral dysfunction. They are referred to, however, as *health*-related quality of life measures¹⁰ which contradicts their scope in assessing *ill*-health only.

Indicators such as the OHQoL-UK, the DIP, and the GOHAI focus on some positive impacts of oral disorders in an attempt to identify features of positive health and a respondent's ability to function optimistically (Table 2.5). The GOHAI, for example, has three of its 12 frequency questions framed as "how often were you *pleased* with the looks of your teeth and gums, or denture?"³⁵ But because both positively and negatively worded questions co-exist in the GOHAI, it is not clear how to calculate and interpret the overall score. Locker and Gibson⁶⁹ argued that such difficulties exist because the frequency scores on either the positive or the negative questions must be reversed to get the final score for the GOHAI. However, in reversing the scores, it is assumed that positive and negative questions measure the same underlying domain of OHRQoL and that the scores are interchangeable. There is no evidence to support such assumptions as addressed by Locker and Gibson.

The number of questions present in an SDI may influence the context in which the indicator is used in either small or larger samples of respondents. The

number of questions also affects the ability of the indicator to differentiate from a wide range of psychosocial impacts. For example, short instruments like the OHRQoL and the OIDP seek a global impression of the negative consequences of oral disorder from a large number of participants,⁷⁰ but reveal little about specific consequences of oral disorders. In contrast, indicators like the OHIP or the SOHSI with more than 40 questions were developed for more intensive and detailed investigations^{38,39} but in clinical and small samples of participants.⁴⁸

There is no agreement on what or how many domains should be included in an indicator, or whether an indicator with five domains is better than another with three.^{71,72} There is also no apparent consensus on the names assigned to the domains, or on the content of the questions that a specific domain covers. 'Function' in the SIDD³³ and 'physical function' in the GOHAI³⁵ share the same set of questions but are named differently. On the other hand, similar questions may address totally different domains. For instance, questions on 'appearance' relate to the domains of: 'psychological discomfort', when a person is uncomfortable with facial features (e.g. the SIDD);³³ 'confidence', when self-conscious about appearance (e.g. the OHIP);³⁸ and 'social disability', when unable to mix socially (e.g. the OHQoL-UK).⁴⁵ With no standardized nomenclature or range of domains, researchers can feel restricted when searching for an SDI suitable for a particular purpose.¹⁰ More importantly, concerns about domains revolve largely around the appropriateness of the negative theory of dysfunction and ill-health used to define them.⁵⁰

There is little evidence that domains in most of the SDIs are important to the respondents.⁷³ Indeed, there is indication that investigators and respondents to dental questionnaires rarely agree on the relative importance of the domains addressed.^{74,75} In particular, elders may not necessarily be concerned about oral impairment, disability or handicap because of their ability to cope and adapt to the usual consequences of tooth loss,⁷⁶ and the fact that self-perceived health status and expectations fluctuate in response to changing emotional and psychological events.^{75,77}

Not all of the SDIs, including the DENTAL and the SIDD, were tested for internal consistency, and even when it was reported (Table 2.7), it is not always clear how the value should be interpreted. When Cronback's Alpha is negative, it may mean that questions are unrelated, or that they are ambiguously worded and assess different 'things' in 'different ways'.⁵⁶ For example, the OIDP and the LORQ had negative coefficients in some of their questions. In the case of the LORQ, the developers retained those questions with the explanation that the negative Alpha only occurred because of the mix of questions asking for satisfaction and absence of problems (e.g. not homogeneous in scope), and not because of redundancy or ambiguity. When the internal consistency of different SDIs were compared, they had high Alpha scores which accounts for the similarities of the negative content of their questions, as reported for the LORQ, the SOHSI and the OHIP.^{39,48} Lastly, internal consistency appears to be

influenced by the number of questions in the indicator, with higher numbers offering better consistency.⁵⁶

The review presented here also gathered six other questionnaires that incorporate aspects of oral health, such as beliefs about severity of diseases, and coping strategies to oral problems. Although they are not classified as an SDI according to Cohen and Jago, they may be used in conjunction with existing indicators. The Dental Indifference Scale -DIS,⁷⁸ for example, has 8 questions that measure the lack of concern for dental health⁷⁹ and related coping behaviours⁷⁸ used to minimize or prevent disablement. The Dental Beliefs Survey -DBS,^{80,81} in contrast, lists 28 possible beliefs about factors that disturb access to dental treatment.⁸² The Index of Dental Needs -IDN⁸³ identifies treatment needs and different types of health behaviours including prevention and neglect.⁹ The Oral Health Grading -OHG⁸⁴ presents questions about the overall conditions of teeth, periodontium and dentures, assuming that a poor oral condition results from a neglectful behaviour.⁹ The fifth questionnaire explores the emotional effects of tooth loss⁸⁵ and covers lowered self-esteem and altered self-image.⁸⁶ The sixth questionnaire assesses oral health satisfaction through questions about concerns and desires for dental treatment⁸⁷ and behavioural and adaptive components attached to how people experience and report the impact of a given complaint.⁸⁸

The two abstracts that I eliminated because information about the 'content or structure' of the SDI was missing deserve a brief discussion. When I was

reading the methods section of the abstracts, I found information about a 17th indicator called the Dental Health Status Quality of Life - DS-QoL. Even though I eliminated formally both abstracts from my search, I obtained the full publication of one of the abstracts, and found that the text only presented the domains covered by the DS-QoL's questions and the name of the authors. There was no example of questions or how the questions should be worded or phrased. I contacted the authors by email, but no further information was available from them about the development of that indicator.

Lastly, the eight publications that I found in Portuguese (5 papers), Spanish (2 papers) and Italian (1 paper) did not provide a new dental indicator. They were either presenting the translation process used to generate the Portuguese and the Spanish Version of the GOHAI and the OHIP, for example, or simply reporting on the use of the Italian version of the OHIP.

2.6 Conclusions

The aim of this chapter was to synthesise the SDIs described in the literature between 1970 and 2006. The 16 SDIs have more similarities than differences in theoretical foundation, scope and orientation of questions. Despite similarities, there is no 'gold standard' for subjective oral health measurement. Consequently, the variety of sociodental indicators is likely to confuse investigators who are seeking a measure of the positive and negative

psychosocial impacts from oral disease and related conditions in daily life, and the potential for positive contributions from an aging dentition.

2.7 Limitations of the review

Although comprehensive, the set of key words I employed may have excluded indicators that are not catalogued under such set of key words, or that have been published in a different language other than Portuguese, Spanish, Italian and English. The small number of publications found in Portuguese and Spanish may be due to the fact that I did not search in engines such as "LIBROS EN VENTA en América Latina y España (Spanish-language Books in & out of Print)" and "LILACS database - Latin American and Caribbean Health Sciences Literature". The ¾ of the titles I eliminated may have excluded publications that might have been useful for this review, but were not included because they did not give a clear idea about the content or focus of the paper. Although this chapter has written in May 2007, I did not include SDIs that might have been published after I performed this search in April 2006. Some other limitations may be due to publication bias. For example, it is less likely that indicators showing negative results are published in good English language journals. Consequently, I might not have included such indicators.

2.8 Acknowledgments

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2.9 Link to the next chapter

The limitations on the theoretical and empirical development, and on the negatively oriented questions and domains on the existing SDIs have implications on their validity as measures of OHRQoL. Consequently, I use Chapter 3 to answer my second research question: *"How have the existing dental indicators been validated?"*

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CHAPTER 3

THE CONCEPT OF VALIDITY IN THE SOCIODENTAL INDICATORS

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3.1 Introduction

Tooth loss has been a valid clinical measure of structural consequences of oral disorders for more than 60 years.¹ However, tooth loss alone does not address the psychosocial consequences of the oral disorders upon well-being and quality of life. The need for broadly-based dental psychosocial measures was established by Cohen and Jago² in 1976 who then introduced the term sociodental indicator - SDI, referring to a dental psychometric as an oral health-related quality of life measure.³ As described in Chapter 2, at least 16 SDIs have emerged to portray impairment and disability mostly as a dysfunctional burden on society, with the patient passively accepting and reporting the consequences of illness, and the physician interpreting and treating the sickness,⁴ which overlooked the role of coping and adaptation to illness.^{5,6} Nonetheless, any health indicator has to be valid which is a psychometric property that demonstrates the extent to which that indicator measures what it intends to measure in a meaningful and useful way.⁷ However, the validation approach used to test the existing sociodental indicators seems to be confusing and controversial.⁸ Consequently, through a review of the literature, the objective of this chapter is to answer my second research question *"how have the existing dental psychometrics been validated?"*

3.2 Traditional attributes of validity

3.2.1 Construct validity

Construct validity reflects how well the instrument projects the theory on which its questions are based.⁹ As I discussed in the proceeding chapter, most of the SDIs are based on Parsons' Sick Role Theory.¹⁰ In brief, Parsons argued that acute illness was more a social than exclusively a biomedical condition in which the sick individual was exempted of normal roles and functions but had to seek for care and to comply with the medical treatment until health was re-established.¹¹ Parsons' Sick Role empowered the physicians as holders of the truth about the illnesses^{12,13} and based the Sickness Impact Profile -SIP, a generic psychometric instrument for measuring such behavioural dysfunction relating the *ill*-health.¹⁴ The SIP had influenced the structural design of questionnaires such as the SDIs. Parsons' thinking had also supported the framework of negative terms relating to disablement that was adopted in 1980 by the World Health Organization -WHO¹⁵ for the International Classification of Impairments, Disabilities and Handicaps - ICIDH. The ICIDH was also very influential on the development of sociodental indicators. Similarly to the Sick Role, but related more to chronic conditions, the ICIDH portrayed the consequences of disease and disability as socially destructive impairments to the functional and work-related role of individuals in society.^{16,17} The theories of disability and dysfunction that supported the construction of most SDIs took an overwhelmingly negative approach to oral impairment, and they overlooked the

positive behaviours and beliefs along with the coping and adaptive strategies of many disabled people.

Consequently, the construct validity of an SDI has been tested as how well its questions highlight a specific disorder that provokes a particular dysfunctional behaviour in the respondent. For example, the Social Impact of Dental Disease - SIDD¹⁸ has several questions about the presence or absence of difficulty chewing and toothache. The developers of the SIDD assured its constructed validity because respondents who experienced oral disorders and had difficulty chewing and eating did assume a dysfunctional sick-role in terms of day off work. For the developers of the SIDD, an individual with tooth decay who takes a day off from work because of the difficulties in chewing or pain is confirming the construct validity of the indicator.¹⁸

Alternatively, construct validity has been gauged by comparing the overall score from an instrument with the response to single question addressing a global assessment of oral health. For example, the construct validity of several of the more popular SDIs has been supported by close associations between low scores on their questions and positive responses to global questions about oral health. This association demonstrates that when the respondent reports fewer psychosocial consequences from oral disorders, he also perceives a good oral health status.¹⁹

Convergent validity, which is an expression of construct validity, refers to a convergent or similar response to like-questions, either within the same instrument or between instruments with the same theoretical base. Therefore,

most SDIs with similar questions should display strong convergent validity because they are rooted deeply in Sick Role Theory. For example, the Liverpool Oral Rehabilitation Questionnaire - LORQ was compared to the responses from the Oral Health Impact Profile - OHIP. The responses on both indicators correlated very high (e.g. high internal consistency coefficient) as they present similar questions to measure the aspects of oral health dysfunction.²⁰

Discriminant validity,^{xvii} which is another expression of construct validity, addresses the ability of an instrument to discriminate and segregate between respondents who experience the same phenomenon in different ways.^{21,22} This is usually the case for most of the indicators what assess the consequences of tooth pain, for example. The Geriatric (General) Oral Health Assessment Index - GOHAI has a question about frequency of "taking medication to relieve pain",³⁷ but because people vary in the way they experience pain,²³ it is expected that they would respond to that question differently anyways.

3.2.2 Content validity

Content validity reflects usually the clarity, comprehensiveness and relevance of the questions in the instrument.^{24,25} Typically in almost all of the dental questionnaires, experts have been used to judge the content of the

^{xvii} In the general psychometric literature, convergent validity refers to different measures that theoretically *should* be related to each other and are, in fact, related to each other. Discriminant validity, on the contrary, refers to different measures that theoretically should *not* be related to each other and are, in fact, not related to each other.

questions, although there are a few notable exceptions, including Dental Impact on Daily Living - DIDL²⁶ and Dental Impact Profile – DIP,²⁷ where lay folk or non-experts were also asked their opinions. Content validity has been also addressed as logical validity when experts deem the questions to be logically sound, and as face validity when questions reflect the supporting theory “in the surface”.²⁸

More broadly, content validity can also denote the range of the instrument's questions. For example, the higher the number of questions, the broader the areas covered by the indicator usually in terms of clinical problems and their consequences.²⁹ Whether a shorter or an extensive instrument is preferred depends on the purpose of the study.^{30,31} A broader and more detailed indicator is favoured, such as the OHIP or the Subjective Oral Health Status Indicator - SOHSI, if the goal is to discern clinical outcomes from different dental treatments by asking for specific information. A simpler and shorter instrument is suggested, such as the Oral Health-Related Quality of Life Measure - OHQoL or the DENTAL, if the intention is to have a global impression of the consequences of oral disorders in a larger population. However, most of the existing SDIs serve only to qualify, report the presence, or quantify the negative or bothersome impacts of oral impairment, which befits their theoretical foundation in Sick Role Theory, but yet challenges their characterization as oral health-related quality of life measures since they favour illness to the exclusion of health.

Content validity can also refer to how the indicators' questions were developed. For example, some SDIs had the content of their questions derived solely from theory or from another translated and 'valid' instrument,^{32,33,34,35}

including the Oral Impacts on Daily Performances – OIDP,²⁸ and the Oral Health-related Quality of life – OHQOL.³⁶ In other cases, the developers used also interviews with non-experts to provide empirical evidence for the content of the indicators' questions, including the GOHAI³⁷ and the OHIP.³⁸ However, interviews with the non-experts were usually guided by Sick Role-related inquiries, and most of the time the interviewees were ill-patients from hospital or dental clinics. The result of this bias had probably limited the focus of the instruments towards the impact of disability and dysfunction on a minority of population that suffered *ill*-health and had told nothing about the majority of those who were healthy.³⁹ More fundamentally, however, the information from participants was collected in the form of a series of statements and analysed and distilled by experts into a relatively small number of questions to form the instrument. In this stage, non-experts had rarely taken part in the process.

3.2.3 Criterion validity

Developers of psychometrics have been testing the validity of their instruments against specific criteria, such as current (concurrent validity) or future (predictive validity) beliefs and behaviours.⁴⁰ In essence, the instrument is said to hold criterion validity when its responses were associated with 'concurrent' conditions or criteria, or were used to 'predict' future observed conditions or criteria. For example, a variety of studies attempting to establish health care programs or to provide dental treatment have been employing SDIs to predict the

percentage of respondents who would seek care and thus, benefit from such programs or treatments.^{41,42,56} Unfortunately, the SDIs currently available do not predict oral health-related beliefs and behaviours very well^{43,44} possibly because respondents adapt to their impairments and limitations as time passes,⁴⁵ or are simply frustrated with past dental treatments.^{46,47,43}

Indeed, more often than not, patients and respondents to SDIs view the need for healthcare and treatment quite differently when compared to clinicians and researchers.⁴⁸ Such differences confirm yet again the need for input from non-experts when developing psychometric instruments. Criterion validity can be tested also against the known properties of an existing instrument, particularly if it embodies a gold standard. Unfortunately, gold standards relating to oral health have been difficult to find.⁴⁹

3.3 Limitations of the current validity testing

3.3.1 Relevance of the theoretical framework

Validity is closely linked to relevance. As I explained above, most of the existing SDIs dwell heavily on the negative impacts of oral disorders. Consequently, they ignore the positive contributions of teeth to various aspects of life such as eating and self-confidence. Moreover, they lack of sensitivity to incorporate the socio-cultural environment factors that might influence on how disability is perceived and accommodated in different societies.^{16,50} Hence, the appropriateness of the psychosocial portrayal of impairment and disability mostly

as a dysfunctional burden on patients and society as viewed by the Sick Role and the ICIDH seems to have been overlooked.^{5,6}

There have been some attempts to reconcile dental psychometrics with a broader interpretation of health and disability.⁵¹ However, most SDIs still overlook the adaptive and coping strategies often employed by older adults to minimise or prevent disability.^{44,52} The recently presented International Classification of Functioning, Disability and Health - ICF⁵³ favours a more existential or self-directed interpretation of health, and attempts to accommodate the less dysfunctional aspects of disorders. It portrays disability and physical impairment as an integral part of the social, cultural and psychological context of people's lives but yet subject to the ever-changing fabric of positive and negative values. Consequently, it might be a more encompassing conceptual framework for a psychometric instrument to measure oral health-related beliefs and behaviours.⁶

For example, participants who answer "yes" to the question "*did you experience difficulty opening your mouth wide?*", from the SIDD,¹⁸ might be quite bothered by the restriction. In the context of the ICF, however, they might have accepted the difficulty without concern. Additional questions, such as "*is the ability to open your mouth widely important for you when eating or, talking?*" or "*are you concerned that you cannot open your mouth widely?*" could help to identify respondents who are not bothered by the impairment, but answered "yes" to the initial question.

3.3.2 Confusing Attributes

Distinctions between construct, content and criterion validity, as implied above, are frequently unclear and they may in fact overlap. Moreover, there are others terms in use such as factorial validity, translation validity, intrinsic validity and practical validity which add more confusion to whether these attributes are distinct or part of the same 'thing'.⁸ For example, criterion validity alone has been approached as convergent, discriminant, concurrent, and predictive validity.⁵⁴ This apparent interchangeable use of different terms confuses some developers who favour either construct⁵⁵ or criterion validity⁵⁶ as the most important attribute to be tested in their SDIs. However, it is evident that validity is a broader concept that requires clarification and continuous evaluation in a process that also tests the predictive potential of an instrument and the inferences made from their scores within a theoretical framework that accommodates the broader range of social and cultural characteristics of the population under investigation.^{7,8}

3.3.3 Misinterpretations

Individuals respond to psychometric instruments within the context of a particular ethno-cultural environment, and not as "naked individuals stripped of all historical, social, institutional and convictional connections."⁵⁷ Some ethno-cultural groups, for example, respond to pain and tooth loss very overtly,⁵⁸ whilst others respond with less obvious expressions of emotion.^{23,59,60} Although the existing indicators may be able to discriminate individuals who experience pain or

tooth loss differently, they do not capture the reasons people vary in their experiences probably because the indicators' questions do not offer room for expression of such ethno-cultural groups' nuances.

Consequently, the limited interpretation that respondents can make upon the structured questions posed by the instrument enhances further the possibilities for misunderstanding. An affirmative response to the OHIP question: *"have you had difficulty chewing any foods because of problems with your teeth, mouth or denture?"*,³⁸ or to the GOHAI question: *"how often did you limit the kinds or amounts of food you eat because of problems with your teeth, mouth or denture?"*³⁷ reveals vaguely that the respondent has had difficulty or problems but reveals nothing about whether or not the respondent is concerned about them. Some foods are naturally difficult to chew, so acknowledging this reality does not necessarily imply concern or a negative impact on quality of life.⁶¹

Likewise, an affirmative response to the DIDL question *"have you tried to avoid showing your teeth when smiling or laughing?"*²⁶ could reflect normal behaviour in some Asian societies where it is boorish to display teeth, but anxiety in western countries where there is a disturbing preoccupation with dental appearance.⁶² Similar challenges were faced by studies employing more general health psychometrics. In one example, follow-up interviews with the respondents revealed that they understood some of the questions differently than initially conceptualized by researchers, which demonstrates that some of the items were

either unclear or ambiguous. Consequently, the value of their answers may have been affected.⁶³

3.3.4 Translations

Questions posed within a particular ethno-cultural context⁶⁴ can miss the nuances of natural conversation and may lose their original meanings when translated from one language to another.⁶⁵ Yet, some words have no relevant or direct translation.⁶⁶ Awareness of this potential for irrelevance and misunderstanding led to the elimination of seven questions in the Malay version of OHIP.⁶⁷ Similarly, the Portuguese version of the OHIP question "*have you had to interrupt meals because of problems with your teeth...?*" was translated with a different nuance, and now reads "*have you had to stop your meals because...?*"⁶⁸

Other examples of potential misunderstanding are seen with the French translation of 'comfortably swallowing' from the GOHAI because the French equivalent for *comfortable* has a different meaning than that expressed in English.⁶⁶ The Italian version of the OHIP question "*have you been self-conscious because of problems with your teeth...?*"³² was also misunderstood by the respondents because apparently 'self-conscious' has no meaning in the Italian context. On the other hand, questions have been added to the Greek version of the ODP⁶⁹ and to the German version of the OHIP⁷⁰ to enhance their relevance to the experiences of Greek and German respondents. In all, despite

reasonable attempts to provide sensitivity to linguistic nuances, the impact of the translation on the validity of an instrument remains challenging.

3.3.5 Significance and utility of scores

It is difficult to interpret the significance of a psychometric measurement when it is reported simply as a numerical score, and even more so when it denotes only negative impacts. All too frequently, scores are interpreted misleadingly as indicators of concern and offer little insight to the utility or significance of a psychosocial impact.⁷¹ This dilemma is evident when interpreting the implications of similar scores derived under different circumstances. If, for example, a respondent answers 'very often' to the first 18 questions of the OHIP, and answers 'never' to the remaining 31 questions, the final composite score of 72 reflects disturbances to quality of life caused mostly by pain and physical limitations. However, the same score of 72 is achieved by answering 'never' to the first 31 OHIP questions, and 'very often' to the remaining 18 questions, but it reflects disturbances caused mostly by disability and handicap. Evidently, a score of 72 can denote very different conclusions about the impact of oral impairments.

The current thinking about validation process emphasises that inferences made from a given score need validation as much as does the instrument.⁸ Similarly, Juniper *et al.*⁷² suggest that the score is useful only if it associates with an important change in impact, while Locker *et al.*⁷³ recommend scoring each set

of domains from an indicator, if indeed this is possible given that people do not readily segregate life into stable, well-defined and measurable domains.

