## On Oral Health-Related Quality of Life in Swedish young adults

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#### **ABSTRACT**

#### On Oral Health-Related Quality of Life in Swedish young adults

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Young adults in Sweden have grown up with dental care free of charge until the age of twenty. Their self-perceived oral health has been reported as being good, but rapid changes in society have led to a weaker economic situation for many young adults, which may influence their dental attendance and priorities concerning oral health and oral health care. The overall aim of this thesis was to explore the views of young adults on dental care, oral health and Oral Health-Related Quality of Life (OHRQoL).

The thesis is based on four scientific papers which all apply a qualitative approach. In Paper I, the views of young adults on dental care were explored. Paper II investigated the views of young adults on their oral health and OHRQoL. In Paper III, measures of OHRQoL were described and analysed from a public health perspective, and in Paper IV, the views of young adults on the relevance of three measures of OHRQoL were explored. In Paper I, II, and IV, data collection was performed through qualitative interviews. The selection of informants was strategic with reference to age (21-29 years), sex and education. For Paper III, a literature search for OHRQoL measures was made in the PubMed database. The data in Paper I was analysed in accordance with the constant comparative method (inspired by Grounded Theory), and in Papers II, III and IV, qualitative content analysis was used.

The results showed that young adults were satisfied with the dental care that they had received but reported specific views and demands on dental care (Paper I). They perceived their oral health as good, but an array of oral health problems was described (Paper II). The young adults' perceived control of their OHRQoL depended on their future prospects of oral health, in relation to their perceptions of their past and present oral health. In Paper III, the search for measures of OHRQoL in the PubMed database generated 22 measures. The measures were analysed with regard to their theoretical framework and in relation to four principles of health promotion. Some elements of public health principles were found in all the measures, but most of them originated in disease-oriented theories. The occurrence of oral problems was reflected in young adults' views on the measures of OHRQoL (Paper IV). The analysed measures were deemed to have both advantages and disadvantages but to be fairly equal.

The conclusions are that young adults' OHRQoL was dependent on their earlier experiences of dental care and their former and present oral health, as well as their future prospects regarding oral health. Elements of public health principles were present to a varying degree in all the measures of OHRQoL. Young adults regarded the frequently used measures of OHRQoL as being equal. The measures were mainly disease-oriented and no specific measures had been developed for young adults.

Key words: measures, oral health, quality of life, young adults

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#### SAMMANFATTNING PÅ SVENSKA

#### Munhälsorelaterad livskvalitet hos unga vuxna

Unga vuxna i Sverige har vuxit upp med fri tandvård till och med det år de fyller 19 år och de upplever ofta en god munhälsa. Snabba samhällsförändringar har bl a medfört sämre ekonomi för många unga och detta kan ha påverkat deras tandvårdsbesök och deras prioriteringar vad gäller tandvård. Det övergripande syftet med avhandlingen var att utforska unga vuxnas syn på tandvården, deras munhälsa och munhälsorelaterade livskvalitet (OHRQoL).

Avhandlingen baseras på fyra studier. I Studie I undersöktes unga vuxnas syn på tandvården. Studie II undersökte och beskrev unga vuxnas syn på sin munhälsa och OHRQoL. I Studie III beskrevs och analyserades mätinstrument för OHRQoL ur ett folkhälsoperspektiv och i Studie IV beskrevs hur unga vuxna ser på tre mätinstrument för OHRQoL. I Studie I, Studie II och Studie IV samlades data in genom kvalitativa intervjuer. Urvalet var strategiskt i förhållande till ålder (21-29 år), kön (hälften kvinnor) och utbildning (gymnasienivå/mer). De flesta deltagarna i studierna besökte tandvården regelbundet. I Studie III gjordes sökningar i databasen PubMed för att finna mätinstrument för OHRQoL.

Data i Studie I analyserades genom komparativ metod som är inspirerad av "Grounded Theory". I Studie II, Studie III och Studie IV genomfördes dataanalysen med kvalitativ innehållsanalys.

Resultaten visade att unga vuxna var nöjda med den tandvård de erhållit men att de hade speciella önskemål och krav på denna (Studie I). Unga vuxna beskrev sin munhälsa som god men angav trots det en mängd olika munhälsoproblem. Deras upplevda kontroll över sin OHRQoL var relaterad till deras syn på sin framtida munhälsa i relation till tidigare erfarenheter av tandvården och synen på sin egen munhälsa (Studie II).

I Studie III genererade datasökningen 22 mätinstrument för OHRQoL. Mätinstrumenten analyserades utifrån deras teoretiska utgångspunkter och i relation till fyra principer för folkhälsoarbete (empowerment, medinflytande, holism, rättvisa). Aspekter av de fyra principerna återfanns i varierande grad hos alla mätinstrumenten varav de flesta hade sin utgångspunkt i sjukdomsinriktade teorier. I Studie IV framkom att de unga vuxnas upplevelse av sin egen munhälsa hade betydelse för deras syn på de tre undersökta mätinstrumenten för OHRQoL. Alla mätinstrumenten ansågs ha föroch nackdelar men bedömdes som ungefär likvärdiga.

Konklusionen är att unga vuxnas OHRQoL är beroende av deras tidigare erfarenheter från tandvården och deras tidigare och nuvarande munhälsa samt i deras syn på sin framtida munhälsa. Principer för folkhälsoarbete uppfylldes i varierande grad i analyserade mätinstrument för OHRQoL och unga vuxna ansåg att mätinstrumenten var ungefär likvärdiga. Mätinstrumenten var i huvudsak sjukdomsinriktade. Det saknas ett speciellt instrument för att mäta unga vuxnas munhälsorelaterade livskvalitet.

#### LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- Johansson, G., Fridlund, B. (1996) Young adults' views on dental care – a qualitative analysis. Scand J Caring Sci 10:197-204.
- II. Johansson, G., Östberg, AL. Oral health related quality of life in Swedish young adults. Submitted December, 2014.
- III. Johansson, G., Söderfeldt, B., Wärnberg Gerdin, E., Halling, A., Axtelius, B., Östberg, A-L. (2008) Measuring oral health from a public health perspective.
  Swed Dent J 32:125-137.
- IV. Johansson, G., Söderfeldt, B., Östberg, AL. Young adults' views on the relevance of three measures for oral health-related quality of life.
  Int J Dent Hyg. 2014 Nov 14. doi: 10.1111/idh.12107.

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#### **ABBREVIATIONS**

OHRQoL Oral Health-Related Quality of Life

QoL Quality of Life

PDS Public Dental Service

WHO World Health Organization

OHIP Oral Health Impact Profile

OIDP Oral Impacts on Daily Performances

OHQoL-UK Oral Health-Related Quality of Life-UK

#### 1 INTRODUCTION

Since several decades, Swedish children and adolescents have enjoyed free dental care until the year they reach the age of twenty (SOU, 1998). It has been reported that many young adults refrain from seeking dental care when they are no longer entitled to it for free (Nordenram, 2012). They may have other priorities, such as housing, clothes and leisure time activities (Östberg et al., 2010). Most young adults have good self-perceived oral health; however, there are indications that oral health problems are unequally distributed (Nordenram, 2012). Little is still known about which factors young adults consider as important for their oral health and Oral Health-Related Quality of Life (OHRQoL). Studies focusing on the views of young adults of their oral health, oral health needs and preferences are needed for the planning of dental care. For this purpose, a deeper understanding of the experiences and expectations of OHRQoL of young adults was the focus of this thesis.

#### 1.1 Health and Quality of Life

#### 1.1.1 Health

Health is a broad concept with many different definitions. It has traditionally been described from a pathogenic, biomedical perspective as the absence of disease (Boorse, 1977). Already in 1948, the World Health Organization (WHO) defined health as a broader concept, as "a state of complete physical, mental and social well-being, not merely the absence of disease and infirmity." (WHO, 1948). Later, the health concept was developed and health has been described as a resource for an individual's ability to live a good life (WHO, 1986), and as a dynamic concept (Üstün & Jakob, 2005). A prominent example is the concept of Sense of Coherence (SOC), developed by Aaron Antonovsky, using a salutogenic orientation for how to reach and maintain health (Antonovsky, 1987). Antonovsky regarded health as a dynamic concept that moves between the extremes of good and bad on a continuum.

Likewise, in Sweden, Nordenfeldt (1995) defined health as a dynamic, holistic concept that varies over time; however, he also related it to the individual's ability to act in order to attain his/her vital goals. Further, Nordenfeldt considered health and disease as two different concepts, making it possible to experience disease and health at the same time. For example, an

individual may experience health despite having a disease, if the disease does not constitute an obstacle to the individual to reach his or her ultimate goal for daily living. It is also possible to experience ill health without having a disease.

#### 1.1.2 Oral health

The concept of oral health, as well as the concept of general health, has undergone obvious changes during the past decades. Physical aspects of the mouth, like the absence of disease, have dominated the views on oral health for a long time (National Library of Medicine, 1965). Viewing the mouth as a solely biological construct excludes the impact of mental and social aspects. The views on oral health have gradually changed and the focus has shifted from a biologically defined disease concept to a multidimensional holistic perspective, including physical, mental and social aspects (Gift & Atchison, 1995; Locker 1997). There has also been a long tradition of separating the mouth from the rest of the body (Locker 1997), but The World Oral Health Report from 2003 concluded that oral health is integral with general health and well-being (Petersen, 2003). Consequently, it is important to connect the mouth with the rest of the body and with the body to whom the mouth belongs (Surgeon General Report, 2000). Dolan (1993) defined oral health from a functional aspect dealing with the individual's ability to reach a goal through having "a comfortable and functional dentition, which allows individuals to continue in their desired roles." WHO (Petersen, 2003) presented a definition of oral health which describes it as being "free of chronic oro-facial pain, oral and pharyngeal (throat) cancer, oral tissue lesions, birth defects, such as cleft lip and palate, and other diseases and disorders that affect the oral, dental and craniofacial tissues, collectively known as the craniofacial complex" (Petersen, 2003). A Swedish consensus conference concluded that oral health is a part of general health and contributes to physical, mental and social well-being with experienced and satisfactory oral functions in relation to the individual's conditions and absence of diseases" (The Swedish Dentist Association, 2003). Many explanations of the concept of oral health have their origin in the negative consequences of oral disease. After a great deal of criticism of the existing theories of oral health for describing the effects of oral disease more than of oral health, MacEntee (2006) and Brondani & MacEntee (2014) suggested an existential oral health model. In this model, oral health was described as a dynamic concept that is sensitive enough to reveal how positive aspects can also influence OHRQoL (Figure 1).

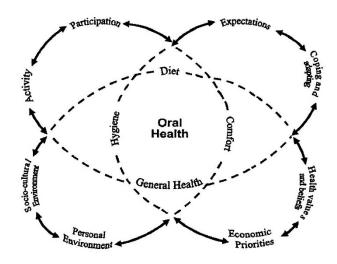


Figure 1. Refined model of oral health. Reproduced by permission from Springer. Brondani & MacEntee 2014. Quality of life