3.3.6 Unstable scores

Dental psychometric instruments have been used to measure the quality and impact of treatments and the effectiveness of oral health services. There is an assumption that a change in scores over time indicates, for example, an improvement in the signs and symptoms of oral conditions as a result of the intervention or service.⁷⁴ However, there is little evidence on how well psychometric scores reflect changes that are clinically meaningful and individually relevant.⁷⁵

Yet, score-changes are also said to demonstrate the presence of positive health.⁷⁶ It is difficult to know, for instance, whether an increase in a GOHAI³⁷ score from 10 to 20 over a given period of time indicates that conditions have positively improved twofold or that the respondents simply had a change of mind or feeling during the same period.⁷⁷ Clearly, perceptions of health and disability are influenced by the social, cultural and political context in which they are assessed.⁵³ Therefore, despite their popularity, the psychometric instruments relating to oral health do not explain why respondents with severe dental impairments can rate their oral health as good and satisfying, whilst others complain in bitter distress.^{5,49}

This chapter deals exclusively with validity, but yet other psychometric properties exist. For example, reliability, or the consistency to which an indicator yields the same results over repeated assessments, and responsiveness, or the ability to detect differences in the results over time^{78,79} have been extensively tested on the SDIs. However, there is an ongoing debate on whether responsiveness represents a distinct property, an expression of reliability, or an aspect of validity.^{9,80,81} Although relevant to a psychometric instrument, I did not discuss them here simply because I believe that validity tends to override the other psychometric properties since an instrument can be reliable and responsive but not necessarily valid.⁸ In the case of the SDIs, despite attempts to demonstrate their reliability and responsiveness, they still favour dysfunctional and ill-health as the most valid oral health-related quality of life aspect to be measured,³ limiting their focus.

3.4 Conclusions

The validity of most psychometric instruments used in dentistry has been tested on how well they reflect their theoretical framework, how clear and relevant is the content of their questions, and how accurately they predict a given criteria. However, these steps do not guarantee that an SDI is a valid and appropriate measure of the broader psychosocial aspects of oral health because:

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- The content of the questions used by many SDIs are ambiguous, vague, or limited in scope, which detracts from their ability to address the complexities of health measurements;
 - Questions about concurrent mouth-concerns are reasonably dependable. However, their responses in general are poor predictors of health-related beliefs and behaviours probably because they overlook the ever-changing sociocultural environment in which people live;
 - The meaning of SDIs' questions to the respondents, and the interpretation of the responses to these questions by the researchers are often unclear;
 - Sick Role Theory, which forms the conceptual basis the SDIs, has been challenged by theories offering a more positive and realistic interpretation of impairment and disability;
 - The process of evaluating the validity of SDIs needs a broader scope of attention to evaluate continuously the content of the questions, the predictive potential of the scores, and their theoretical framework.

3.5 Acknowledgments

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3.6 Link to the next chapter

Since the negative theories and models of *ill*-health that support the questions of the existing indicators challenge their validity, new or alternative models of *health* are needed to either modify existing, or base the development of a new SDI. Since MacEntee presented a promising model of oral health in 2006,⁶ I use the methods I describe in Chapter 4 to evaluate and refine his model as later presented in Chapter 5.

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CHAPTER 4

USING FOCUS GROUPS WITH A WRITTEN VIGNETTE TO DISCUSS ORAL HEALTH WITH OLDER ADULTS

A version of this Chapter has been prepared for submission in **The Qualitative Research Journal**

Brondani MA, MacEntee MI, Bryant RS. Using written vignettes in focus groups among older adults to discuss oral health: the V+FG Approach.

4.1 Introduction

The World Health Organization¹ and others^{2,3} have repeatedly stressed the need to look beyond the absence of illness to explore the more subjective social and psychological dimensions of health and disease in general,⁴ and oral disorders in particular.⁵ As a result, at least 16 psychometric or sociodental indicators have been developed to complement clinical measures of oral disease. The existing indicators focus on the psychosocial consequences of missing teeth in daily life, for example, by posing a set of structured questions (Chapters 2 and 3).

The answers given to a sociodental indicator's questions do not allow respondents to explain the significance of the psychosocial consequences of oral disorder, however. Moreover, structured questions offer no room for respondents to express their experiences, feelings, values and beliefs relating the oral health, impairment and disability beyond the formal responses allotted to the questionnaires.⁴ There is a growing awareness that subjective dimensions of health are better understood qualitatively from individual interviews to group discussions.⁶ Therefore, this chapter is aimed at my third objective, which is to describe my experience of using a written vignette to promote discussions about oral health as a possible sensitive topic in a series of focus groups among older adults. I first situate qualitative investigations in the context of dental research and compare focus group with individual interviews.

4.2 Exploring oral health

Little is known about the nature and complexity of personal and social factors that affect the perception of oral health and well-being.⁷ For example, there are widespread differences in how researchers, clinicians, and patients understand and value 'oral health' or 'oral problems'.^{8,9} Such differences in oral health-related values and beliefs can be explored through an inductive and systematic analysis of qualitative information from people who have experienced disease and disability.^{10,11}

Qualitative research employs a variety of methods ranging from simple observations to more intimate and direct interactions with individuals or groups.^{12,13} In dentistry, for example, qualitative interviews usually through open-ended questions have been used to explore how dental problems detract from the pleasure of eating and lead to social embarrassment,^{14,15,16} and to reveal how older adults can accommodate to and accept oral dysfunction and disorders.^{16,17} Open-ended interviews have been employed also to develop questions for sociodental indicators,^{18,19,20} as discussed in Chapter 3. Other than individual interviews, focus group discussions^{xviii} provide an approach for exploring the experiences, perceptions and meanings of health and quality of life in old age.^{21,22}

xviii Other forms of group discussions exist. Nominal groups, for example, collect views from group members individually and circulate them for comments. The Delphi technique is a particular application of a nominal group where experts individually forecast a specific situation, and their views are summarized and circulated until consensus is reached, which is not necessarily the case in a focus group.

4.3 Focus groups and individual interviews

A focus group allows participants to explore feelings, experiences, opinions and new ideas.^{23,24} When compared to individual interviews, the advantages of focus groups include the possibility of gathering information from a variety of participants at the same time and being less costly.²⁵ Through active and dynamic interaction, participants manage to typify a representative characteristic of each other's experiences about everyday life²⁶ in which contrary opinions and new areas of understanding are explored. The participants also question one another, explain and elaborate specific points, seek clarification, pose comments, and prompt the group to refine the information generated through a process of socialization in which participants construct a shared reality through their opinions and experiences^{21,27} despite their uniqueness.²⁸ Lastly, the information generated in a group goes beyond the face-to-face interactions of individual interviews in which the absence of group dynamics could reduce the enthusiasm of participants to volunteer information about the topic.²⁹

The disadvantages of focus groups over individual interviews include the need for equal opportunity of participation and control of participants who dominate the conversation.³⁰ There is an unavoidable bias towards attracting participants who are out-going and self-confident to express their thinking in a group, while tensions between participants can interfere with the free flow of ideas. Hence, the context in which the discussions occur may not reflect the natural environment of the participants, and can generate discomfort and anxiety. A false sense of

consensus or agreement can arise also if some participants are reluctant to contradict others with a conflicting opinion,³¹ or when the topic under discussion requires a personal disclosure that causes embarrassment.^{32,33} Lastly, if the idea is to describe the meaning of individual 'pure' experiences, focus groups are not feasible because the group interaction 'contaminates' the discussion about personal experiences in the context of the discussions.³⁴

4.3.1 Focus groups assembling and dynamics

The process of recruiting and selecting participants for focus groups ranges from direct contact by mail or telephone to public advertisements on buses and newspapers, and in a variety of social places including community centres and malls.³⁵ General, a focus group of 6-10 participants meeting once for about 2 hours promotes a good interactive rapport while allowing for an adequate flow of the discussions.^{24,35} The discussions are usually facilitated by an outside moderator who is familiar with the topic of inquiry, encourages equal participation in a safe and respectful environment, and promotes discussion by posing open-ended questions and encouraging responses.³⁶ The purpose of focus groups is not to establish a consensus from the participants but to give everyone an opportunity to discuss the topic,³⁵ even if only by nodding in agreement with group members.²¹ The number of group discussions needed to explore a given topic fully is usually determined by the principle of 'saturation', which is achieved when no new information emerges relevant to the focus of the discussion and the content is

repetitive.³⁷ Participants are selected through a variety of strategies based overall on the principles of purposeful sampling. The researcher can aim at getting maximal variation of nationalities, professional backgrounds, age, work experiences and so on, or at achieving a more homogeneous set of characteristic that simplifies analysis and facilitates interviews,³⁸ although the extent of the homogeneity is difficult to determine.

4.3.2 Focus groups in dentistry

Focus groups have been used in dental research for a variety of reasons. For example, May and Waterhouse³⁹ organized groups of children and teenagers to evaluate the influences of peer groups on the effects of acidic drinks in the mouth. Newsome and Wright⁴⁰ assessed satisfaction with dental care through focus groups with younger adults, and found the approach more efficient and less expensive than individual interviews. Kwan and Holmes²¹ favoured focus groups to study general health values and beliefs associated with oral health under the assumption that participants would “not be willing to express their views in one-to-one interviews in order to avoid confrontation” with the interviewer. In most of the dental research using focus groups, however, older adults have been rarely selected as participants to address issues relating to oral health.

4.3.3 Focus groups and vignettes in dentistry

There is some evidence suggesting that oral health and disablement are difficult topics for some people to address in an open forum,^{41,42} whereas others have favoured focus groups for discussions about oral health as an approach to avoid the 'embarrassment' of one-to-one interview.²¹ The study conducted by Kwan and Holmes,²¹ for example, gathered culturally specific participants to make the environment more 'appropriate' for sharing ideas about sensitive topics. Others advocate vignettes as effective initiators of discussions among participants from different backgrounds, or when the topic under discussion could be perceived as personal or sensitive.^{43,44}

Typically, vignettes expose personal matters and experiences indirectly through text, images, songs or other forms of information framed within a scenario or a story about a hypothetical situation.^{45,46} The distancing of the sensitive topic through a vignette allows participants to express their ideas at any time without feeling personally exposed to the interviewer or other participants in a focus group as they project their opinions from the scenario.^{47,48} In dentistry, vignettes have been used along with individual interviews involving health professionals and students to discuss the appropriateness of dental treatments,⁴⁹ to record dentists' opinions about dental neglect and abuse,⁵⁰ and to investigate dental students' acceptance of various behaviour-management strategies for patients.⁵¹ I could not find studies using a vignette to prompt discussion of oral health and disablement as possible sensitive topics among older adults gathered in focus groups.

4.4 Methods

4.4.1 Development of the vignette

I developed a short situational vignette to portray a realistic scenario⁴⁸ relating to the experiences of two people with oral health and disorder (Figure 4.1). The vignette was presented on a 100cm X 60cm poster in 120 font so that the participants could read it easily from a distance. Participants also received a paper copy of the vignette in 14 font so that they could as they wished write comments, observations and thoughts.

Figure 4.1 - The situational vignette used to prompt the focus group discussions

"Rosita resides in the same building with her friend Victor in a Spanish neighbourhood. They are very active within the local community. Rosita argues frequently with Victor because, according to her, he seems to not care about his mouth because he does not wear his dentures all the time. She keeps telling him to wear his denture to "look better". Even when eating, Victor sometimes does not wear his dentures. He often goes to the community centre without them and seems not to be upset about it, but not Rosita! She never goes out without her dentures and now she avoids Victor's company outside the building."

After reading the vignette at a pace I considered suitable for the groups, I asked if everyone understood its content. I then posed open-ended questions to prompt discussion on the definitions and perceptions of oral health, to gather the participants' values, beliefs and behaviours pertaining to oral health and disorder,

and to explore ideas on how edentulous people deal with dentures.^{15,18,21} For example, when I asked “why do you think Rosita always wears her dentures even with discomfort, and Victor does not?”, and “why do you think such behavior might vary or not among different groups of people?”, the participants offered opinions about adapting and coping with dental problems, and also identified the importance of the socio-cultural environment even though I did not introduce such terms directly in the questions (for the entire guideline, see Appendix 5). Throughout the discussions I continuously probed for more information and clarification on issues raised during the discussions. Typically in each group, discussion on the vignette lasted about 45 minutes, which seemed sufficient to explore all of the questions about the vignette and to probe for related information.

4.4.2 Composition of the groups^{xix}

I recruited participants purposively to identify men and women: 1) aged more than 65 years from different locations including residential buildings, seniors and community centres and retirement homes (Appendix 7); 2) comfortable speaking English; 3) willing to share their ideas within a group; 4) who had different marital and educational background; 5) with different perceptions of general and oral health; and 6) with different dental status (teeth or dentures) to provide a broad range of characteristics that could enrich the discussions³⁸ (Appendix 8). I

^{xix} I received Ethical approval for this study from the Behavioural Research Ethics Board, University of British Columbia (Appendix 1).

did not seek for representativeness of the characteristics outlined in 4, 5 and 6, but for maximal variation.

4.4.3 Focus groups in my thesis^{xx}

I moderated all of the focus groups with support from research assistants who helped to control the length of discussions, and provided field-notes to identify the sequence of each participant's contribution (Appendix 3). The observer's notes helped to keep track by numbers the comments of each participant when I analysed the transcripts. The identification by numbers also assured confidentiality of the information and the anonymity of the participants.

I promoted a non-threatening and comfortable environment to facilitate group discussions, probe for comments, cover important topics from the prepared outline (Appendices 5 & 6), and encourage involvement of each participant. I began the discussions of the vignette with a short introductory period of about 10 minutes to ease the anxiety and social reserve of the participants.²⁴ During this period, I explained the purpose of the study, and obtained the written informed consent to have the discussions tape-recorded, transcribed verbatim, and analysed (Appendix 2). I encouraged participants to share their thoughts and ideas freely and without concern. Each group met on one occasion for about 90 minutes with 10-15 minutes of rest for refreshments after 45 minutes. I used the first half of

^{xx} A methodological discussion about the use of focus groups and a vignette in the context of my thesis is given in Chapter 6.

each discussion to explore opinions on the issues identified from the vignette, and the second half to evaluate the model of oral health developed by MacEntee (see Chapter 5). I concluded each section by asking if there were issues or concerns that required further clarification or that had not been addressed.

4.4.4 Group rapport

I promoted rapport within each group by: 1) allowing the participants to collectively select the best time for the group meeting; 2) encouraging everyone to use first names and name tags; 3) offering a friendly environment for the meeting; 4) providing snacks and non-alcoholic drinks; and 5) expressing my gratitude by delivering a "*Thank You*" card to each participant at the end of the session.

4.5 Analysis of my experience with focus groups and a vignette

I analysed my experience of using a written vignette in focus groups with older adults to discuss oral health as a possible sensitive topic by asking myself: 1) did the vignette allow discussion of sensitive topics? 2) did the vignette encourage disclosure of personal experiences? and 3) did the groups' members interact and offer opportunity for equal participation? In each answer I drew from the literature on these issues and from the participants' responses during the discussions.

4.6 Results and discussion

Six focus groups gathered a total of 42 elders between ages of 64 and 93 years (average: 74 years). Each group had a minimum of 5 and maximum of 9 participants, as others have recommended.^{21,25} and I did not have the same participant attending more than one discussion. Following the recommendations offered by Denton *et al.*,⁵² one group consisted only of men and another only of women to encourage discussions that could be specific to either gender (Table 4.1). The group of men was composed by gay seniors and happened by chance as I did not select participants based on sexual orientation.

Table 4.1 - Composition of the focus groups according to gender and location

Focus group	Gender distribution		Location^{xxi}
	Women	Men	
1	6	0	Residential Building
2	5	2	Senior Centre
3	7	2	Senior Centre
4^{xxii}	0	5	Community Centre
5	5	2	Senior Centre
6	7	1	Retirement Home
TOTAL	30	12	

^{xxi} Location does not have address or specific names to maintain confidentiality.
^{xxii} The participants of this group were gay men.

Although the majority of the older adults in Canada live at home independently or with family members, about 10% reside in 'collective dwellings' such as nursing homes, hospitals, religious institutions, retirement homes, and hotels, and who may require different levels of assistance.⁵³ I attempted to gather older adults from a retirement home who required different levels of assistance. I also gathered seniors from a residential building living independently, and from senior and community centres.

I selected these different locations also regarding the possibility of having participants expressing different perceptions of general and oral health. For example, those participants living independently could have experienced fair or good health to live on their own, which I supposed would influence their views of health in general and oral health in particular. Since I did not know whether such views were predominant, I conducted one focus group in a retirement home which houses seniors with some levels of impairment and frailty to live on their own and who could express a different view on health and oral health.

I also attempted at gathering participants from different ethno-cultural backgrounds to provide a variety of cultural health values and beliefs. Although I visited senior centres and retirement homes in China Town, Burnaby and Richmond, none of these facilities were interested in helping me to recruit participants. This happened probably because I sought elders who spoke English fluently. Consequently, although most of my participants were Caucasians from Canada and the United States, in different groups I had one participant from each

of the following countries: Poland, Germany, Yugoslavia, England, Italy, Russia, China and India.

From the 42 older adults that I gathered, most of the participants were well-educated (Table 4.2), which confirms the report provided by Gutman *et al.*⁵⁴ in which the elderly population in B.C. tends to present high levels of schooling. Most of the participants were either single or divorced, and reported that they felt healthy and had most of their natural teeth (Table 4.2), which confirms the findings from Corson *et al.*⁵⁵ that the elderly are retaining their natural dentition for longer. However, I interpreted the participants' self-reported assessment of their teeth and dentures with caution because discrepancies occur between self-assessment and clinical assessment. As stated by Vered and Sgan-Cohen,⁵⁶ the self-reported status may not reflect the actual oral status of the participants. In all, the mix of gender, marital status, educational background and age promoted a diversity of opinions that enhanced discussions and identification of particularities in values and experiences.²⁴

Table 4.2 - Self-reported characteristics the 42 participants in the six focus groups

Characteristics	<i>Number of participants</i>
Age range (years)	
64-74	23
75-84	12
>85	7
Marital status	
Single	18
Married/Common-law	6
Divorced	10
Widowed	8
Education	
University	11
College	9
High school	17
Elementary school	5
Self-assessed oral health status	
Natural teeth	6
Natural teeth & denture	30
Complete dentures	6
Self-assessed health status	
Healthy	38
Unhealthy	4

4.6.1 Did the vignette allow discussion of sensitive topics?

Overall, the vignette allowed most of participants to talk with ease about oral health and related disorders. However, my initial concern about the sensitivity of the topic was acknowledged by a 71 year-old woman from the group 2 who just got a set of new dentures and who were concerned about food staining in her new teeth. She raised her concerns about bad breath:

"I can talk to anybody about my teeth or whatever, and now getting new dentures has been a topic of conversation, but [I cannot talk] on body odour or bad breath, no way (she puts her hand over her mouth). It is not easy."

Bad breath, for example, has been referred to as potentially detrimental for social interaction and conversations, as advertised by dentists⁵⁷ and manufactures of dental products.⁵⁸ Surprisingly, the interaction within the group while discussing the vignette prompted that same participant later to testify:

"Well, I guess I can talk now (she laughs). Maybe something I ate, like garlic. We know how garlic tastes and smells like, you can feel on people's breath and people can make a big deal about it, like Rosita may be avoiding Victor also because of that (she gives her two thumbs up)."

Even though the vignette seemed to work positively for this participant in the group, the personal meanings attached to oral health and disablement might have remained very personal for others, as voiced in group 4 by a 72 year-old man with dentures:

"[m]aybe people have different issues to talk about, one with appearance, the other with some other issues in life, maybe other problems (he pauses for a few seconds) with dentures, people just don't talk, it is personal."

Contrary to the experiences of others,⁵² opinions about the vignette were not influenced by gender or the composition of the groups. For example, the first group comprised of women only told me that facial aesthetics was a universal concern, independently of gender. Consequently, I explored this assertion with the other groups, and particularly with the group of men (Group 4), and found that they all agreed with this widespread concern for appearance regardless of gender. Likewise, similar opinions about the vignette were expressed by seniors living in retirement home, residential building, or gathering in community and seniors centres.

4.6.2 Did the vignette encourage discussion of personal experiences?

Participants, as suggested by Barter and Renold,⁴³ did share very personal and difficult concerns and issues around oral health by presenting their own struggles at any stage of the discussions. They did so to either agree or disagree with Victor and Rosita. For example, a 65 year-old woman from Group 1 expressed her own experience when trying to understand the argument between the vignette's characters:

"[a]nd this is true (the argument) because my husband, his first set of teeth was absolutely dreadful, and I said to him 'what have they done? Go back there, this is not right because we paid good money for this, and they have to make it right'. He could not eat properly; he was feeling like he had a bag in his mouth."

Personal experiences were shared again when I probed further for reasons why Victor did not wear his dentures. Experiences with cancer as a potentially difficult topic were voiced by another 64 year-old woman from Group 5 who explained that:

"[i]t is like my husband not shaving and I asked him 'why don't you shave anymore?' It is because of his cancer, and he says 'by the time I stand and try, I get tired, and I can't be bothered'. And the same with his dentures, and he does not use them. I don't say anything. If he walks around the building looking like a bum, he looks like a bum, and that's the way it is."

Cancer was also the topic when a 64 year-old man from the Group 3 shared his brother's experience with oral malignancy:

"[w]hen he went to the dentist, he had a toothache, the dentist removed the tooth and told my brother that he should go to see his doctor right the way. Two months later, my brother had part of his jaw removed; part of his head removed; yes, cancer (he pauses). But he is alive."

Moreover, during the discussions, participants showed their dentures, brought forth family incidents with teeth, and explained their experiences in the first person, apparently without embarrassment. These attitudes and behaviours demonstrated that, if oral health was a sensitive topic for open discussion initially, it was not apparent later in any of the focus group.

4.6.3 Did the groups' members interact and offer opportunity for equal participation?

4.6.3.1 Group interaction

Throughout the group discussions, it was clear from the interaction that the participants either agreed or disagreed with the vignette,⁵⁹ or with each other's opinions. For example, a dynamic conversation between two women, one 66 year-old (participant A, who felt healthy), and the other 75 year-old (participant B, who reported a variety of health problems), took place in the Group 3 when discussing impairment from a toothache even though they seemed to disagree:

Participant A: *'I don't think [toothache] generally impairs you. I mean, if I have to, I can still go out and buy groceries. It doesn't impair me from doing other things.'*

Participant B: *'But you see, I have spinal problems since I was 23, and now I'm 75. I have to exercise, but I want to exercise, and every time I go over, I come back and I have to go to bed [to rest]! What do you do than? It is not good, is it? The difference between me and you though, is, for example, if I'm shopping, and tired, I can sit down for a while, but you cannot do anything about your toothache.'*

Participant A: *'Well, I know you can't, but it doesn't really impair you to go out and still walk along, it doesn't really impair you, I don't think.'*

This friendly exchange of opinions about impairment continued later in the discussion when I asked the reasons why Rosita was wearing her dentures even with discomfort. Participants brought the terms 'coping and adapting' in the discussions but expressing different opinions, and engaged a 72 year-old man (participant C, who had visited his dentist recently):

Participant B: *'Yes, well, that is coping and adapting, that's what I'm doing, that's what she is doing.'*

Participant A: *'If I had a bad toothache, the only way to cope with it was getting some antibiotics from the dentist and have that tooth fixed, that's how I cope with it, that is the only way to cope with it. A toothache is different than a backache, I mean, I have backaches too, but to cope with the toothache, for instance, that's the only way to cope with it, to get it fixed!'*

Participant C: *'That's how I cope with...doing something about it.'*

Participant B: *'You mean, to go to the dentist and get it out or something...is that what you are saying? Why would you cope with it if you can do something about it?'*

Participant C: *'But that's how I do, resolve it.'*

A similar interaction occurred when a different group was discussing facial appearance and the social implication regarding Victor's lack of teeth. At this time, the discussions prompted an 88 year-old woman with natural teeth, from the Group 6, to explain:

"[w]e were sitting in a bus stop, all different ages, and we were waiting quite a while, and all of sudden a worker passed by in an overall and a hard hat. We all turned our heads and followed him, and I thought 'Why we did that?'

[The group's participants nodded their heads, and the 88 year-old female continued:]

"I don't know, but he was so appealing in those clothes and he was eating a sandwich. I guess if he smiled showing a missing tooth, or no teeth at all, it would change [our view of him] because [it] would be kind of, not fitting with the picture!"

And another participant from the same group, a 69 year-old female added to the 'bus stop event' her ideas about bad breath:

"[t]he same with bad breath. If he'd approached you asking for the bus schedule or something and you could feel that bad breath, it would be terrible for the 'image' that you were seeing."

I had no difficulty encouraging group members to participate and comment on the vignette as they engaged in an interactive discussion, as foreseen by Lewis⁶⁰ and Kreuger.²⁵ Quite often, I had to remind them of the purpose of the discussions when they went off-topic to talk about a variety of other issues. On other occasions, the participants themselves exclaimed: *"Well, I guess we are off-topic here, aren't we?"*

4.6.3.2 Opportunity for equal participation

Overall, most of the groups optimized opportunity for equal participation, although not without disagreement. In Group 3, a participant with a strong accent was constantly encouraged successfully by the others to express her ideas. For example, they kept asking her for confirmation by saying *"I think you are referring to..."*, and for clarification by stating *"sorry, could you say that again?"*

In other groups, however, I experienced some attempts at dominance.^{24,60} For example, after presenting the vignette to Group 5, one woman immediately started disclosing her unfortunate experience with a dentist:

"He (Victor) is the same as me because my gums are all worn off due to years of problems. So, I went to one dentist and he advised... a new bottom denture, and I trusted him, and I gave him the money. And he did not finish it! When he brought the lower, and he asked if that worked, I said "NOO! That hurts, it doesn't fit". So, I went back about 5 times, and

testing, and testing, it was still hurting and hurting. When I put them in, it looked like a horseshoe was going into my mouth, it was wrong, it doesn't fit, it hurts. Maybe he [Victor] passed through the same experience, and ..."

For almost 10 minutes, whilst others remained silent, she tried to dominate the discussion by voicing her struggles with her new dentures. It was not obvious whether the others agreed or disagreed with her assertions, or whether they were intimidated by her, as studies have shown these possibilities.⁶¹ Such difficulties in interpreting participants' reactions can occur,^{61,59} nonetheless, I tried to bring participants into the discussion by asking "...and what do others think about that? Did any one else have the same experience?", but they simply looked at each other saying nothing. To my surprise, after voicing her experiences, she simply stood up and left. I heard from her later that she simply want others to know how upset she was with her dentist because of the dentures he made for her.

In the Group 6 the participants monitored the discussions by kindly interrupting talkative members. Whilst one man was continuously bringing up his friend's experience in a hospital for dental surgery, a women interrupted him:

"Hummm, ok...sorry to hear that, I understand what you mean, and it must be difficult, I know [but] I have a friend [who] had the same problem, do you want to hear his story? [she looks at others in the group for approval, pause for a moment, and briefly presents her friend's experience]"

Nonetheless, the analysis of focus group information reflects the interaction of participants,²⁴ and presents challenges when interpreting incomplete sentences, interruptions, and silences accompanied by non-verbal cues.³⁵ For example, after one group member posed an idea or statement, silence may have implied

agreement by some participants and disagreement by others,^{61,62} as I experienced in group 5 described above.

Although I illustrated single participants' ideas and opinions through the quotations, I interpreted such data in the context of a group discussion. Consequently, most of the ideas voiced by the participants were possible only because of their interaction in the groups. In this chapter I did not analyse the information through a thematic approach since it aimed at showing simply how the method worked. A thorough analysis is done in the proceeding chapter.

4.7 Conclusions

The main goal for this chapter was to describe my experience in combining focus groups with a vignette to discuss oral health and disability as a possible sensitive issue for older people. With interaction as the main advantage of using focus group over individual interviews, I was pleased by the dynamism of the discussions in each group and by the amount of information I collected from the interactions. According to Lewis⁶⁰ and Kreuger,²⁵ when participants promptly engage and interact, the moderator is less worried about encouraging participation but more cautious about the time and about equal participation.

Others have successfully used vignettes in focus groups^{50,51} but, as far as I could see, nobody has used a vignette to prompt discussion of oral health and disablement among older adults. All of the groups unanimously concluded that the vignette was "*very interesting*" and cause for reflection. Although lack of desire to

participate is a problem in any discussion, participants moved quickly beyond the vignette with their own insights and experiences. I conclude that the vignette prompted discussion, encouraged participants to disclose personal experiences and enabled group interaction and opportunity for equal participation with few attempts at dominance and little serious disagreement.

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4.9 Link to the next chapter

With the benefits of using focus groups prompted by a written vignette to discuss of oral health and to generate rich data, I propose this method to evaluate and, if necessary, refine MacEntee's model in Chapter 5.

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CHAPTER 5

RE(DE)FINING A MODEL OF ORAL HEALTH IN OLD AGE

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5.1 Background

Worldwide efforts to portray the limitations and restrictions of health and disease as a biopsychosocial phenomenon with consequences that could be either positive or negative led to the development of the World Health Organization - WHO' International Classification of Functioning, Disabilities and Health¹ - ICF (Figure 1.7, page 14). The ICF acknowledges the dynamic interaction between environmental and personal factors, while distinguishing between an individual's capacity and performance in the usual 'activities' and 'participations' of life.² Consequently, limitations and restrictions may or may not be a consequence of a particular health condition.^{3,4,5,6}

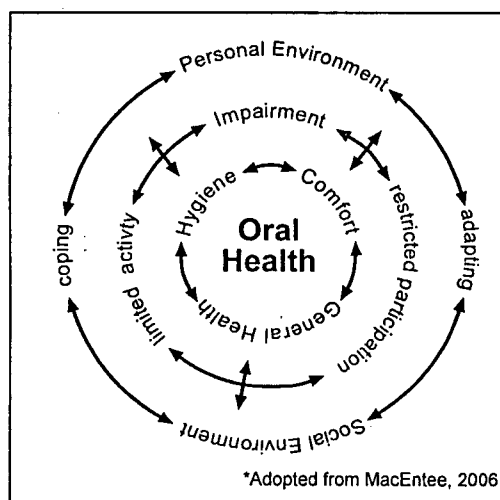
In the context of oral health, the ICF framework helps us to understand that two elderly persons with a missing front tooth may be equally impaired, however, one may feel handicapped as a public speaker, while the other may feel completely unrestricted within a community where tooth loss is accepted as a normal part of aging. Impairment and disability, in essence, do not always restrict the activities of daily life⁷ since reaction to a missing teeth can vary.

The ICF is a complicated classification, prompts different interpretations, and has been used to document and plan for the consequences of diseases through a unified and standardized language.² But it has limitations.⁸ For example, the ICF recognizes the importance of 'personal factors' but does not openly classify them to include expectations, willingness or motivation.⁹ Although it assesses the capacity and performance of activity and participation positively

and negatively, these components are quantified in a traditionally negative way with response options such as *no problem*, *mild problem*, *moderate problem*, *complete problem*.¹⁰ Others have criticised the graphic representation and content of the ICF because it was developed mostly from experts' understanding of health conditions without inputs from people who were disabled and who have experienced disease with little dysfunction,^{11,12,13} as I discussed on pages 16 and 17.

Nonetheless, despite the limitations of the ICF, a model of oral health was developed in 2006 using the language and general framework of the WHO 2001 classification and current concepts of health and disability as its theoretical basis. The model was also developed using the information gathered from interviews with older adults about health values and beliefs as its empirical element.¹⁴ Overall, the model focuses on the psychosocial aspects of function and disablement of the mouth (Figure 5.1).¹⁵

Figure 5.1 - The existential model^{xxiii} of oral health proposed by MacEntee (2006)*



The model from Figure 5.1 illustrates that oral health is a dynamic phenomena with ebb and flow within the different aspects of function and disablement of the mouth and within a variety of components outlined in the concentric circles. The components emerged from an inductive process of analysis with the information gathered from individual interviews with 24 older adults who were encouraged to freely express their ideas through open-ended questions about health. The analysis revealed that oral hygiene and comfort with dental appearance had both personal and social significance, while general health had significance mostly at a personal level (inner circle). Hence, the interviewees acknowledged the potential for oral impairments that might or might not restrict participation or limit activity since oral disorders did not always cause dysfunction (middle circle). A more positive outline for the model was favored

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As noted in Chapter 1, I will refer to 'original model' throughout the thesis as that proposed by MacEntee.¹⁵

since older adults experience oral health and illness within a variety of personal and social factors as they cope with and adapt to impairments and limitations (external concentric circle).¹⁴

Although MacEntee's model portrays a more optimistic perspective of oral disability when compared to previous studies,^{16,17,18} it still presents a slightly negative language through components such as limitations, restrictions and impairment. Moreover, despite its qualitative empirical foundation, the elderly participants did not have the opportunity to confirm the outcome of their narrative analysis nor to assess the structure and content of the model.

In terms of evaluating the structure and content of models, qualitative studies have recommended different criteria for such evaluation. For example, Brathwaite¹⁹ evaluate a variety of models for guiding the design of research intervention in nursing through a set of criteria including comprehensiveness and congruence of such models. Similarly, Moody and colleagues,²⁰ with advice from experts, recommended that models of quality assurance should be assessed through a framework addressing the *completeness* and *relevance* of the components relevant to quality assurance, and well as the clarity of the relationships among (*e.g. interdependence*).

With an eye to my fourth research question, I employed a lay perspective on Moody's criteria because the content and structure of MacEntee's model might assist professionals in planning patient-centred care, evaluating patient outcomes, prioritizing research and treatment options, and supporting the

development of a sociodental indicator relevant to older adults.^{21,22,23} In order to provide such assistance, the model has to show clear structure and portray relevant content to older adults who would benefit from services and treatment. Through a qualitative study focused on the model's content and structure, participants can confirm that the components and relationships originally presented by MacEntee are applicable or not to their oral health experiences.

Consequently, I use this chapter to describe a qualitative study using the methods presented in Chapter 4 and the methodological discussion I provided in Chapter 6 to evaluate and refine the model presented by MacEntee, particularly relating to its *completeness* in all aspects of oral health, its *relevance* to the elders, and the *interdependence* of its components and graphic representation.²⁰

5.2 Methods

5.2.1 Focus groups

Upon informed consent (Appendix 2), I conducted a series of focus groups²⁴ to expose experiences of older adults with oral health. I purposefully²⁵ sampled elders who responded to advertisements in residential buildings, senior and community centres and retirement homes (Table 4.1, page 89) to obtain a wide variety of oral health-related experiences^{26,27} related to gender²⁸ and health status as explained in Chapter 4.

I transcribed and analysed the information concomitantly with the focus groups in an iterative process, and continued the recruitment until the information emerging from the analysis was obviously saturated.²⁵ In all, 42 elders in 6 groups participated in my study (Table 4.2, page 92). Each group met once for approximately 90 minutes. None of the participants attended more than one discussion.

I moderated each focus group with help from observers who recorded field-notes (Appendix 3). The field-notes identified each participant by a number and matched their sequence of participation in the discussion by key words or short statements. The notes also outlined non-verbal interactions²⁹ and the number assigned to each participant helped as I transcribed the discussions.

As oral health may constitute a sensitive topic for open discussion,³⁰ I started the focus groups with a written vignette (Figure 4.1, page 86) as a projective technique to generate debate for the first 45 minutes or so in each group (Chapter 4, pages 86 and 87).³¹ The vignette also set the stage for discussing the original model of oral health. I also gave to each participant a pen and a printed version of the vignette and the model for their comments or ideas, which they were encouraged to write as the group discussion occurred.

5.2.2 Evaluating the original model

Evaluation of the model was a natural step after the participants discussed indirectly most of its components within the context of the story presented by the vignette. Consequently, after a break of about 10 to 15 minutes for refreshments, I presented the original model on a large easy-to-read poster for a discussion about its content and structure for another 45 minutes and was satisfactory for the groups to discuss the model in depth and yet to prevent draining the participants.

I was interested in how participants defined each of the original and new components, if any, and how they connected such components. I started to evaluate the model by asking each group for their thoughts and ideas about the meaning of each component, and about what they felt was right, wrong, missing, excessive or misleading in the model.³² The participants were free to evaluate and refine the model as they wished after I explained that there was no right or wrong interpretation of the model and, if necessary, there was room for improving it to better reflect their own experiences.³³ All the groups were asked to evaluate the original model through questions addressing completeness, relevance and interdependency of its components according to the Appendix 6.

5.2.3 Analysis^{xxiv}

5.2.3.1 Definition of the ORIGINAL and NEW model's components

I analysed the transcripts from the group discussions, the field-notes provided by the observers, and the participants' written comments.³⁴ I used the framework approach³⁵ for my initial deductive analysis of the components in the original model even though some groups offered new components (please, see Chapter 6). After getting the sense of each transcript, field-notes, and participants' comments, I started identifying a thematic framework with categories^{xxv} by which the components of the original model were examined sequentially and comparatively.³⁶ From the categories, I identified inductively³⁷ the essential codes and themes to assure the completeness, accuracy and relevance of the components. The categories, codes and themes were then linked in maps with Power Point® (Microsoft Office 2003) (Figure 6.3, on page 160 in Chapter 6, shows the rationale behind assigning categories, codes and themes).

Modifications to the maps, for each component, were made through a constant comparison with preceding groups so that emerging categories, codes

^{xxiv} A methodological discussion about the use of grounded theory and framework analysis in the context of model evaluation is given in Chapter 6.

^{xxv} For each of the model's components, I deductively assigned categories as broad characteristics or attributes of the particular component, and I inductively assigned codes as specific characteristics or attributes of each category, and themes as specific characteristics or attributes of each code.

and themes were added and connected till saturation^{xxvi, 38,39} I stopped collecting information soon after I reached saturation between the 4th and 5th focus group, and it was apparent during the 6th (final) discussion that no new information emerged⁴⁰ (Appendixes 10 to 20, from pages 209 to 230, show the *saturated* map I developed for each component, after the 6th discussion). Saturation, however, is difficult to attain, may not be an appropriate aim in studies about experiences,⁴⁰ and lacks guidelines for estimating “data adequacy”.³⁹ Consequently, I am not claiming that the understanding of a complex experience such as oral health (and its components) can become *saturated*. Although I was interested in a general definition of oral health, it is unlikely that the meaning and significance of its nuances and particularities would be fully elicited in this study.

5.2.3.2 Connection of the ORIGINAL and NEW model’s components

Each group gave me different ideas on how to represent the relationships of the components of the original model when I asked “*would you suggest a different arrangement? Why? How?*” I did not reach saturation on how the components should or could be connected because there are unlimited ways of linking or connecting the components (please see Chapter 6 for a more extensive discussion of how I managed the interdependency of the components). I produced from each group a different outline for the relationships of the original

^{xxvi} I use the term *saturation* to refer to the point in the maps where the information collected became repetitive and “marginal improvements were becoming small”.³⁸

and new components. The different outlines, one per group, represented my interpretation from the data, not from direct interaction with the group members. However, I consulted individually 32 of the original participants who were willing to give me their feedback in the context of a member check for their response to my interpretation of the discussions. The 32 participants saw only the model I developed for their particular group. During the member check, I gave each participant a short report presenting the original and the modified model (Appendix 9 shows one of the six reports I developed) and I recorded their responses in writing rather than tape recording. The 32 members gave me suggestions and modifications for each outline, after which I reviewed the original model, the transcripts, and each of the six outlines I had produced. The review allowed me to produce a new and more refined model, encompassing the six groups' ideas, for further advice and suggestions from 11 of the original participants since the others were out of town, hospitalized, or simply did not want to participate again. I advised these 11 participants that this refined model was a representation of others groups' opinions as well, not only theirs. I recorded their advice in writing, and again made few small adjustments to the outline as the end of my analysis.

5.3 Results

5.3.1 Defining the ORIGINAL model's components

5.3.1.1 Oral Health

When I asked about the meaning of **oral health**, participants told me in general that it refers to a comfortable and functional mouth. They perceived oral health beyond the absence of diseases, and agreed with the importance of the mouth for smiling, socializing and participating in many of the usual tasks of daily life. For example, a 72 year-old woman participant who wears complete dentures explained that:

"[n]obody wants to go around with the dentures showing what they ate 5 minutes ago... hygiene in the mouth is as important as body hygiene, it is a good feeling."

Within the discussion about oral health, participants brought up the components of the model. For example, a 69 year-old man who has natural teeth told the group that:

"[oral health] is taking care of your mouth, your dentures, your tongue, and make sure you floss and brush, because if you don't have hygiene you would not have general health, and you would not have comfort."

Participants referred also back to their discussions about the vignette to make sense of oral health. For example, they raised the possibility of Rosita more than Victor being worried about appearance, and wearing her dentures while coping with discomfort. On the contrary, the participants believed that

Victor could have understood oral health differently by placing more importance on comfort than on appearance.

5.3.1.2 Coping and Adapting

Coping, according to a 64 year-old man from one of the senior centre who moves around with the help of a walking device and has natural teeth, implies:

"[g]etting along with a different situation... you can cope with a situation, do nothing, or change it if it's not going the way you want."

For others, coping relates only to a positive action such as *"doing something about the problem that is bothering you"* (71 year-old woman who wears dentures, from a residential building). For most of the participants, however, coping strategies were linked to **adaptation** as part of a continuum preparing for the main problem:

"[t]o adapt to a situation you have to cope with little problems that hit you before you get to the main problem." (82 year-old woman from a retirement home and who was getting new dentures).

Coping and adaptation were clearly present in the daily lives of the participants. For example, a 79 year-old gentleman from a senior centre stated that *"people, if they are out having dinner, sometimes they would order something that is easy, even if they would love to have pork steaks, or something else, [but] they would order something that is softer, something easier to eat."* Some groups discussed the positive and negative nuances attached to coping and adapting, as a 64 year-old man from a community centre explained:

"[c]oping has a more negative connotation [when it is] just putting up with a situation. Adaptation has quite a positive connotation because you positively do something [to] adjust or change."

The vignette prompted one 79 year-old man who did not wear dentures to realize that people may adapt to being toothless rather than cope with dentures because:

"[y]ou can adapt to the fact that you have a prosthesis, false teeth, but you may not cope well with that foreigner thing. You adapt to what you have to have. You can eat and talk [with it], but you may not cope with that whole experience that is in your mouth, and it is affecting you."

Participants also believed that some people refuse to wear dentures so they can intentionally avoid the company of others, as a 72 year old man said about Victor, from the vignette: *"[maybe] he is trying to drive [Rosita] off and he knows that she does not like people without their teeth"*. Adaptation was closely related to accepting the "pitfalls life presents" in general, or accepting others, as understood by a 71 year-old woman who had worked as a nurse in a long-term care facility:

"[y]ou have to accept the way the [residents] are, and if you are seeing something that is not acceptable, or you think it is not acceptable, you tolerate and adapt to it."

In terms of adapting to and accepting different ethnicities and cultures, a 64 year-old participant who recently travelled to Asia explained that *"we are one world, doesn't matter where [we] came from, we have the same heart. We may react differently because of our social upgrading, or whatever, but I think that universally we adapt to them and them to us."*

5.3.1.3 Limited Activity, Restricted Participation and Impairment

Limited activity was understood mostly as a negative situation, such as when *"you haven't got your teeth and you cannot chew"* (72 year-old woman from a retirement home who latter told the group about his friend's experience with uncomfortable dentures). However, limitation depends on the social environment, and is not associated solely with negative experiences, because, as stated by a 65 year-old man from a senior centre:

"[I]f you have a tooth that is just hanging by the root, you would probably not play soccer, and [that] would affect your physical activity, but if you stayed at home, [it would not] affect your physical activity."

Some groups had difficulty defining **restricted participation** because they felt it was *"too disease oriented, in a category of illness, or disease"* (woman, 66 year-old from a community centre). However, some participants associated 'restriction' with 'limitation', especially when biting and eating. In this context, they acknowledged that difficulties biting food could restrict participation in social activities, such as family meals or dunking apples at a Halloween party.

Participants also had difficulty linking **impairment** to the mouth because they associated the word *impairment* with catastrophic events, such as losing both legs rather than losing teeth. *"[I]f it is just dentures, false teeth, or something, it is not an impairment"* according to a 71 year-old denture-wearer woman from a senior centre who uses a trolley to move around. Consequently, some participants felt that impairment, along with restriction and limitation, were emphasising a negative connotation that may not be the case, and not

necessarily appropriate components for the model. The participants supported the opinion that the impact of oral limitations, restrictions, and impairments are very personal attributes that depend largely on the context in which they occur. I also collected printed versions of the original model in which four participants had struck out the words restriction, limitation and impairments, which I interpreted as confirming that such words were inappropriate for the model.

5.3.1.4 Social Environment

The groups understood **social environment** broadly because, as stated by a 67 year-old woman who meets each week with her Chinese and East Indian friends, *"it not only covers the 'social' part of it [like our society, different places, this building], but also covers different [people from] different cultures [who] are living together, and the place where [they] live"*. The social and cultural environment also includes social support. For one participant, a 73 year-old woman who recently received her first partial denture for her lower jaw, this support was significant when she realized by talking with others she was not the only one who was trying to *"get along with...something new in your mouth."* Social support was also important to life broadly because, according to a 71 year-old woman who had breast cancer:

"[t]here is always somebody worse off than you, and you get on that, support and energy, and strength from them. [It] is very important at our age."

5.3.1.5 Personal Environment

Participants highlighted that the **personal environment** encompasses not only education and friendship and other “*family values*”, but also anatomical deformities and diseases passed from one generation to the next. They attributed also a social context to one’s personal environment along with personal characteristics such as physical and psychological well-being that influence a willingness to interact in society. In particular, depression was discussed as one of the reasons people may not bother wearing dentures. Adaptability independently of age was addressed also within the context of a personal environment, because, according to a 69 year-old East Indian man from a community centre:

“[t]o be adaptable, it all depends on the characteristic of the person [and] his or her personal attitude. Some people can have very good health and lots of money, but [still] live miserably. The most important thing is your attitude to life, and a good circle of friends, and not being too critical about the world.”

5.3.2 Modifying the ORIGINAL components

There were suggestions to change the term socio-environment to **socio-cultural environment** to reflect current views on the role that ‘culture’ plays in societies, especially where many different cultures live together. Participants did not clearly see culture within that original component, however, they had difficulty explaining exactly what they meant by the term when I challenged them.

Nonetheless, they explained that the social environment in many senior centres, especially in Canada's multicultural society, attracts older adults from different countries with different native languages and habits.

5.3.3 Adding NEW components

When I asked the participants *"do you think the [original] model misses anything, any other component, and, if so, what that might be?"* they suggested that: 'diet', 'economic priorities', 'expectations', and 'health values and beliefs' be included.

Diet in the original model was loosely associated with eating under **comfort**, however, the participants in several focus groups want diet identified on a par with to the original triad of **general health-hygiene-comfort** (Figure 5.1) *"because sweets wreck your teeth, and bad teeth come from poor food"* (72 year-old woman from a senior centre who made this comment while pointing to the candies before her). Diet was understood broadly and not only in terms of the amount and composition of daily meals. For example, the groups discussed the importance of diet to the social and psychological role that eating has in almost every cultural group and society because *"[the families] don't have dinner together, mom is working, the kids want this and that, and you will find out that they don't have the family meals and there is no relationships, no social talking"* and because *"a balanced meal offers vitamins and nutritional value that helps to*

keep your mouth and body healthy", as understood by an 85 year-old participant with a Master's degree in nutritional science.

A component identifying **economic priorities** is required in the model because, according to the participants, these priorities influence not only out-of-pocket expenses for oral care but also the social context in which health and healthcare is determined. The participants acknowledged that the priority people give to their financial capability is a personal choice because some individuals would *"appear in modest means, but still have excellent teeth"* (64 year-old man from a community centre) whereas others would spend more on expensive clothing rather than personal oral healthcare and going to a dentist.

Expectations from teeth, previous dental treatments, and other aspects of oral health are distinct features in the lives of the participants, and they wanted this identified as a specific component of the model. For example, people may normally expect a certain degree of limitation or impairment with age because:

"[c]hanges in your opinion as you grow older are quite normal. You change the way of thinking about things [and] it is quite normal to change expectations." (72 year-old woman from a retirement home)

They believed also that people change their expectations *"to stay positive"* as the mouth and teeth change with advancing age. When talking about expectations in general, a 69 year-old woman, who was going blind, testified:

"[I]f life is a survival. We all have that choice to make. Some people have the denial of things, but you have to stay positive even when you expect to have some changes."

Health values and beliefs simply reflects the things participants valued and held relevant to oral health in the model. To emphasise the *“things that are affected by beliefs [because] if you think that oral health is brushing and flossing, you will brush and floss”*, one group said *“it would be a good idea to put [beliefs and values] in the model”*, as a component. Moreover, when I asked about the value of dentures to daily functioning, a 66 year-old man from a community centre who did not wear a denture believed that *“dentures are important not only for appearance, but to speak and enhance the way [we] pronounce the words”*. Clearly participants valued aesthetics and function of dentures, and believed that appearance is equally relevant to both men and women despite *“the myth that women are more concerned about appearance”* (72 year-old woman from a community centre).

5.3.4 Connections and relationships between the ORIGINAL and NEW components

Each group gave me different ideas on how to portray connections between the components. The six outlines illustrated my interpretation of each groups' ideas about the original model (Appendices 21 to 26).

For example, I heard from one group that, in the original model, *“some of the words are upside down [and] it is difficult to read”*. In another group, some participants suggested a different outline to *“cluster words that are similar [such as] personal and socio-cultural environment [in one cluster], and coping and*

adapting [in another]". In a third group, the food pyramid was the layout of choice for re-arranging the original model because "[the food pyramid] is quite descriptive with visual, and with more explanations".

Although the groups did not participate directly in the development of the graphic displays, I asked 32 of the participants to critically appraise my displays from their respective groups. They agreed that the outlines, compared to the original model, represented a different view of oral health, although some of them could not describe how they perceived the differences. Others emphasized that the differences were related to the orientation of the words, as the original had some of the components written upside-down. Some gave me further ideas of putting oral health in the centre and the other components 'equidistance' around it rather than using concentric circles. Others suggested that I try a different arrangement to show how one component influences others, but connected somehow to show equal importance. These member checks helped me to integrate and synthesise the information from all the groups in one final outline as the main objective of my framework analysis.

5.4 Discussion and conclusions

I attempted to reveal the ways in which participants described their experiences as they reflected on the model's components. Contrary to other empirical studies on models of oral health¹⁸ or general health,^{13,12,11} I encouraged

participants to define each of the components and to focus on the completeness, relevance, and interdependence of the content and graphic representation.²⁰

5.4.1 ORIGINAL and NEW components of the model

Overall, the meaning of **oral health** as a positive experience was similar to the meaning suggested by Dolan,⁴¹ and more recently by MacEntee *et al.*,¹⁴ which may reflect the fact that the focus group participants for the most part felt in good health. The groups included **diet** in the original triad of 'hygiene-comfort-general health'. Although diet was contained within the context of 'comfort' in the original MacEntee's model, the participants here saw diet as a separate component prominently related not only to nutrition⁴² but also to the important social context of food as an integral part of human relations.^{43,44}

The groups understood **coping** as a behavioural and psychological strategy for stressful conditions through a regulatory process, going along with the definition provided by Lerman and Glanz⁴⁵ and Folkman *et al.*⁴⁶ According to Hwiyink,⁴⁷ coping signifies positive or negative reactions depending on the stressful situation and personal style, which includes 'emotional coping' by seeking support, or 'problem solving coping' by doing something about the stressful situation. Some participants believed that the same individual, depending on personality, can have both positive and negative reactions to a stressful situation, as discussed by Allison *et al.*⁴⁸ For other participants in my

study, coping implied a positive reaction to stress only when an action was required to solve or minimise stress. **Adaptation** was repeatedly voiced by the groups as an adjustment to prevent or minimize disability, and as a positive response to stressful events.⁴⁷ In some cases, however, neither coping nor adaptation is sufficient to come to terms with a dental condition, such as the foreignness of dentures.^{49,50}

The view of **impairment** as a catastrophic event coincides with opinions expressed by MacEntee *et al.*¹⁴ and others⁵¹ that dental conditions for older people were rarely more than 'indispositions'. This may explain why participants felt that impairment was not an appropriate term for the model. Healthcare providers, in contrast, tend to view functional impairments as chronic conditions that need treatment.⁵² Similarly, the difficulties some groups had in defining **limited activities** and **restricted participation** support the view that limitations, restrictions, and impairments in health are very personal attributes influenced strongly by the context in which they occur.^{1,6}

The groups highlighted the need to incorporate 'culture' as part of the social environment probably because of their personal experiences in the multicultural community of Vancouver, and in the senior and community centres. Social support, as part of the social environment, was highlighted as important to strengthen positive responses when stressors intensified or became more persistent.⁵³ Generally, social support influences how people adapt psychologically to stress as they perceive personal risks and try different coping

strategies,⁴⁵ including comparisons to others with more distressing problems. Apparently, comparisons with others less well-off can help people to manage stressful events.^{54,55}

Participants also discussed the influence of mental illnesses and depression on the **personal environment** as they explained why some people without teeth do not wear dentures. Psychological conditions have been identified as important contributors to social withdrawal and inability to work.⁵⁶ According to the participants, personal environment can be influenced also by financial status, education, and family values, and by biological structures and genetics when, for example, people with bone abnormalities are born with no teeth, which acknowledges the influence of genes and family values upon health and well-being as discussed by Brunner and Marmot⁵⁷ and others.⁵⁸

The WHO⁵⁶ and others^{59,60,61} have identified also the dynamic influence of **expectations** on health and the fact that people typically expect a certain degree of limitation or impairment with advancing age. The relevance of **economic priorities** to the participants supports the view that poverty contributes to disability and impairment.⁶² The inclusion of **health values and beliefs** as a distinct component reflects emphasis that the participants placed on the need for researchers and healthcare providers to seek and respect the values and beliefs of those to whom the research or services are directed, rather than relying solely on the opinions of experts.⁵⁰ Although these three new components may submerge in either **personal** or **socio-cultural environment**, participants saw

them as individual components in the model.

Unlike the findings of others, the men and women in the focus groups had similar views about oral health.²⁸ The discussion about aesthetics, for example, made it clear that both men and women valued the appearance and function of dentures equally. The studies showing differences in gender conducted by Prus⁶³ and Denton *et al.*,²⁸ for example, focused on access to health services and social resources, not on the significance or meaning of health.

5.4.2 The six outlines in a blending model

I favoured a spherical or circular representation in most of the six outlines I produced from Appendices 21 to 26 to demonstrate a multiply determined, dynamic, and complex phenomena such as oral health.^{64,65} Typically, triangles and squares illustrate a concentration or hierarchy, or even a lack of continuity and flow, and reduction of the idea of complexity and dynamism,⁶⁶ but yet one group favoured the 'food pyramid' as a possible portrayal for oral health (I provide further discussion on the use of circles, squares and triangles to represent modes in Chapter 6, pages 162 to 164). With the 32 member checks, I re-visited the six outlines and the transcripts.

While re-visiting the six outlines, for example, I noticed similarities in the way I had displayed specific groups of components, which suggested to me a single amalgamated outline that might portray more appropriately the

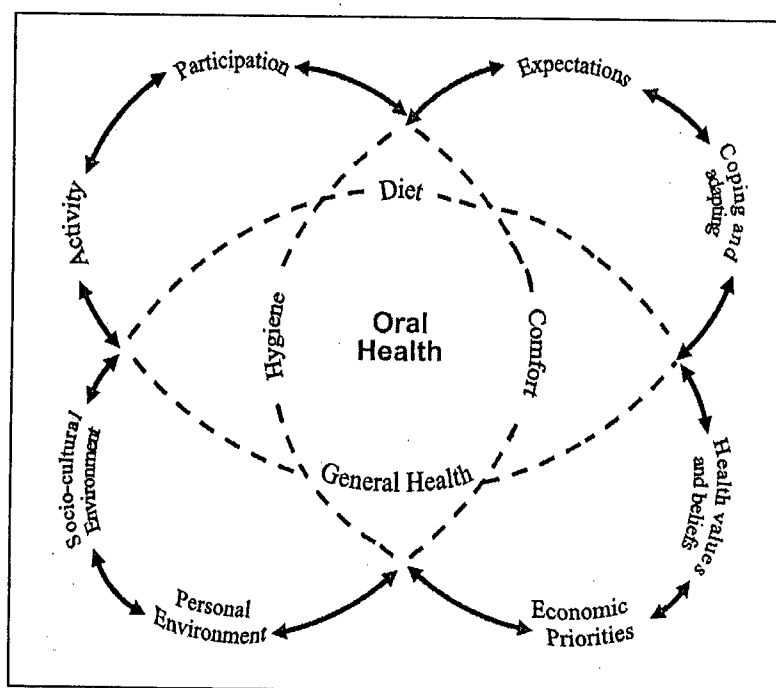
relationships mentioned during the group discussions. Figures 6.4 to 6.6, pages 166 and 167 in Chapter 6, show how my thinking progressed on these matters.

When I was re-reading the transcripts, one group suggested “*clustering words that are similar, [such as] “personal” and “socio-cultural environment” [as one cluster], and “coping” and “adapting” [as another cluster],*” but with the addition of a few new components, such as **health values and beliefs** and **economic priorities**. It was also clear that all the groups approved the triad of **hygiene-comfort-general health** and added **diet** as a forth component for that cluster. Hence, there was general agreement on the need to use **activity** and **participation** in a positive context without reference to restriction or impairment. Consequently, I used this idea of ‘clustering’ words that I felt similar in meaning through a single model, including ‘activity-participation’ as one cluster, ‘personal environment-socio-cultural environment’ as a second cluster, ‘coping-adapting-expectations’ as a third cluster, and ‘health values and beliefs-economical priorities’ as a four cluster (Figure 5.2).

The way I chose to link these clusters with oral health came from the participants’ idea to display “*the equal effect [of the components] to oral health [through] an equal circle*”, from my bias favouring circular or elliptical outlines to express such ‘equal’ effect, and from another group’s idea to put “*oral health and [should be] more centred, and [from] there, what affects or impacts it, equally.*” Consequently, all of these ideas let me to expand my view of oral health as a dynamic and amalgamated four clusters in an elliptical configuration.

The placement of diet, comfort, general health and hygiene 'running along' the four clusters, not as an isolate circle, emphasises the mutual relationships of different components. For example, *hygiene* could bring *comfort* to the mouth if there is a *belief* that daily oral care promotes *oral health*. Hence, if there is an *expectation* that *oral* and *general health* should be maintained in old age, older adults could be informed about the importance of a healthy *diet*. *Coping* and *adaptive* strategies could overcome the possibility of impairment in chewing resulting from tooth loss when *diet* is modified to maintain nutritional value and the *socio-cultural environment* accepts missing teeth overtly.

Figure 5.2 - A Refined Model of Oral Health



I brought Figure 5.2 on a final round of individual member checks to 11 of the original who suggested minor modifications and gave me approval, with one particular participant commenting *"how interesting it was to see all the words [components] connected to oral health in a 'coming and going way', almost showing 'movement'"*.

5.4.3 The refined and the original model

The new components and graphic portrayal of oral health probably emerged due to the active interaction in the focus groups as participants questioned one another and refined the information provided. Since such interaction is absent in individual interviews, I am not sure whether the same richness of information would happen if I had approached the participants individually.

The refined model of oral health demonstrates the value of evaluating relevant components empirically through the opinions of lay participants who have experienced health in many ways.^{13,12} Participants saw the links and connections between components differently than portrayed in the original model, and had a change to discuss the graphical portrayal. Both models present circles or ellipses to demonstrate how one factor influences the other.⁶⁷ In the original, however, the concentric circles were giving the idea of different importance, or different 'levels' or dimensions, as advised by Bronfenbrenner.⁶⁸ The participants

highlighted that such concentric circles would not convey the 'equality' of all the components on oral health even though circles represent the complex system of relationships influenced by multiple factors.

The content of Figure 5.2 remains positively oriented whereas the original has its middle circle more negatively focused. Such negativity was not confirmed by the participants who did not restrict their views only in terms of limitations, restrictions and impairments. Consequently, participants who are the experts on their health conditions helped me to move towards a more positive understanding of oral health even in presence of disease.

5.4.4 The quality of my study

The strengths of the refined model relate to the rigor⁶⁹ with which I developed it. For example, I attempted to gather participants from different backgrounds that could give me a variety of health-related experiences. I let them free to express any ideas and criticisms they wished about the model, without imposing my own. I identified also the links between the ideas and beliefs expressed by the participants in the outline portrayed in Figure 5.2, and between my findings and the existing literature.^{70,71} Hence, I conducted member checks twice to allow participants to comment on my analysis and interpretations.⁷²

Member-checking improved my analyses that emerged from the iterative method and the internal validity^{xxvii} of the models I produced.^{73,74}

Although I moderated all the focus groups, I had research assistants in each focus group who helped me to control the time of each discussion, and to provide field-notes. I did the transcriptions myself and consequently, I listened to each audiotape several times, and I read the field-notes to complement what might be missed in the tapes. Although no other researcher audited the process of transcription and analysis,⁷⁵ I had regular meetings with my PhD committee to discuss the process of collecting and analysing the information.

The potential weaknesses on my study relate to bias and reactivity. Bias could happen when collecting and analysing the information. I could introduce bias by imposing my own definition of the components instead of asking how participants defined each of them. I decreased bias by posing a situational vignette to encourage an open discussion about oral health and the original model. I could introduce bias if I had presented the original model as 'mine' which could have unsettled or discomforted the participants who wanted to change the model. I posed the model as one idea to illustrate the vignette, but in need for further evaluation if necessary. I did not pass judgments on any of the participants' comments and opinions and I emphasized that there was no right or

^{xxvii} Generally, *internal validity* refers to the "truth" about inferences relating to cause-effect relationships, either in a model or a treatment intervention typically in a classical experimental setting. I use the term when referring to the extent (as assessed by a member check) to which the description and interpretation of my participants' experiences are adequately portrayed in the model.

wrong understating of the vignette and the model. I allowed participants to express their thoughts about health and about disease and dysfunction openly and freely.

Bias in analyzing the data implies selection of specific information that might fit my preconceptions and confirm the completeness, relevance and interdependence of the original model as it was presented. Again, I decreased this bias by being open to the criticisms offered by the participants, by conducting member-checks to confirm my analysis and internal validity of the models I produced, and by discussing my findings with members of my PhD committee.

Reactivity, or the effect of my influence upon participants, could make them provide only information they thought I was interested in hearing, but not necessarily what they actually believed. I decreased reactivity by encouraging rapport, avoiding leading or judgmental questions during the discussions, and by not imposing hierarchical relationship within the groups. I did not intimidate the participants, and gave them time to respond without pressure. When necessary, I rephrased or repeated the questions in a friendly and informal approach.

One of the main values of a research rests on its ability to extrapolate the findings beyond the context in which they occurred. *Generalizability* and *transferability* relate to an extrapolation of the findings from one study to the general population and to another study, respectively.⁷⁶ Complete generalization loses its meaning in my study because there was no representative sample of the population. However, the participants did hold characteristics of the

Canadians as a whole,⁷⁷ and of British Columbians in particular,⁷⁸ by showing high levels of education, being generally health, having predominance of females over males, and living in residential buildings and retirement homes.

Nonetheless, participants were mostly Caucasians and consequently, different ethnicities may highlight other components and/or a different outline simply *"because things change and different people have different opinions"*, as one of the participants reminded me. However, the relevance of components such as coping, activity, economic priorities, and personal environment may remain pertinent to oral health across different cultures when participants have a chance to focus not only on illness, but also on health. In all, the significance of most of the components to oral health overall allows transferability to other older adults with similar characteristics.^{79,80} As Casey and Krueger emphasised,²⁴ "those who seek to use the results should look over the study, examine the procedures, methods, and analysis and then decided the degree to which this might be applied to their situation."

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5.6 Link to the next chapter

Since I employed the methods described in Chapter 4 to produce a refined model of oral health, the methods require further discussion. Consequently, I use Chapter 6 to examine and discuss the methodological perspectives, rationale and assumptions supporting the use of focus groups prompted by a situation vignette in the context of phenomenology, grounded theory and framework analysis.

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CHAPTER 6

METHODOLOGICAL DISCUSSION ABOUT THE USE OF FOCUS GROUPS AND A WRITTEN VIGNETTE IN THE CONTEXT OF PHENOMENOLOGY, GROUNDED THEORY AND FRAMEWORK ANALYSIS TO EVALUATE MACENTEE'S MODEL OF ORAL HEALTH

A version of this Chapter has been prepared for submission to **Forum: Qualitative Social Research**
Brondani, MA. A challenge: phenomenology and framework analysis through focus groups in dentistry.

6.1 Remarks on this chapter

In this chapter, I address my fifth objective *to explore the methodological perspectives of Phenomenology, Grounded Theory and Framework Analysis in the context of model evaluation through focus groups and a vignette*. I promote a discussion about the methodological perspectives, rationale and assumptions supporting the approach I used to collect, analyze and interpret the participants' experiences with, and opinions about, the vignette and the model oral health.

6.2 Focus groups in the context of my research

The discussion generated by focus groups, as I described in Chapter 4, allowed the exploration of feelings, personal experiences, and differences in opinions through a dynamic interaction as participants questioned one another, explained and elaborated specific points, sought clarification, and posed comments.¹ While interacting, participants explored new areas of understanding and voiced their values and beliefs to typify a representative characteristic of each other's experiences about everyday life without necessary establishing consensus.²

I was the moderator of all the focus groups, and I posed a vignette in a projective technique to promote discussion about oral health, appearance of dentures and other aspects of tooth loss (Figure 4.1, page 86). The vignette also introduced indirectly to the participants some components of the original model

developed by MacEntee, including coping, adaptation, and the social environment as I probe participants with questions (Appendix 6). This approach was successful in eliciting from participants comments that were relevant to the original model. The discussion about the vignette took an average of 45 minutes, and, after a 10-15 minute break for refreshments, I presented MacEntee's model with a request for the group's opinions on its content and graphic representation which took another 45 minutes or so. This time was adequate to pose all the predetermined questions about the model, to probe for more related information, and to allow an unrestricted discussion without tiring the participants.

I now discuss the use of phenomenology to explore the experiences³ of group of participants about oral health.

6.3 Phenomenology as a perspective to explore how do older adults in a focus group understand and talk about oral health

Phenomenology, both descriptive and interpretative, is used by researchers to study consciousness and the way people experience the world.⁴ Descriptive phenomenology, according to Husserl,⁵ provides a conceptual basis for exploring and describing personal experiences as reflected by a person's memory, imagination, and emotion. Typically, the exploration occurs between a researcher and an informant through multiple open-ended individual interviews to uncover the essence of the informant's experiences.⁶ Husserl⁵ emphasis the

need for the researcher to 'bracket' or suspend personal preconceptions and presuppositions while describing the information relayed by the informant.

Bracketing, he believed, is necessary to eliminate outside interferences, and to produce a description of the experience or phenomenon rooted firmly and solely in the information offered by the informant, and devoid of influence from the researcher's personal opinions. By bracketing, the researcher should be able to extract the essential features of the phenomenon as experienced by the informant.⁷

In interpretative phenomenology, Heidegger⁸ agreed with Husserl that the purpose of phenomenology is to explore human experiences, but he disputed the possibility or the necessity of bracketing. He believed that informants and researchers alike interpret the meaning of their actions through the context of social relations, and under the influence of an accumulation of knowledge and past experiences. Believing that people's activities are always existential to their lives, Heidegger disagreed with Husserl about the need to disconnect or bracket from the surroundings or the past. Recently, Gearing⁹ explained various types of bracketing based on the researcher's epistemological orientation. These include the philosophical and descriptive bracket when using Husserl's ideas, the existential bracket as interpreted by a Heideggerian researcher, and several others including analytical and reflexive bracketing, when ethnographical and cultural studies are conducted, and pragmatic bracketing which seems to refer to situations where researchers bracket in a vague or freely defined format.

As the moderator of the focus groups I did not fully bracket or suspend my knowledge about oral health as would be expected under philosophical or descriptive bracketing. Instead, as recommended by Creswell,¹⁰ I reflected continuously upon the bias and personal experiences I brought to the group discussions. I made a conscious effort not to direct the discussion to a specific aspect of oral health other than to pose the predetermined questions when appropriate, which I believe follows the direction of existential bracketing.⁹ For example, when I asked about the possible physical and psychological effects of a toothache or a missing tooth, I let the participants express their opinions freely without directing them towards my own beliefs as a dentist about impairment and dysfunction. Moreover, when participants evaluated the original model, I let them define each of its components and give me ideas to re-arrange them graphically as they believed was appropriate without imposing my own opinion. They were free also to make personal notes as they wished about the model on the paper copy they received.

Consequently, like Gearing,⁹ I questioned the belief that my external and contextual suppositions could or should be bracketed in order to understand the oral health-related experiences of the participants. Rather, I reflected upon my own existential suppositions as I moderated the discussions, and later as I analyzed the transcripts.

6.3.1 Phenomenology, focus groups and Alfred Schutz

There is controversy about using phenomenology to explore groups' experiences. Webb and Kevern¹¹ believe that phenomenology is the study of "the totality of the lived experiences that belong to a single person",¹² which suggests that this research framework is incompatible with the collective discussion of a focus groups. They used Husserl's ideas on *descriptive* phenomenology to argue that the dynamic interaction of ideas and opinions within a focus group 'contaminates' the experiences of the single informant. Similarly, a vignette or story that sets the stage for a focus group discussion could hinder the possibility of getting the 'pure' uncontaminated experiences of the participants.

Whereas Husserl was concerned with how we construct our reality in general, Alfred Schutz¹³ focused on how we construct our social reality in particular. Alfred Schutz related the ideas of Husserl to the social world, but believed that the nature of human experience reflects the 'intersubjectivity' or social context of everyday life in which our activities are part of a social reality and shared with others despite of our uniqueness. Schutz¹³ understood human action as conceived and executed in a cultural and historical context to which one is existentially committed, but has various interpretations of the world. Consequently, I used Schutz's phenomenological ideas on socially constructed opinions to interpret the experiences elicited in group discussions since reflection and interaction dissolve the uniqueness of individual experiences.¹⁴ Like Heidegger, Schutz's phenomenology interprets the meaning of our actions

socially, and acknowledges that socialization is influenced by the personal baggage and 'stocks of knowledge' that each participant holds as pre-existing experiences of a given phenomenon. Through interaction in the group, participants manage to understand and describe each other's stock and typify a representative characteristic of each other's experiences about everyday life.¹⁵ Group discussions can offer a larger and more varied stock of opinions and experiences that would normally emerge from a personal interview. It was this enlarged and varied stock of knowledge about oral health, and its portrayal through the vignette and the original model that I interpreted the phenomenon of oral health as experienced by participants.

Consequently, my study was guided by the principles of Schutz's phenomenology and Heidegger's existential bracketing to help explore the focus group discussions. I now explain how I prompted the groups to evaluate the original model using their variety of interpretations about oral health.³

6.4 Criteria to evaluate models of health

As I explained in Chapter 5, there are different sets of criteria to evaluate models. Moody and colleagues,¹⁶ for example, sought the opinions of experts to evaluate models using a set of criteria which included the following: 1) *completeness* or depth and breath of the components; 2) *relevance* of the components; and 3) *interdependence* or clarity of links of the components.

I selected Moody's criteria to evaluate the original model because I believe such criteria helped me focus on content and structure, two important characteristics of the internal validity of the model that might assist professionals in planning patient-centred care, evaluating patient outcomes, prioritizing research and treatment options, and supporting the development of questions for an existing or a new sociodental indicator.^{17,18,19} I posed open-ended questions to participants relating generally to the content and structure of the model (Appendix 6).

6.5 Data analysis of group experiences with oral health

The focus group discussions about the original model were audio-recorded and generated considerable information when transcribed *verbatim*. I also used the field-notes provided by the observers (Appendix 3), and the participants' written comments on paper provided during the discussions. Consequently, the transcripts, field-notes and comments gave me an extensive amount of information for analysis. There are many ways to analyse qualitative data and make sense of it, including Grounded Theory and Framework Analysis.²⁰

6.5.1 Grounded Theory

Glaser and Strauss²¹ introduced Grounded Theory as an inductive process for explaining and describing social phenomena that are available.²² They purposed that this approach would generate knowledge by discovering theories based solely and faithfully on the information collected typically as narrative or text. Grounded Theory consists of a series of steps taken or principles applied to 'guarantee' the emergence of a new theory based solely on the content of the narrative or text to explain relationships between different concepts and themes that emerge.²² The information is usually gathered in an iterative way following a pre-determined outline prompted by open-ended questions and observations that change and evolve during the study, which allows researchers to change the research questions and prompts to address unforeseen issues that emerge from the interviews or discussions as they occur. By analysing information constantly as it emerges, the process allows for changing opinions and for new and unexpected ideas.²³

6.5.1.1 Data collection through Grounded Theory

For some grounded theorists, the researcher has to enter the research setting 'bracketed' of pre-existing hypothesis, *a priori* knowledge and biases about the phenomenon in order to produce a theory based solely on the information collected.²⁴ Information usually comes from different media, including

interviews, discussions, observations, official documents, newspapers, and books. To compile relevant information about a phenomenon, a refinement of the process involves theoretical sampling, which allows the researcher to decide what information to collect next and where to find it based on the emerging knowledge. The researcher selects participants purposefully for optimal opportunities to help develop a theory and may interview them multiple times to refine the information collected.²⁵ This sampling strategy guides the researcher to the point of 'theoretical saturation' where the information gathered has sufficient breadth to form the theory and fulfill the objectives of the study.²³

6.5.1.2 Data analysis through Grounded Theory

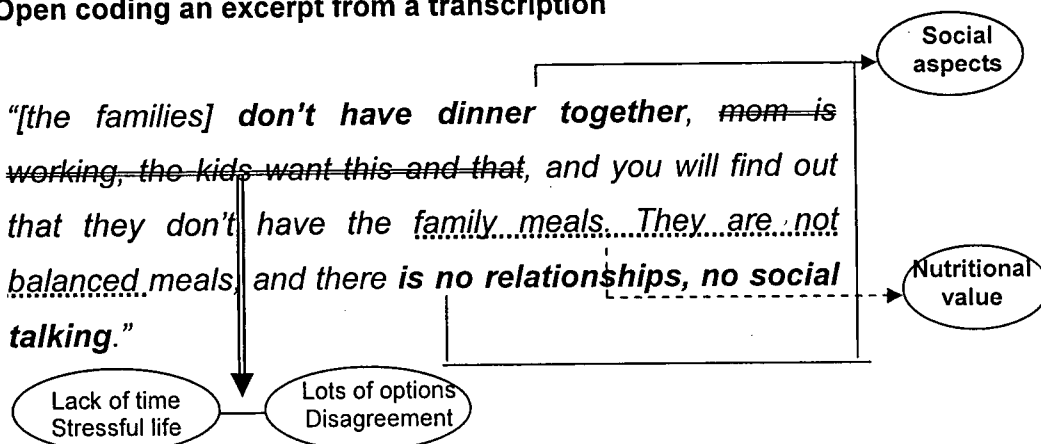
In Grounded Theory, inductive analysis by constant comparison is a systematic approach for identifying key themes (codes, concepts) within the narrative or text. It uses a process of 'open coding' by which the researcher assigns themes to a line, sentence or paragraph in the transcript.²⁶ Themes or codes identify special attributes of an action (verb), quality (adjective) or property (noun) of a line or sentence, and can be repeated in different lines or sentences and organized into categories of similar themes. The researcher proceeds to 'axial and selective coding' that links the themes and categories, and highlights similarities, differences, causes, reactions, explanations, or other relationships (Figure 6.1).

Figure 6.1 - Data analysis in Grounded Theory

-Interview question: How do you see today's life style in relation to daily meals?

-Open coding an excerpt from a transcription

"[the families] **don't have dinner together**, ~~mom is working, the kids want this and that~~, and you will find out that they don't have the **family meals**. They are not **balanced meals**, and there **is no relationships, no social talking**."

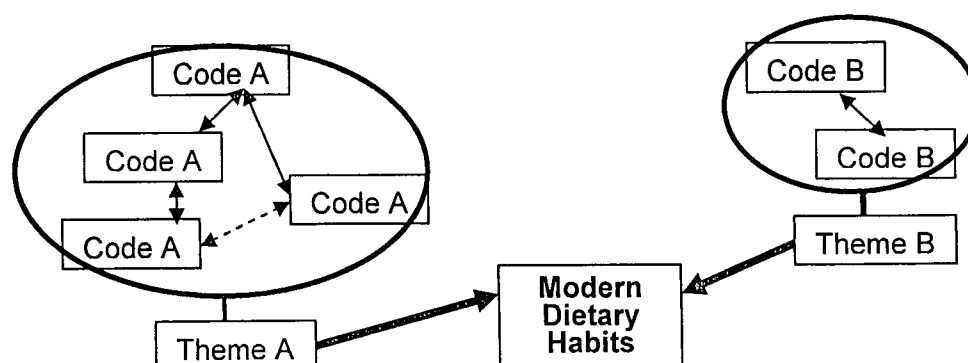


Codes type A: 'Lack of time/Stressful life' – 'Lots of options/Disagreement'
Theme assigned for codes A: *Causes*

Codes type B: 'Nutritional values' – 'Social aspect of eating'
Theme assigned for codes B: *Meaning*

Themes '*Cause*' and '*Meaning*' refer to a general **category** that I may call '*Modern dietary habits*'.

-Axial coding



6.5.2 Framework Analysis

Ritchie and Spencer²⁷ developed framework analysis as “an analytical process which involves a number of distinct though highly interconnected stages” to examine the structure of the data in the context of applied policy research and health-related studies. In contrast to Grounded Theory, this process focuses on outcomes or recommendations from the research's findings, and usually requires a pre-designed sample and pre-determined issues that the researcher will address.

6.5.2.1 Data collection through Framework Analysis

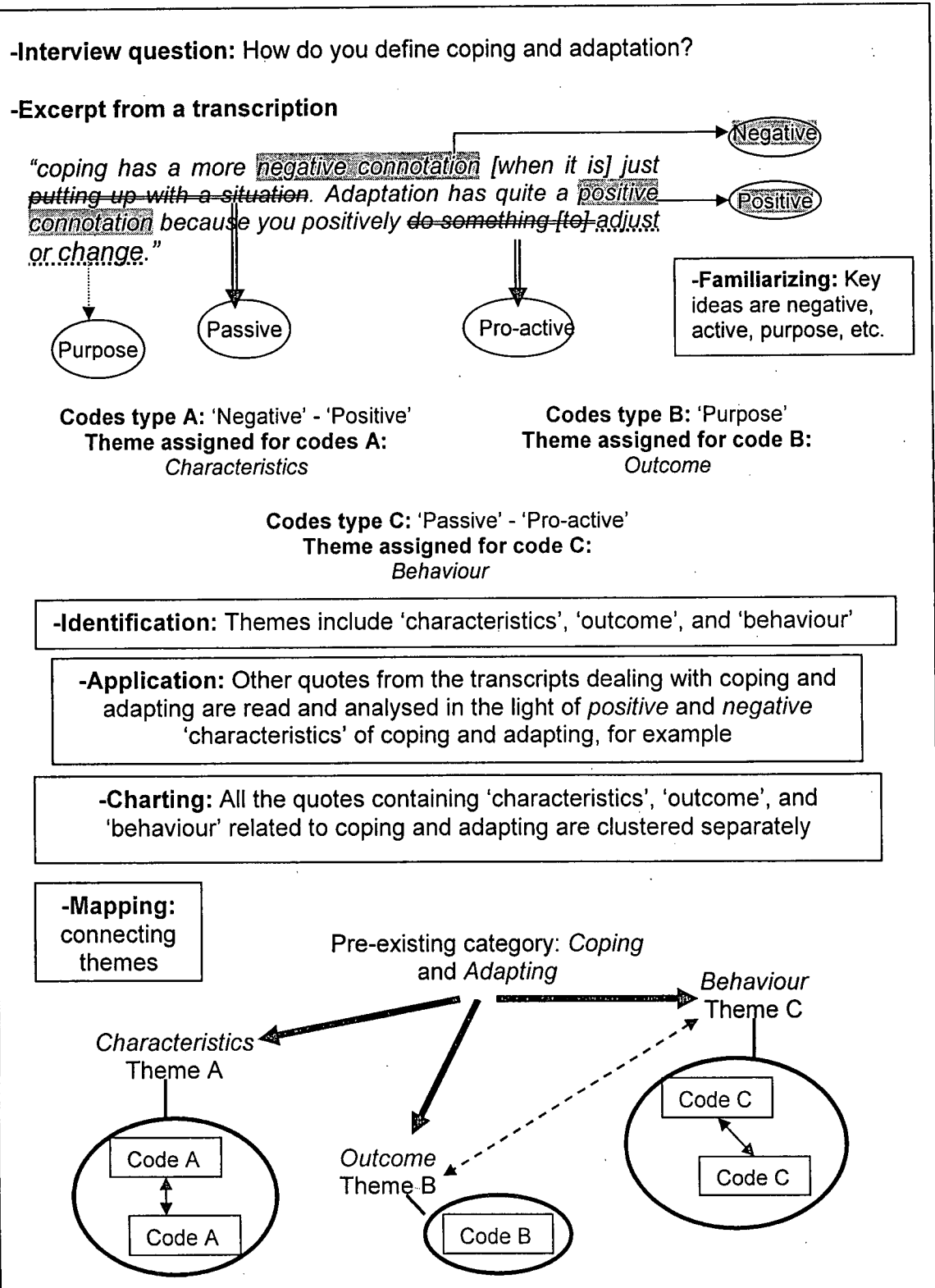
The researcher plans the collection of the data with an *a priori* theory or set of hypotheses that the study will evaluate, test and refine to provide recommendations or practical ideas. The objective is set in advance and researchers collect data using a relatively structured way compared to other qualitative methods.²⁸ Participants are usually selected to represent a certain group of individuals who will potentially address particular objectives and concerns of the researchers.²⁹ Framework analysis can be used for data generated from both individual and focus-group interviews, as suggested by Krueger.³⁰

6.5.2.2 Data analysis through Framework Analysis

Ritchie and Spencer²⁷ suggested five key stages outlined in a framework analysis to make sense of the data (Figure B):

- 1) familiarisation with the data as a whole before breaking it into parts by listening to the audiotapes and reading the transcripts and field-notes to emerge with key themes and codes;
- 2) identification of a framework with codes and themes from the texts so that data can be examined to develop categories forming the framework or index, and referenced for subsequent retrieval and exploration;
- 3) application of the framework or index systematically throughout the data by annotating transcripts with quotes related to specific themes, and comparing both within and between themes;
- 4) charting or rearranging data according to themes by extracting quotations from their original context and re-arranging them in light of the themes;
- 5) mapping and interpreting data for connections and associations among themes to show relationship between the quotes, and links between all of the components in the study.

Figure 6.2- Data analysis in Framework Analysis



Framework Analysis and Grounded Theory overlap as they both use a thematic analysis that reflects the original accounts and observations of the participants. They allow for continuous and interactive analysis of information as it is collected. However, unlike Grounded Theory, Framework Analysis allows themes to be developed both *a priori* from the research questions and grounded in the narratives of the participants.²⁸ Consequently, the framework approach starts deductively from pre-set objectives and themes but allows the researcher to inductively assign themes to better describe and interpret what happens as the information is collected.³¹

6.6 Data collection and analysis in my research

I selected participants through posted advertisements in a variety of places where seniors meet to purposefully gather participants with different oral health experiences, gender and opinions about health and illness (Chapter 4, Tables 4.1, page 90; and Table 4.2, page 93). I met only once with the participants gathered as a group. I was interested in cross-group comparisons to elicit similarities and differences in how the participants defined and connected the components of the original model. Consequently, I posed similar open-ended questions to each group (Appendices 5 and 6).

Such characteristics of my research design made it impossible to rest solely on the principles of Grounded Theory. For example, I met only once with

each group, unlike the usual follow-up meetings through multiple interviews. Moreover, both the vignette and the original model very likely influenced how the participants perceived oral health, although I carefully advised them to focus primarily on how their own perceptions and experiences of oral health coincided with the experiences of the characters in the vignette and with the components and relationships of the original model.

Framework analysis, on the other hand, justifies the use of the vignette and the model as presentation of pre-existing ideas and a *priori* set of components to be defined and re-arranged. Even Strauss and Corbin²⁶ believed that preconceived conceptual information can influence positively an emergent theory because there is always interaction between the researcher's pre-existing knowledge and the participant's experiences and beliefs. Although I recognize the outside influences of the vignette and the model, I did not force a meaning on the components of either the vignette or the model.³² Rather, I asked the participants to define each of the components.

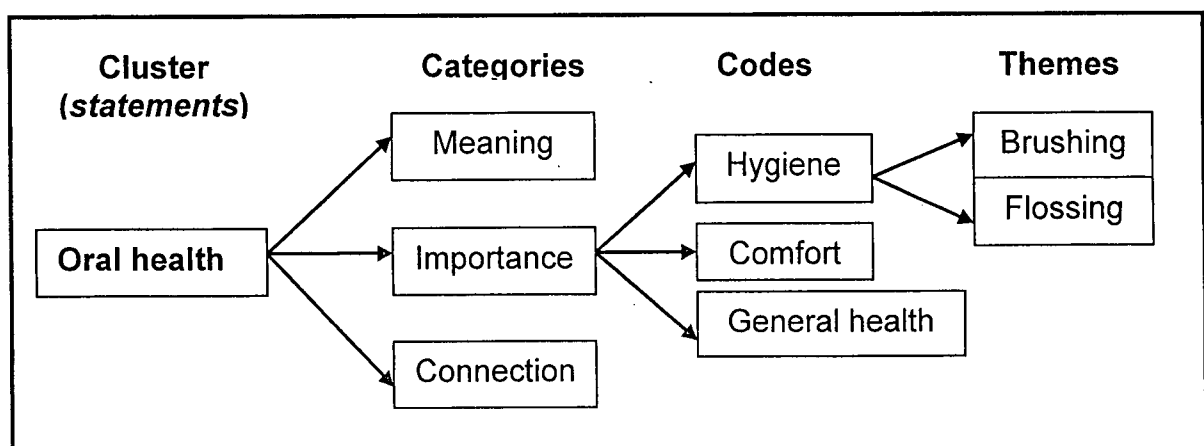
I listened to the participants' ideas, and to the different perspectives they described. I read the transcripts several times as part of the familiarization process to emerge myself in the text so that I could see clearly and identify themes and categories related to different components (Figure 6.2). I coded the text as part of the Framework Analysis to systematically scrutinize the transcripts, and to elaborate on the themes of each component. Through charting and mapping, I developed a map for each component from each focus group to show

links and relationships between the different categories, codes and themes identified. In the first focus group, for example, when I asked the meaning of oral health as illustrated in the model, one participant got agreement from others members when she said:

"[oral health] is taking care of your mouth, your dentures, your tongue, and make sure you floss and brush, because if you don't have hygiene you would not have general health, and you would not have comfort."

I then assigned categories (as broader characteristics or attributes of a given component), codes (as specific characteristics or attributes of each category) and themes (as specific characteristics or attributes of each code) for this statement. For example, I identified **meaning**, **importance**, and **connections** as three categories relating to oral health in the above quotation. I identified **hygiene**, **comfort** and **general health** as codes within the category of 'importance', and two themes: **brushing** and **flossing** as oral hygiene techniques within the hygiene code (Figure 6.3). I used Power Point® to draw the boxes and arrows I used in the maps to link and connect themes and codes.

Figure 6.3 - Mapping



As the research progressed from one group discussion to another, I modified the maps through a constant comparison of old and new themes and categories. I used this process of assigning codes and themes to each component of the model and to new components suggested by the participants. Consequently, the map I presented in Figure 6.3 was modified and expanded as shown in Appendix 10 to accommodate new codes and themes as new focus groups were interviewed and cross-group comparisons occurred. I determined saturation when the codes and themes were repeated from one group to the next without new ideas. It was apparent from my analysis that no new information about categories, codes and themes and their relationships was emerging from groups 4 and 5 and consequently, I had a 6th and final group discussion. Appendices 10 to 20 show each of the components of the original model mapped with all the themes, codes and categories across the six groups.

6.7 Groups' ideas for the outline of MacEntee's model

The major foci of my enquiry were how participants defined each of the original and new components of the original model, and how they connected the components. When I asked about the graphic portrayal of the original model, each group gave me different ideas on how to re-arrange the relationships of the components (I refer to the relationships within each map's categories, codes and themes as mapping through Framework Analysis. I refer to the relationship within

each model's components as addressing Moody's *interdependency*). However, I did not reach saturation on how the components should or could be connected, which would have implied a limitation to the ways in which the components could be linked and rearranged. There are, I believe, possible unlimited links between the components, and it is unlikely that I could identify all of them in any practical way through focus groups.

6.7.1 Model's graphic representations: circles, triangles or squares?

Graphic representations provide a convenient medium for explaining theoretical or abstract constructs.³³ The original model portrays oral health in concentric circles connected with double-ended arrows in which the circles have effects or impacts in each other, and are mutually influenced. The idea of concentric circles is not new, however. In 1979, Bronfenbrenner³⁴ offered a theory of ecological systems to explain the phenomenon of human development within a framework of four concentric circles. The macrosystem or outer circle surrounds the exosystem, the mesosystem, and microsystem or inner circle. He emphasized the complexity of the relationships between the four systems affected by multiple dynamic and continuous influences. Ecological systems theory has been used to understand gender-based violence,³⁵ changes in patterns of career development,³⁶ and contextual factors influencing the development of health research.³⁷ The concentric circles also indicate different

'levels' or dimensions. Applying Bronfenbrenner's ideas in MacEntee's model, for example, the microsystem refers to oral health and its close relationships to hygiene, general health and comfort. The exosystem represents limited activities, impairment and restricted participation that affects the perception of oral health and is influenced by the macrosystem, which represents broader concepts or influences such as social-environment. Concentric circles can also express different levels of importance. In this case, the inner circle would display the most important aspects or components, whereas the outer circle would convey the least relevant characteristics of the construct or phenomenon represented by the model.

Similarly, Guttman³⁸ introduced the term 'circumplex' for portrayals of a single circular ordering with equal intervals among different parts or components. In 1996, Tracey and Rounds³⁹ offered a spherical model to represent the circle of vocational interests when understanding students' preferences to occupational jobs. In this case, one influential factor was a consequence or cause for another in a circular and recurrent pattern. More recently, graphic models have been used to represent dynamic systems theory, chaos theory and complexity theory. Dynamic systems theory is similar to the ecological systems theory proposed by Bronfenbrenner, and generates new ways of viewing non-linear phenomena that are unpredictable.⁴⁰ It provides also a broad representation of phenomena, such as general health^{41,42} and oral health,^{43,44} that are dynamic, multiply determined, interdependent, and complicated. Consequently, as MacEntee emphasised, it is

unlikely that the linearity of the unidirectional arrows on the models presented from Figures 1.1 to 1.6 (pages 7 to 11) can accurately portray the complexity and dynamism of oral health. Nonetheless, variance may occur in the way such dynamism and fluctuation is represented and portrayed. Motion or a dynamic movement, for example, can be illustrated as a pendulum or as polar coordinates.³³

Other than circles, triangles also are used to illustrate connections or relationships. The three-dimensional theory of love, for example, is portrayed in an equilateral triangle in which the length of each side represents the 'amount' of passion, intimacy and commitment in a relationship.⁴⁵ Such portrayal implies that a change in one dimension must be accompanied by a change on the other two to keep the triangular format, assuming that the dimensions are dependent of one another.³³

Triangles representing pyramids are also common. The energy pyramid, for example, depicts different species of animals in their appropriate hierarchical levels (producer, consumer, and so on).⁴⁶ In this case, the species are inside the triangular pyramid rather than on the sides. The pyramidal shape is formed because the total amount of energy generated decreases as the number of species also decreases from the base to the top. However, it indicates also that those concentrated on the top require more energy than those on the bottom to maintain daily functioning. The Food Guide Pyramid⁴⁷ is another example of a hierarchical triangular design in which the base represents what people should

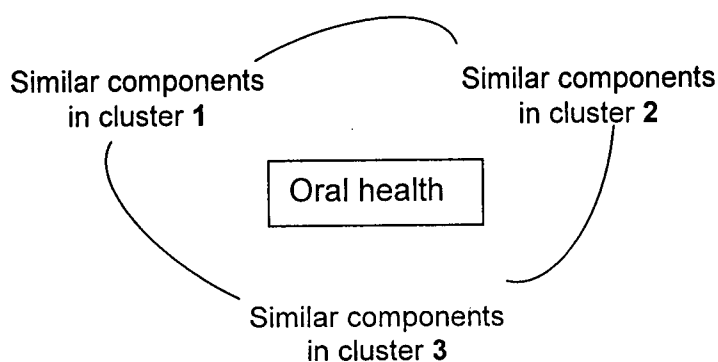
consume the most and on the top, the least. This pyramid in particular is quite illustrative as it shows different information: types of food with pictures, and amounts of food with numbers or percentages. But triangles, squares or pyramidal figures tend to represent disharmony or lack of continuity and flow if they are meant to illustrate dynamic phenomena. The corners or obtuse angles, for example, may indicate 'concentration' or accumulation⁴⁸ which makes less clear the idea of 'equality' or equal effects in a graphic outline to portray oral health, for example.

I produced six different outlines for the relationships of the original and new components, one per each group (Appendixes 21 to 26 on pages 231 to 242 respectively). Such outlines emerged from the analysis of the transcripts after the discussions. The six outlines represented my own interpretation from the transcripts and field-notes, not from direct interaction with the group members.

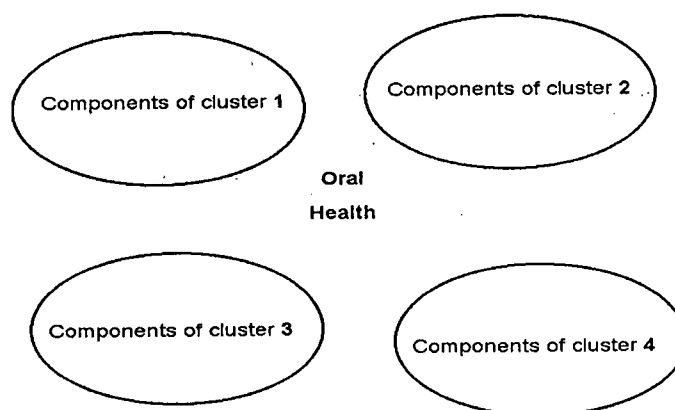
Although the groups did not participate directly in my six graphic displays that emerged from their ideas, I consulted 32 participants individually for further feedback on the outline I developed for their particular group and how they related to the original model (Appendix 3 shows one of the six different reports I produced). In this individual follow-up meeting, I took notes on the participants' comments rather than tape recording the conversations. Few participants had additional comments on the outlines. The feedback I received from the member checks caused me to review the transcripts, the six outlines and the original model in the light of my main objective in the framework analysis, which was to

provide an outcome, or an *end* product. Consequently, I considered the possibility of combining the six outlines since I noticed the similarities in the way I displayed some specific groups, or clusters, of components (Figure 6.4).

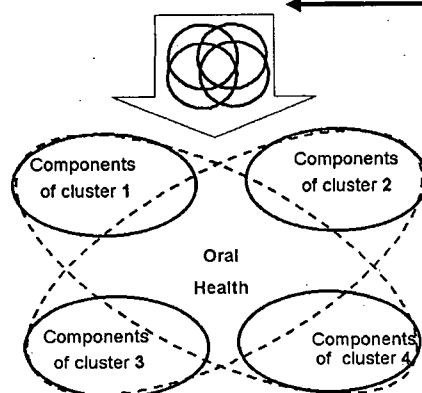
Figure 6.4 - Initial ideas for the new outline



I also found that three focus groups believed that the concentric circles in the original model represented different levels of importance, whereas they believed that there is no difference in the importance of the various components of oral health. Consequently, I expanded Figure 6.4 to include four clusters, each containing the components that I judged were similar in meaning or relationships, and arranged them 'around' oral health to show equal importance (Figure 6.5).

Figure 6.5 - The four clusters and oral health

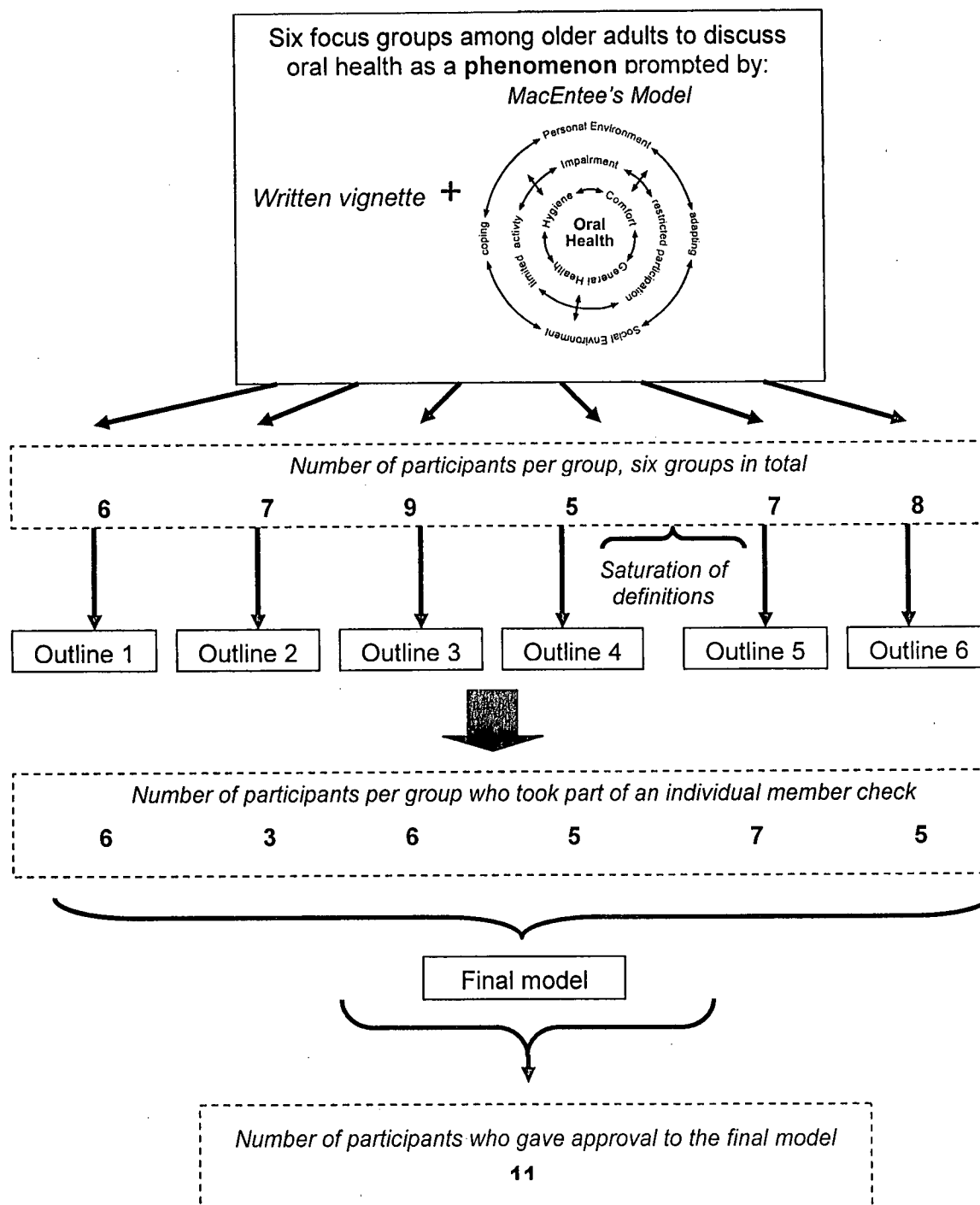
Within each cluster I still had to show how the components on that particular cluster were connected. Such connections, and the notion of equality to oral health, I understood, would be better shown through circles or ellipses, rather than triangles or squares (Figure 6.5).

Figure 6.6 - The overlapping effect

This is a 'model' that I mentally created to show how the 4 clusters would 'interact' around oral health in 'equal importance', that is, 4 circles overlapping

The new outline that emerged from Figure F is presented in Chapter 5, and represents the general ideas of six focus groups. This new outline satisfied a final round of member checks with 11 of the original participants who verified that the portrayal of oral health accurately represented the relationships between the components as they were addressed during the group discussions. Participants were advised that such outline represented the ideas from all of the groups, and not only a reflection from their own particular group. Again, I did not tape record the member checks but, instead, I wrote down the comments made by the 11 participants. The final elliptical model and the six different graphic outlines I developed per each group emerged grounded firmly on the groups' ideas and understandings about oral health following their exposure to a vignette and the original model (Figure 6.7).

Figure 6.7 - Outline of my methods



6.8 Summary

This chapter aimed at giving a methodological basis to the qualitative method described in Chapters 4 and 5. It offered a rationale for my use of focus groups to discuss oral health under framework analysis to evaluate a pre-existing model of oral health. I believe I explored the meanings of oral health through the collective interaction of participants purposefully assigned to six focus groups. Hence, framework analysis allowed me to address my initial objective of refining MacEntee's original model by presenting a more specific and yet elaborate final product.

6.9 Acknowledgments

I would like to thank Andrea Stephan and Brian O'Neill for their inputs on the development of the earlier drafts of this chapter. Support for this study was provided by the Canadian Institutes of Health Research – CIHR (CIHR Grant MOP 66992).

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CHAPTER 7

GENERAL DISCUSSION AND CONCLUSIONS

7.1 Remarks on this chapter

According to the manuscript-based thesis format from Faculty of Graduate Studies at UBC, this last chapter presents a general discussion and conclusion of my doctoral research. I retrieve information from Chapters 2 to 6 to support my arguments and to address the four objectives and research questions I posed in Chapter 1 (page 19). I summarize the shortcomings of my doctoral thesis, provide ideas for further research, and testify on how this research experience influenced me as a healthcare provider.

7.2 Objective 1: To review existing sociodental indicators in terms of the scope, theoretical and empirical support, content and structure, and internal consistency (Chapter 2)

I found 16 sociodental indicators - SDIs currently available in the literature (Table 2.3, page 34). The majority of the SDIs that emerged since 1976¹ pose negatively oriented questions varying in number to cover disease-specific domains,^{2,3,4} and to measure the negative and dysfunctional consequences of oral disorders in old age.^{5,6} However, there is no 'gold standard' against which different indicators can be judged. More importantly, however, my concerns revolve largely around the appropriateness of the concepts or theories underling the questions the indicators pose and the inferences implied from the responses. Consequently, I have serious concerns about the validity of the SDIs as measures of oral health-related quality of life.

7.3 Objective 2: to appraise the validity of existing indicators as patient-based measures of the full range to experiences and dimensions of oral health (Chapter 3)

The sociodental indicators have been assessed as to how well their questions reflect the underlying theories and models of ill-health, dysfunction and disability in which they are based (e.g. construct validity). The *construct* of the SDIs supports the views that an unhealthy, dysfunctional and impaired mouth always disturbs the social and psychological aspects of daily life. There is no acknowledgment of the possibility that chronic illness can have a positive impact on quality of life^{7,8,12} when people cope and adapt to accommodate the constant fluctuation on health and disease that they dynamically experience.^{4,9}

The existing indicators have also been assessed as to how relevant and unambiguous are their questions to portray the underlying theory or model (e.g. content validity). There is indication that investigators and respondents to SDIs rarely agree on the relevance of the *content* of the questions asked.^{10,11}

Moreover, the indicator's question may be ambiguous, vague, or limited in scope^{12,13} and may reveal simply that the respondent has had a difficulty or problem but tell nothing about whether or not such difficulty has caused concern.¹⁴

The SDIs have been assessed as to how well they accurately predict care seeking behaviours, for example (e.g. criterion validity).¹⁵ The ability of an SDI to predict a *criterion* such as health-related beliefs and behaviours remains poor

probably because they overlook the ever-changing socio-cultural environment in which people live.

In all, the SDIs do not always accommodate the oral health, impairment or disability that older people experience, nor do they explain why respondents with severe dental impairments rate their oral health highly whilst others with less impairment report considerable distress.¹⁶ The limitations on the validity of existing SDIs may be due to the models of *ill*-health they were based. Consequently, new or alternative models of oral health are suggested. Recently, MacEntee presented an alternative model of oral health in an attempt to accommodating coping and adaptive strategies to oral impairment and restrictions experienced by older adults.⁸ I proposed to evaluate and refine such model using focus groups and a written vignette in a projective technique.¹⁷

7.4 Objective 3: to describe an experience of using a written vignette in a series of focus groups to investigate oral health among older adults (Chapter 4)

The vignette promoted discussion of sensitive topics, disclosure of personal experiences, interaction, and opportunity for equal participation in the focus groups. Shortly after the discussions began, participants offered personal and family incidents about teeth, mouth and dentures. As found by others,^{18,19,20} the use of vignettes in focus groups in general, and with older adults in particular,

remains a useful method for introducing health-related topics,²¹ and I found it valuable for exploring the perceptions participants had about MacEntee's model.

7.5 Objective 4: to evaluate and refine if necessary MacEntee's model of oral health from the opinions and experiences of the participants in the focus groups (Chapter 5)

I took a step back with a basic enquiry: why is it necessary to listen to the participants of my study rather than to health professionals? Although healthcare professionals are experts in health conditions, their opinions and perceptions frequently differ from those of their patients.²² Consequently, both perspectives on health need exposure when planning patient-centred care, evaluating patient outcomes, and measuring the burden of oral disorder.²³

On rare occasions when lay people were asked to evaluate health models developed from theories, they were mostly patients in hospitals which probably limited their perspective to disability and dysfunction²⁴ as opposed to the broader aspects on health.^{25,26} In the case of my study, the participants were encouraged to focus on health and illness when evaluating and refining the model, and to pay particular attention to its content and graphic representation.²⁷

Apparently, the men and women held similar opinions on oral health, and essentially they accepted the model, but with additions on its content and modification on its outline. Although participants agreed with the portrayal of oral health in combination with hygiene, comfort and general health, they also agreed

that the model excluded important components and it did not reflect the entire range of their experiences. Consequently, their suggestions helped me to answer my third research question: to what extent does the MacEntee's model of oral health graphically reflect the experiences of older adults and their health values and beliefs?

Each group gave me different ideas that I interpreted to emerge with six graphical representations of MacEntee's model (Appendices 21 to 26), and 32 of the participants gave me further suggestions on these six outlines. I revisited the transcripts to amalgamate their suggestions into one final model (In Chapter 6, pages 165 to 168 illustrate my thinking; Figure 5.2, page 132, shows the final model). This final model includes the additional components recommended by the participants in a graphic display of ellipses. The ellipses replaced the concentric circles in an attempt to counter the criticism that circles of different circumferences imply different levels of importance.²⁸ Finally, I confirmed the accuracy of the final model with 11 of the original participants, who agreed that the elliptical model with additional components more aptly reflect their experiences with oral health.

The refined model unifies the empirical information I collected and opposes the utilitarian tradition of depicting disability as an unacceptable consequence of impairment.^{8,25,29} It challenges models of illness that portray oral health negatively and that favoured dysfunction from the perspective of a minority of population that suffers ill-health,³⁰ as exemplified from Figures 1.2 to 1.6 (pages 8 to 11).

7.6 To what extent can the model of oral health be used to modify existing sociodental indicators?

The answer to my final research question represents the future direction of my study and deals with the possible applications of the refined model in suggesting modifications in the existing sociodental indicators. Bowling³¹ has criticized general health measures developed from negative definitions of health because they cover only the minority of the population that experience illness and do not relate to the majority of the population who feel relatively healthy. Consequently, with a focus on health rather than *ill*-health, the refined model provides a conceptual basis for modified or new measures of oral health.

For example, the model could be used to clarify questions in existing SDIs to highlight relevant and positive aspects of health. An answer 'yes' to the Social Impacts of Dental Disease - SIDD original question "did you experience difficulty opening your mouth wide?" might reflect a disability for some people, but an indisposition for others, as suggested by Davis²⁹ and MacEntee *et al.*²² Questions could be derived from the model to highlight these differences, such as:

- Question - *'How important is it to open your mouth wide to eat, talk or bite?'*
 Answer - *'very important', 'important', 'somewhat important', 'not important'* (importance of **personal environment**);
- Question - *'Are you bothered because you cannot open you mouth wide?'*
 Answer - *'yes' or 'no'* (**coping, adaptation and expectations**).

Answers '*not important*' and '*no*' to these two questions, respectively, might help to distinguish from one responded who answered 'yes' to the original SIDD, and felt indeed disabled by that limitation, and from another who also answered 'yes' to the SIDD question, but felt that such limitation was a mere indisposition.

Another type of question that might need clarification is "have you had any problems with food getting stuck between your teeth?" (from the Dental Impact on Daily Living-DIDL). This question implies that 1) food collecting between teeth does constitute a problem, 2) the respondent is bothered physically and/or psychologically by it, and 3) the teeth need treatment. Again, some individuals might indeed feel concerned and limited by food trapped between teeth but others might accept and cope with it without concern. Questions from the refined model could help to elicit **importance** and **copmg-adaptation-expectations**, and to clarify whether or not a respondent to that DIDL question sees 'food getting stuck between teeth' bothersome and in need for management.

The challenge remains to produce measures of oral health that are appropriately grounded in the experiences of elders and that will explain the significance of both health and *ill*-health in old age. Of course modifications I suggest above will need extensive testing to assess their ability to compensate for or overcome the limitations of existing SDIs. For example, validity studies are needed to appraise the value, clarity and comprehensiveness of these clarifying questions from the perspectives of older adults. Lastly, the model could provide also answers to the challenges faced by existing SDIs:

Challenge	Answers drawn from the refined model
<i>Why do some people identify oral problems through an SDI, but do not seek care?</i>	Because they may cope and adapt to that problem so it does not raise concerns about treatment needs.
<i>Why do some people seek care even without a clinical disease?</i>	Because they may feel pressured by society to meet cultural expectations such as whiter teeth.
<i>Why do some people with oral disorders report no impact when filling out an SDI?</i>	Because they may accept some disorders positively as their health expectations fluctuate dynamically.
<i>Why do some people who report high psychosocial impact score on an SDI also report that they have good oral health?</i>	Because they may not identify the impact as dysfunctional, even though the SDIs give responses that are interpreted as such.

7.7 Implications of my study

Existing models of oral health: The refined model challenges existing models of ill-health (Figures 1.2 to 1.6, pages 8 to 11) that: present a linear and unidirectional progression from disease to dysfunction and handicap,³² emphasise the burden of oral impairments and disability, and overlook the potential of coping, adaptation and expectations on everyday life. The refined model demonstrates the need to incorporate aspects of oral health that are important to people.

Research outcomes - SDIs: Models of oral health are useful, for example, in helping to develop patient-centred care, and to evaluate treatment outcomes usually through sociodental indicators.³³ Since the existing SDIs focus mostly on

the negative aspects of oral health, the refined model can provide a set of questions to be added in the existing indicators. This set of questions could include items about coping and adaptive strategies for maintaining oral health, and the relevance of expectations on daily functioning, all important behaviours to older adults.

Research outcomes - oral health: The refined model provides a conceptual foundation for investigating relationships between its components.³⁴ For example, one might ask: 1) is there a difference between the comfort experienced when eating alone compared to eating in the company of others?; 2) under what conditions does pain disturb social interaction?; or 3) does awareness of oral hygiene promote brushing and flossing behaviour?

Clinical practice/services: The refined model can be used for planning interdisciplinary interventions and services that focus on promoting social activity and participation rather than on re-establishing oral function alone. Hence, it encourages dental professionals to identify and consider variables of interest (e.g. the components of the model) when establishing treatment options and promoting care beyond the traditional assessment of clinical change. The model provides also a template for considering preferences for health outcomes in which patients and dental professionals participate together in treatment decisions.

Education: The refined model broadens our understanding of oral health and disease. It also promotes improved communication between a patient and a dentist to acknowledge the patient's willingness to adapt to and cope with oral

disorder. It introduces to the students an interdisciplinary biopsychosocial understanding of oral health beyond the medical model.³⁵ Essentially, the refined model continues to emphasise that a satisfactory level of oral health, function and comfort is defined primarily by the individual.^{22,33}

Policy implementations: The refined model may help to establish policy implementations favouring treatment and therapeutic interventions that are meaningful, relatively simple, and less expensive to individuals, especially to those who are frail or on limited budget. Hence, by emphasising personal characteristics such as economic priorities and expectations, the model balances expensive and invasive treatments with less costly therapies such as pain relief and discomfort management.

7.8 Limitations of my study

1) The literature review has limitations because I may have missed indicators that were not catalogued under the set of key words I used, or published in a different language other than those four I could understand. Hence, I did not include publications indexed after April 2006 nor did I have independent reviewers for the screening process;

2) The six focus groups consisted predominantly of 42 well-educated, older Caucasians who were relatively healthy. Consequently, it provides limited insight to opinions, expectations and experiences of persons from different ethno-cultural groups or from different age groups;

3) I did not explore further the information the group of gay men brought about bad oral health, oral sex, and sexual transmitted infections;

4) The refined model had feedback on its final graphic outline from only one quarter of the 42 participants.

7.9 Future directions

Other than the suggested questions for the existing SDIs, I further reinforce the need for a continuous evaluation of the model to improve understanding and awareness as in any other research that aims at enhancing knowledge.³⁶ Consequently, I expect that new components and outlines may emerge when the model is exposed to different ethno-cultural groups since the distribution and significance of health perceptions is moderated by cultural and social diversity.³⁷ There is a need for an ongoing evaluation because, as one participant said, *"[the model] looks like an automobile. If you take it to the mechanic, he tells you 'the next time you came in, you would have to have this and that done, because it is deteriorating.'"*

Further in-depth analysis from the information collected from the discussions about the vignette is warranted to better understand how participants cope and adapt to their oral status; how they access dental care; and how they perceive the role of dental professionals in promoting oral health in old age. Lastly, I am particularly interested in appraising the model under the opinions of other groups of gay man and women for possible relationships between oral sex

and sexual transmitted infections, and to explore the role of dental professionals in addressing such issues with their patients.

7.10 Final comments

How has this exercise of a PhD research influenced me as a dentist? After almost 10 years of clinical activities embellished by a Masters in Gerontology, I started this graduate PhD program with the intention of 'solving the world's problem in terms of oral health-related quality of life measures'. As I realized throughout the course of the program, the problem did not need to be solved as much as it needed to be understood. I believe my thesis helped me to understand some parts of the problem.

I struggled initially to recognize whether any problem in oral health measurement existed because I was strongly influenced by a very objective understanding of oral health through almost a decade of private practice. Although I was living well within this *objectivity* as a clinician, the PhD program started questioning my professional beliefs. I also questioned whether such objectivity was in fact *subjectively* interpreted through my own values. During my PhD program, I understood that whether or not a missing tooth constitutes a *problem* from my dental perspective, it has also to constitute a *problem* from my patient's point of view and his/her socio-cultural-economical-environmental context. I believe my research helped to narrow down the gap in my understanding.

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APPENDICES

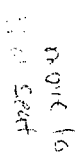
APPENDIX 1
BEHAVIOURAL RESEARCH ETHICS BOARD APPROVAL

APPENDIX 2
INFORMED CONSENT

APPENDIX 3

**ONE EXAMPLE OF FIELD-NOTES TAKEN DURING THE FOCUS GROUPS
BY THE RESEARCH ASSISTANTS**

Impet: malacit



5, 4, 3

⑭ writing name tags for participants.

2:30 PM - ⑦, ⑤

2:32 PM - go over the consent form

left ← ~~5~~ - I don't think I need to sign anything
so I'll

⑤ - 1.5 hr. is too long
④ - Can we get any ideas
what we're signing for.

left ← ⑦ - I thought we were going to learn secrets about keeping good teeth?

2:40 PM what is it about?

2: 44 pm ② joining the group

- giving all passengers a room
- (6) have OH problems that would like to consult (M).

2.46 (5)

unweat weatny { I don't see the difference
unweatny
gag - you're breathing

OBSERVATION

① were the other men
↓
afraid to come?
⑧ (jokingly) → ⑧ laugh

④ shaking her head
when us spell names wro

② I just cleaned my teeth

④ don't call me "you"
 guys" pls, I just do

↳ The group → what about you, ladies

you just
good it's

③ ⑤ - months.

⑥ - taken

② - cleanliness

① - are you defining it by good or bad stuff

① - poor / pend

⑤ - denture

② - sometimes. / position / give them ideas of how to _____

① - 495 - 1a94

⑤ - yes - bad breath



⑧ - good oral health

⑤ - fit teeth carrying conversation

3000

⑨ - 'come to all of us.'

③ - not crazy about going to see a dentist

① - What did you say?

(4) - I said come to all of us

D - Artists..

- (2) - part of your body
- (5) - not related / I don't know
- (3) - teeth taken out
- (2) - why did we take them out
- (3) - cavities
- (5) - taste
- (3) -
- (5) - you lose your taste pretty well
- (2) - I do
- (3) - I'm sure
- (3) - general statement
not affect my body at all in any other way
- (3) -
- (1) - have there ever done any study?
- (8) - not my case
- (1) - pain / personal observation

f.3

- (7) - otherwise it does / infection
- (2) - badly infected tooth that has to go → system
- (4) - yes
- (5) - 3 wnts cleaning → improving my taste
- (6) - can I come back?
Mr. want to see me
- (5) - I don't know difference.
- (2) - very. every 6 wnt.
- (5) - \$10 a tooth
- (1) -
- (5) - \$100 to get a teeth clean
- (2) - timing
- (5) -
- (2) - the longer you spend.
- (3) - handle
- (5) - electric tooth brush?
- (2) - No

f.4

APPENDIX 4
THE SITUATIONAL VIGNETTE

The situational vignette used to prompt the focus group discussions

“Rosita resides in the same building with her friend Victor in a Spanish neighbourhood. They are very active within the local community. Rosita argues frequently with Victor because, according to her, he seems to not care about his mouth because he does not wear his dentures all the time. She keeps telling him to wear his denture to “look better”. Even when eating, Victor sometimes does not wear his dentures. He often goes to the community centre without them and seems not to be upset about it, but not Rosita! She never goes out without her dentures and now she avoids Victor’s company outside the building.”

APPENDIX 5

**THE INTERVIEW GUIDE FOLLOWING THE PRESENTATION OF THE
VIGNETTE**

- Why do you think Rosita always wear her dentures even with some discomfort?
- What reasons do you think she behaves like this?
- Why do you think Victor does not always wear his dentures?
- What reasons do you think he behaves like this?
- Why do you think Rosita wants Victor to wear his denture?
- What do you think Rosita's concerns are?
- How frequent this situation can be?
- Do you think there are any problems here? What and why?
- Do you think Rosita would change her views if Victor wears the upper but not the lower denture?
- Partial denture, natural front teeth
- Do you think this situation would vary among different ethnic groups? Why?
- Do you think there would be any change in this situation (Rosita and Victor behaviours) if they were husband and wife?
- Why do you think Rosita started avoiding Victor's company outside the building?
- Do you think Victor's behaviour would affect other people? Why and how?
- Can anybody criticize Rosita's views (denture/avoidance)? Why and how?
- Can the friendship between Rosita and Victor change (if so, for better or worse)? Why and how?
- Can anything be done to deal with this situation? Why?
- Do you have any other comments?

APPENDIX 6

**THE INTERVIEW GUIDE FOLLOWING THE PRESENTATION OF THE MODEL
OF ORAL HEALTH**

Components

Completeness

Why do you think this model has these specific components?

Do the components include all the aspects of oral health important to you? Why?

Do you think there is any component missing? Why?

Do you suggest any new component to this model?

Relevance

How do you “see”/understand oral health from this model?

Are all the components necessary in the model? Why?

Are these components relevant to oral health? Why?

Is there any component more important than other?

Interdependence

Are the components separated from each other in terms of their meaning?

Are they independent of each other?

Do they overlap?

Do they complete each other?

Outline

Are the components correctly outlined in this graphic/model? Why?

Why do you think the connection between the components mean?

Would you suggest a different arrangement? How? Why?

APPENDIX 7

THE ADVERTISEMENT TO SELECT THE PARTICIPANTS

APPENDIX 8
THE GENERAL FORM TO CHARACTERIZE THE GROUPS

THE UNIVERSITY OF BRITISH COLUMBIA



Department of Oral Health Sciences
Faculty of Dentistry
2199 Wesbrook Mall
Vancouver, B.C., Canada V6T 1Z3
Fax: (604) 822-3562

General information

Name _____ Date: _____ yr _____ mo _____ day

Age _____ years Gender _____

Please place an X beside your answer to the following questions:

1) Your marital status: () Single () Married () Divorced () Widowed
Other (please specify) _____

2) Your educational background: () Elementary school () High school
() Undergrad university degree/College diploma
() Graduate degree () Another _____

3) Your ethnic background: _____

4) Your oral status:
() natural teeth
() natural teeth and partial removable denture
() natural teeth and one complete denture (plate)
() two complete dentures (upper and lower plates)
() no teeth and no denture

5) Have you been to a dentist in the past 6 months: () Yes () No
If yes, for what reason: _____

6) How would you consider your mouth (teeth/denture/tissues):
() Healthy
() Somewhat healthy
() Somewhat unhealthy
() Unhealthy
() Other (please specify) _____

7) How would you consider your general health:
() Healthy
() Somewhat healthy
() Somewhat unhealthy
() Unhealthy
() Other (please specify) _____

Thank you!

APPENDIX 9

ONE EXAMPLE OF THE REPORT USED AS A MEMBER CHECK

Values/beliefs

- Oral hygiene helps you to eat and chew properly.
- Oral hygiene gives you the sensation of freshness, the same with hygiene of the body.
- The habit of (keeping) hygiene is passed through family (from generations).
- Oral hygiene is associated with your "presence".
- Sometimes, oral hygiene is not enough to prevent you from bad breath (if you have stomach problems, sickness).
- Lack of oral hygiene can reflect lack of body hygiene.
- Keep your mouth clean has a positive impact on general health.
- Oral health is not white teeth (not natural).
- Whitening teeth is not good, not healthy (chemicals).
- Meaning of aesthetic is socially bounded and varies within cultures.
- People treat you differently according to the way you look (teeth, clothes, shoes).
- The way you look have a different impact if you have teeth/denture/missing teeth/breath.
- Ageing brings some changes, not necessarily problems.
- Ageing can effects negatively oral health if associated with bad diet and lack of hygiene.
- Ageing is accepting things that you cannot do.
- Different generations think and behave differently as the time changes.
- What suits you when younger does not suit when older.
- We change the way we think as we age.
- General health problem can deviate your attention from oral health (priorities)
- General problems do not affect oral health.
- Oral problem impacts general health and quality of life (connection with mouth/body).
- If you fix teeth/denture you can gain quality of life
- Adapt and cope with dentures is necessary because there is nothing more after.

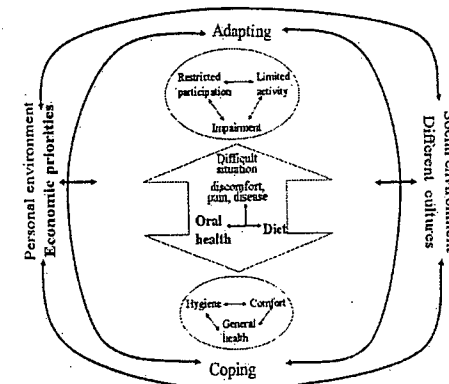
(what the group thought)

- Offer a mint to somebody that has bad breath.
- Go to the dentist for check ups.
- Don't go to the dentist often due to the cost
- Modify people's behaviours (friends) by arguing what is good/bad for them.
- Help close related and friends with daily activities and social activities.
- Accept close related problems/difficulties.
- Don't stand without denture even during the night.
- Use denture to not feel uncomfortable (embarrassed).
- If have problems with teeth/dentures, go and fix it.
- Take dentures out just to clean them.
- Can take or not the dentures out to sleep, depending on personal judgment.
- Use the denture, even when hurting, till get used too.
- Don't go out without dentures.
- Eating out: change the menu to eat without discomfort; Chew soft food to not feel discomfort.
- Eating at home: if uncomfortable with dentures, don't put them in.
- Don't do lots of thinks due to age, but don't bother.
- Get used to lots of things (there is nothing that you cannot get used to).
- Get used with changes outside (world).
- Adapt to feel happier.
- Don't limit going out with walking devices.
- Brush (teeth and dentures) and floss teeth regularly.
- Use clothes because wants to, not because it is dictate.
- Like clean clothes as like clean mouth (hygiene) and the body (the feeling/sensation).
- People can use other's behaviour to feel better/to get energy and strength.
- Dentures make you eat better, but not all foods
- Dentures make people feel comfortable. You can

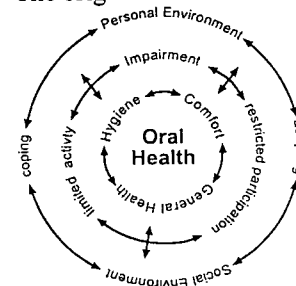
- Dental cleaning is necessary, but might remove "something" from the teeth by scaling.
- Some foods help to clean teeth (solid, apples), but some others can cause problems.
- People have priorities: they decide what come first, and this can affect their behavior.
- TV commercials show people with good teeth as synonymous for oral health.
- Sometimes people don't like to wear dentures. They got used to.
- The outcome from a dental treatment should be aesthetically and functionally acceptable, and has a good and bad impact on the patient and the others (family, friends).
- Lack of money put you away from the dentist.
- The dentist is co-responsible for people's health (should tell what is good/bad).
- Not wearing denture means problems with it (ill, discomfort, teeth in wrong position) or lack of money to fix it. It can happen to all cultures.
- Sensitive tooth/mouth can affects you.
- Quality of life is good health, and decreases if medical problems occur (unhealthy).
- Quality of life is having relationships, friends, community events.
- Quality of life is not directed related to oral health, but to the whole body.
- Problems with dentures (ill-fitting) affect general health and quality of life.
- Quality of life changes and differs in different groups in different times (people have different necessities while they grow older).
- You have to adjust to changes in life, and it is easier when you are younger (but can be difficult in any age).
- If you adapt to the changes, you can have quality of life.
- Quality of life is making choices in life, and it is better with support (somebody at the same situation).
- It is good to look at people worse off to realize your own health and quality of life.

- feel impacted by not wearing them.
- Gums shrink and denture are not expected to fit well anymore.
- By not fitting well, denture can hurt and cause pain and discomfort, it should be fixed.
- Lack of teeth can affect your speech, but not always.

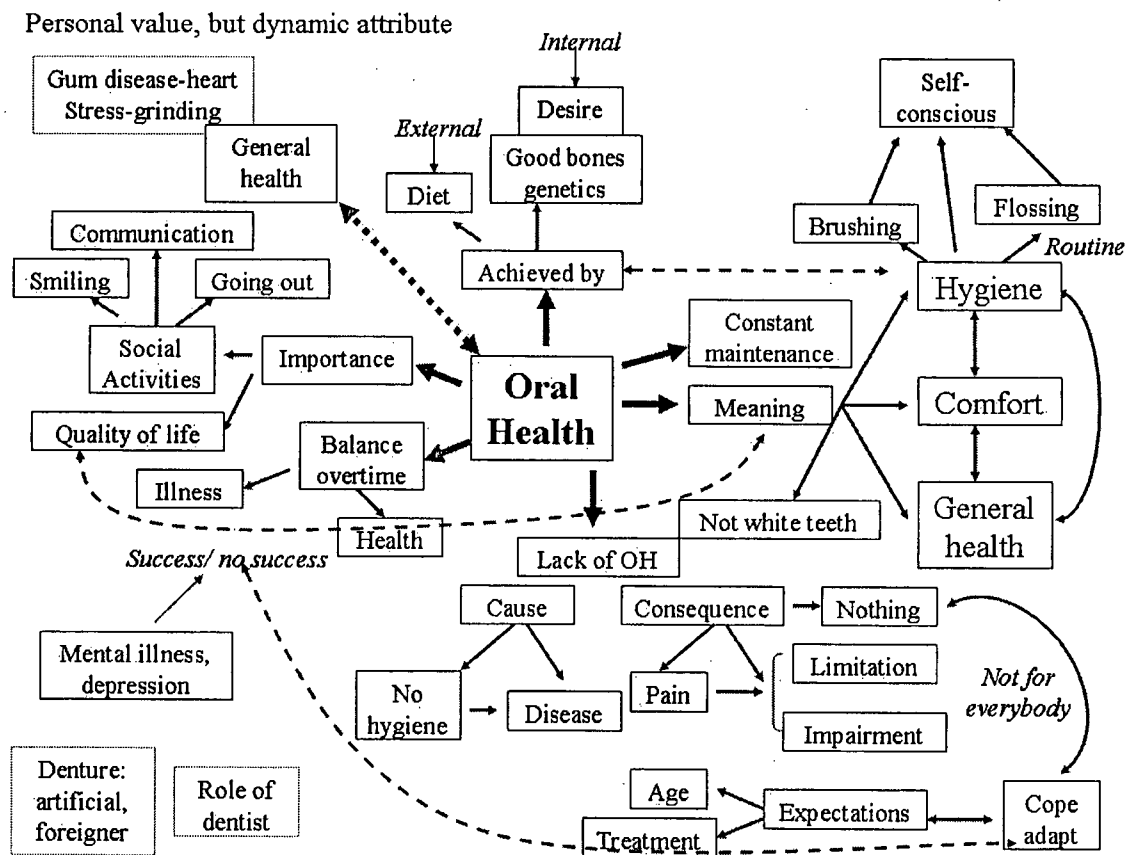
The model the group suggested



The original model

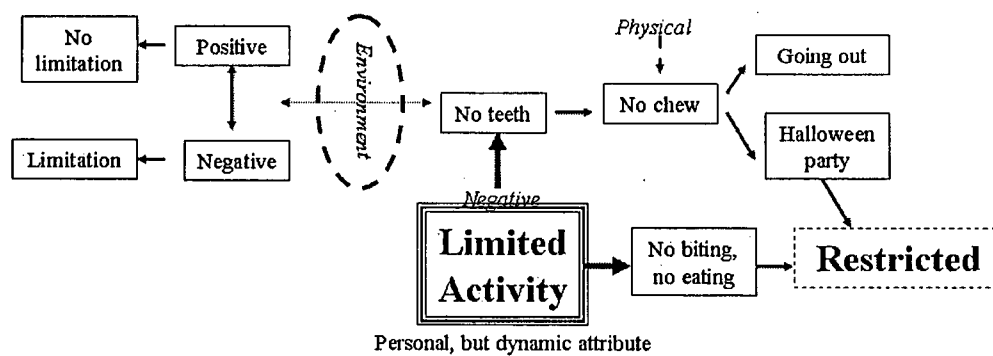


APPENDIX 10
MAP OF ORAL HEATH



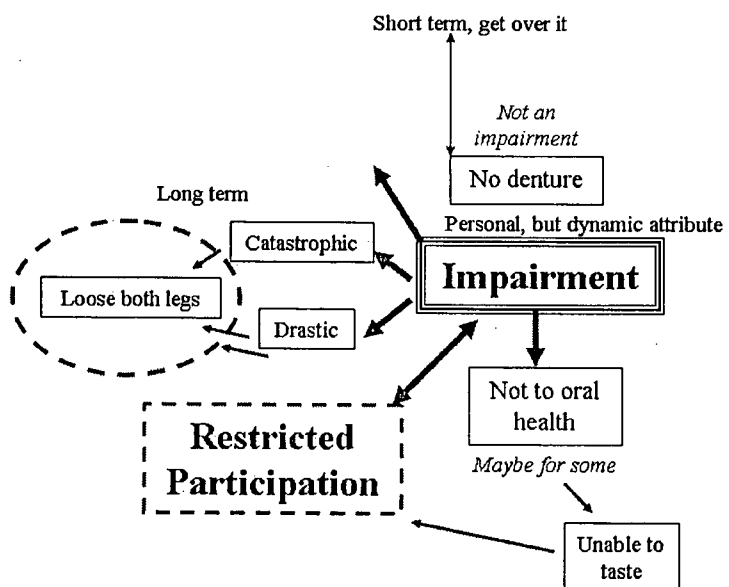
APPENDIX 11
MAP OF LIMITED ACTIVITY

Too negative



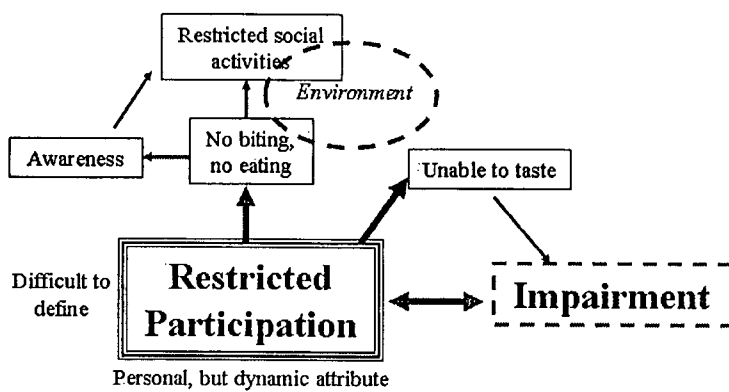
APPENDIX 12
MAP OF IMPAIRMENT

Inappropriate for the model



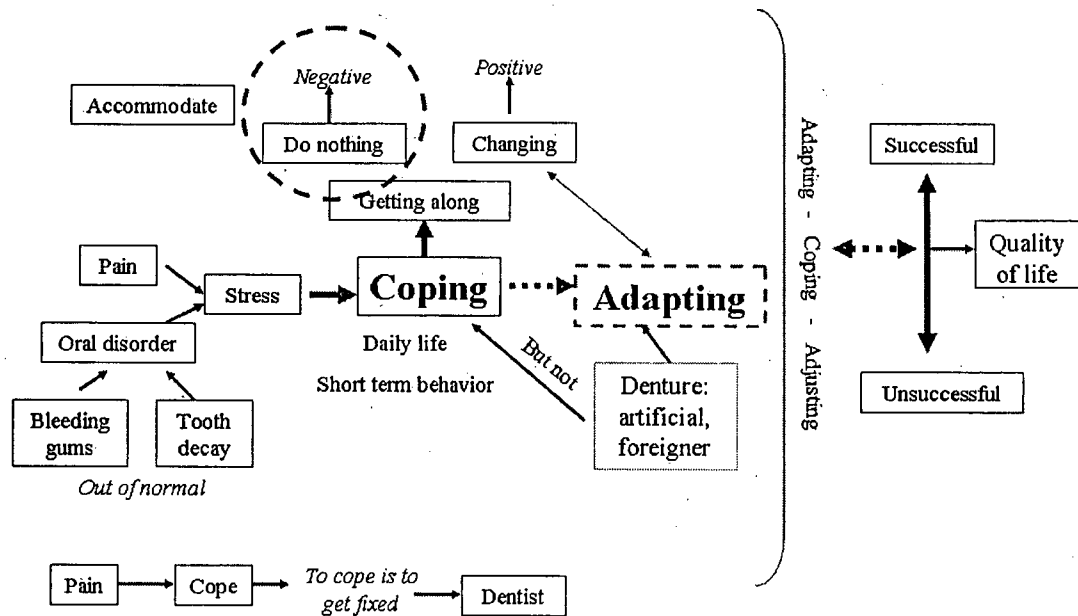
APPENDIX 13
MAP OF RESTRICTED PARTICIPATION

Too negative



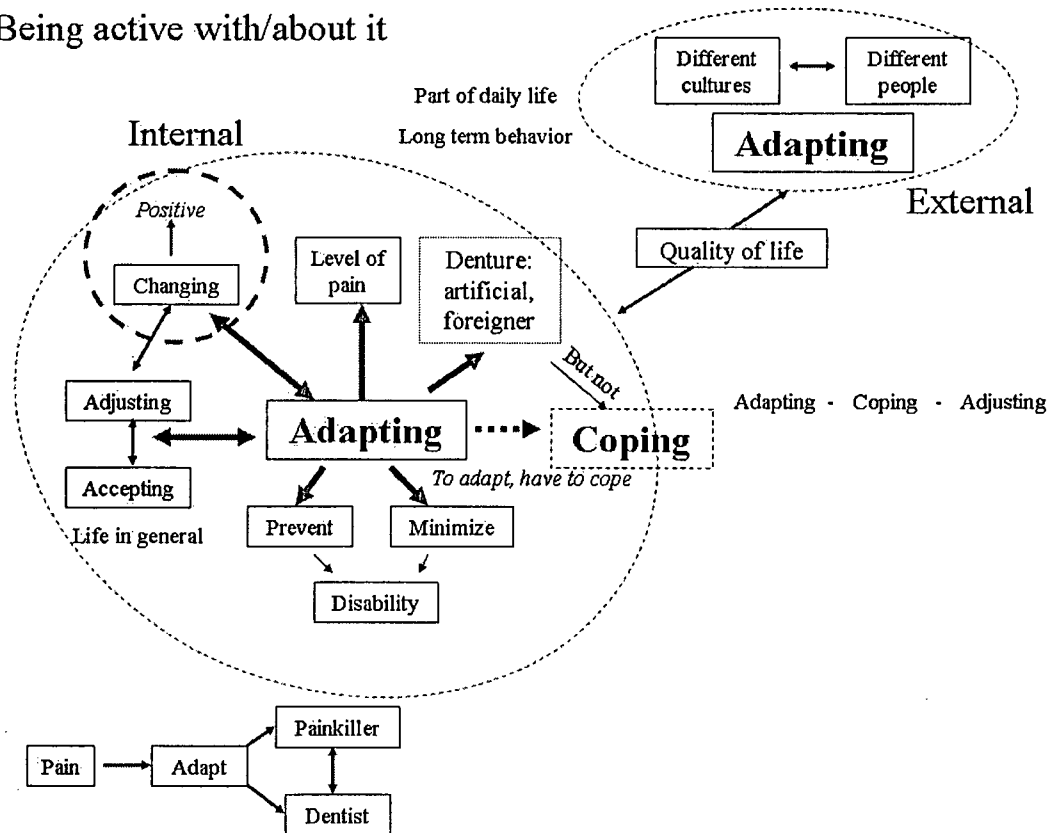
APPENDIX 14
MAP OF COPING

Being passive with/about it

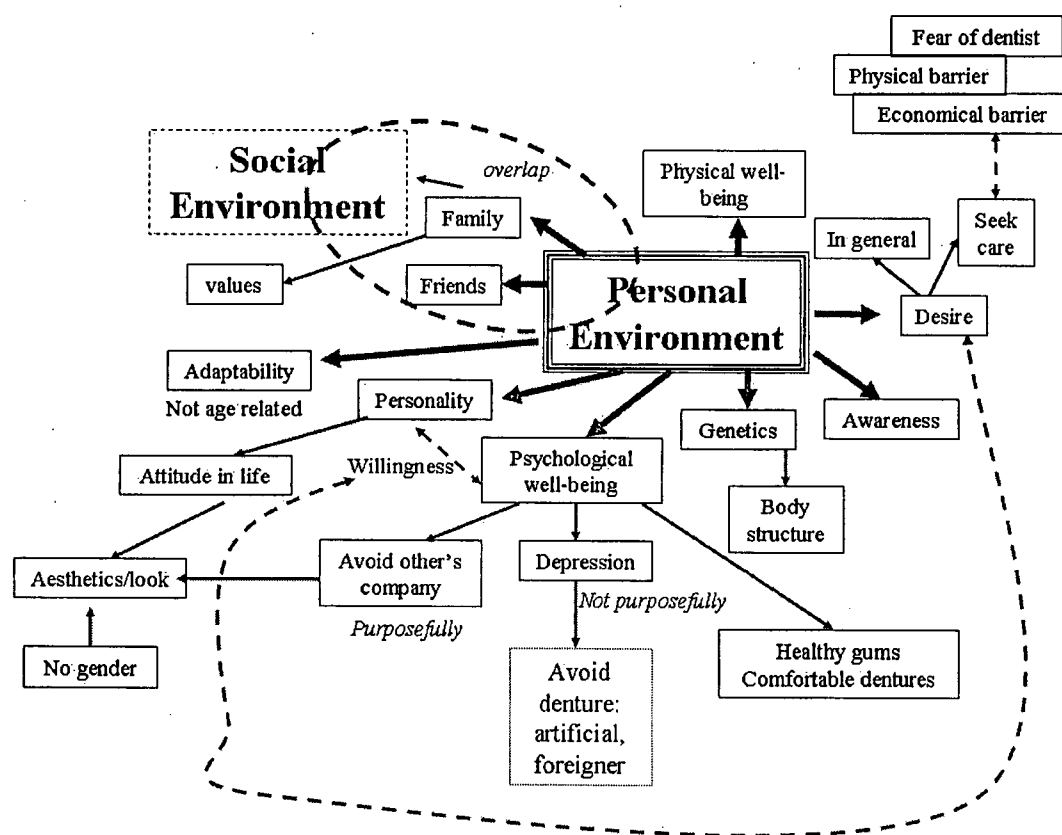


APPENDIX 15
MAP OF ADAPTING

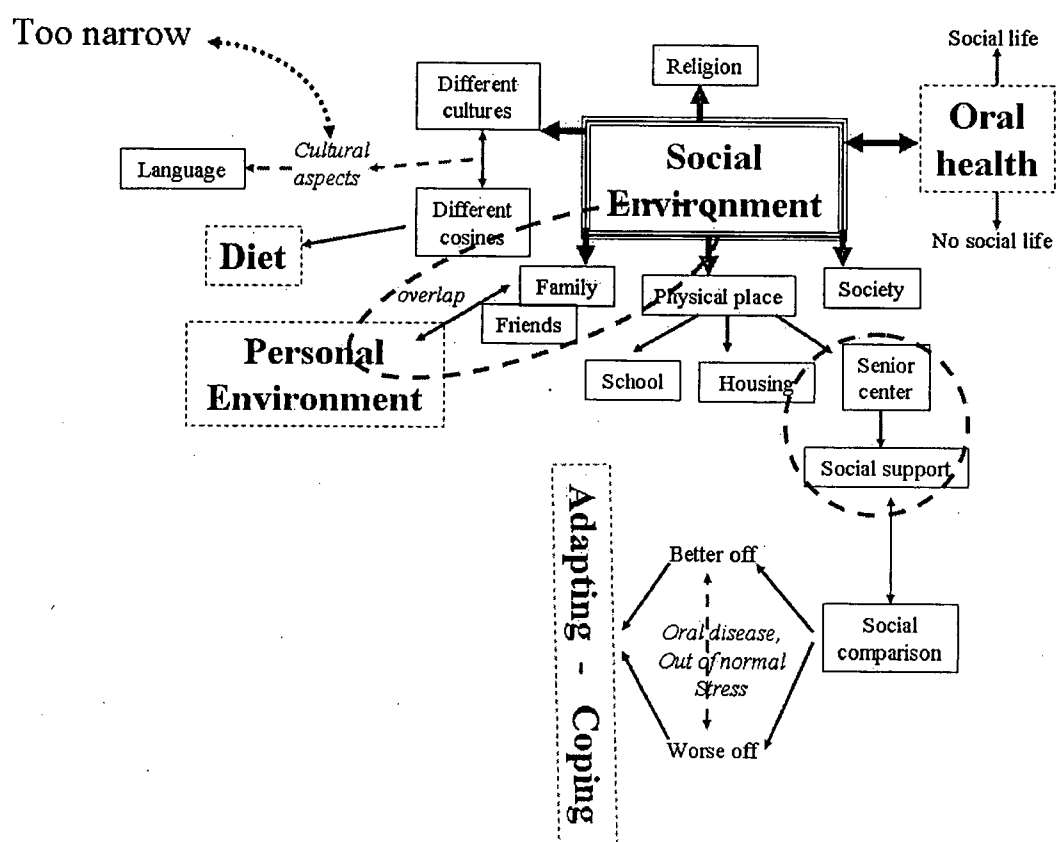
Being active with/about it



APPENDIX 16
MAP OF PERSONAL ENVIRONMENT



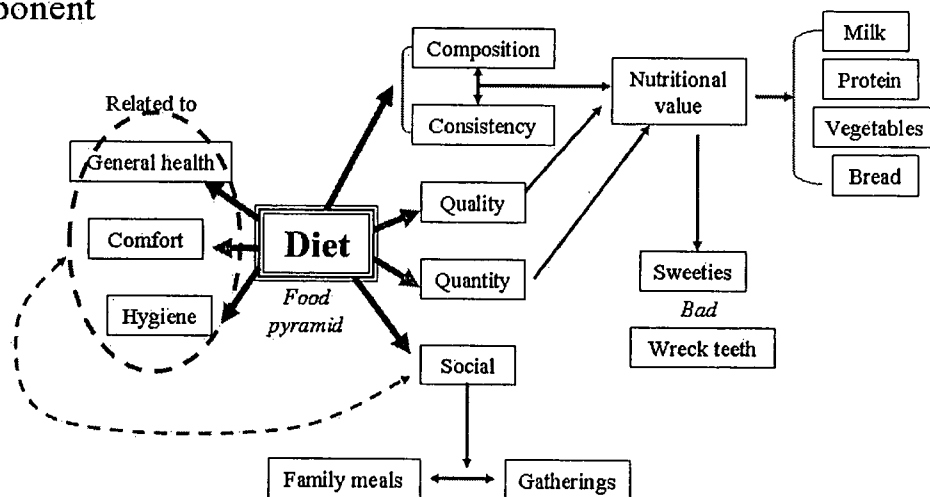
APPENDIX 17
MAP OF SOCIAL ENVIRONMENT



APPENDIX 18

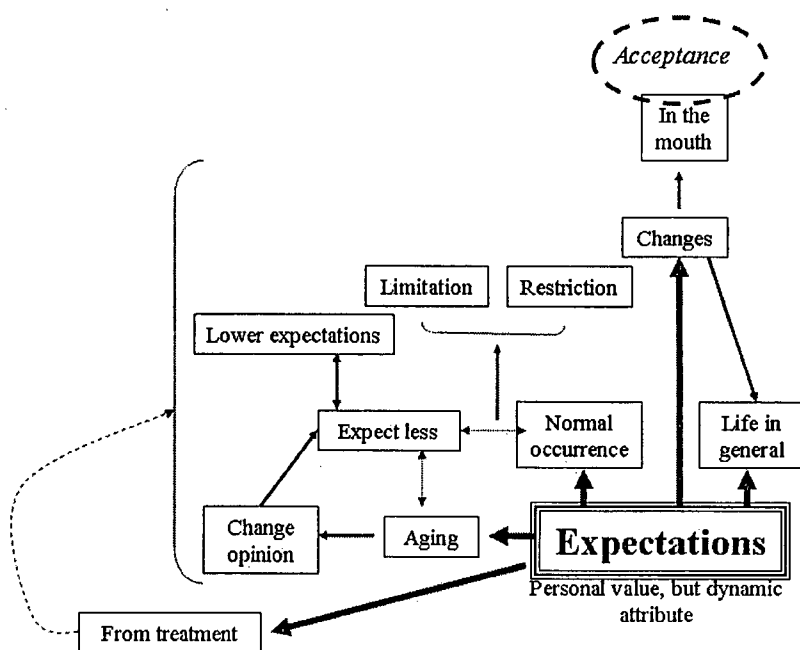
MAP OF DIET

New component



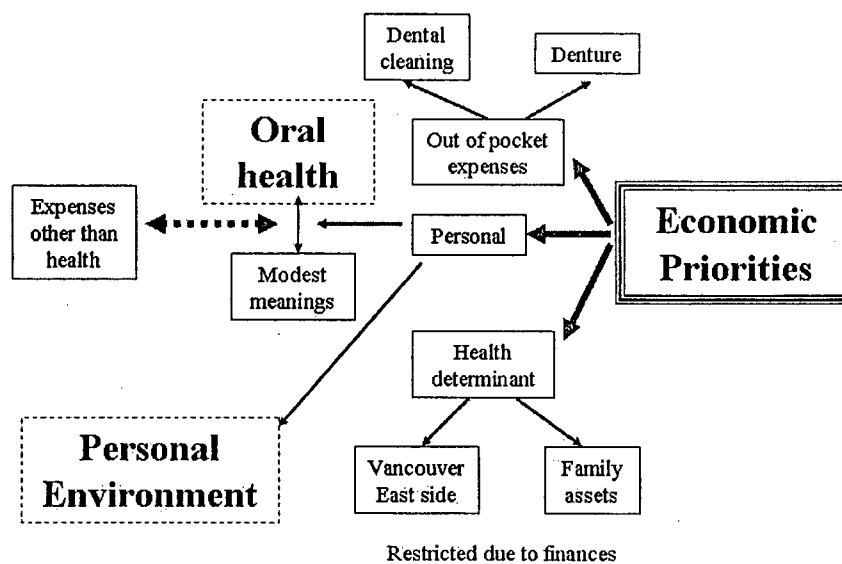
APPENDIX 19
MAP OF EXPECTATIONS

New component

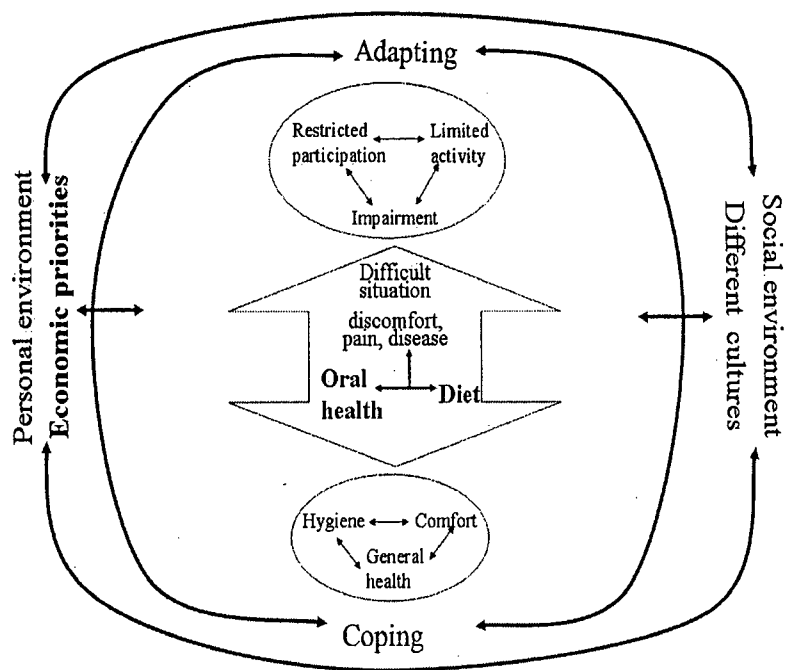


APPENDIX 20
MAP OF ECONOMIC PRIORITIES

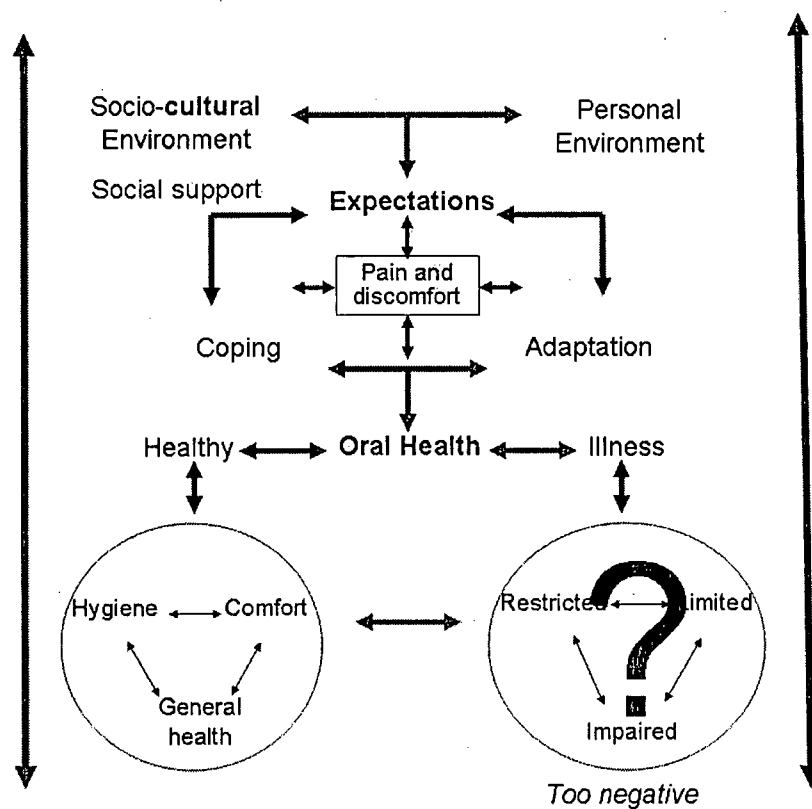
New component



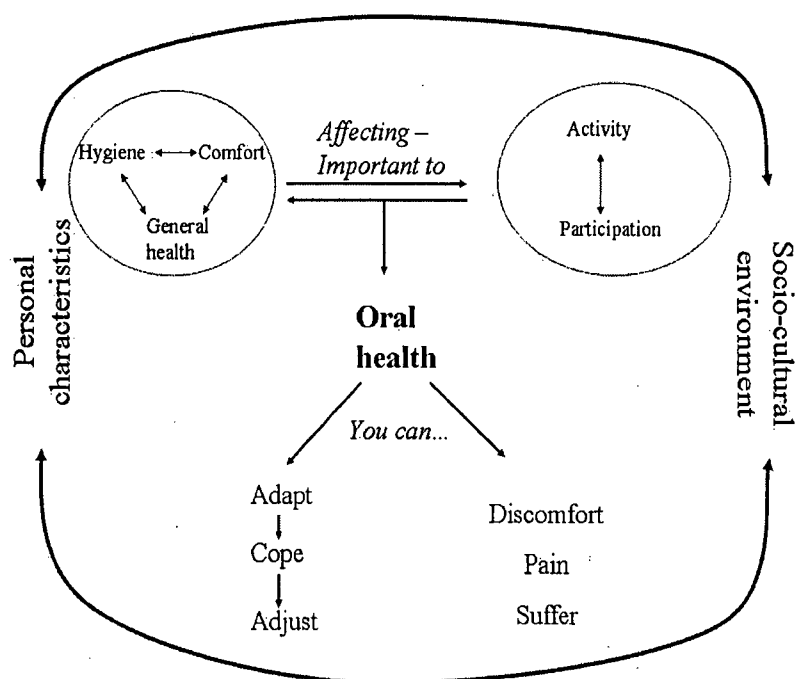
APPENDIX 21
MODEL FROM FOCUS GROUP 1



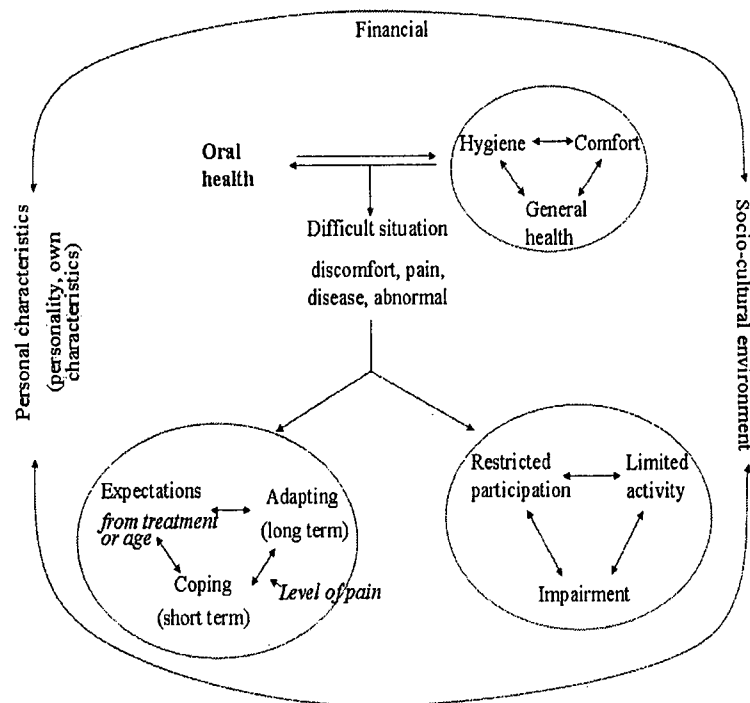
APPENDIX 22
MODEL FROM FOCUS GROUP 2



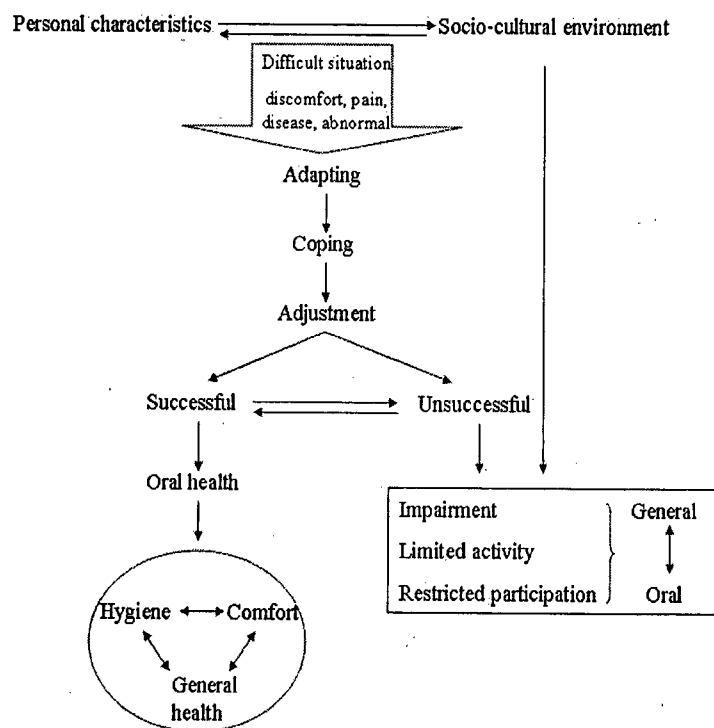
APPENDIX 23
MODEL FROM FOCUS GROUP 3



APPENDIX 24
MODEL FROM FOCUS GROUP 4



APPENDIX 25
MODEL FROM FOCUS GROUP 5



APPENDIX 26
MODEL FROM FOCUS GROUP 6

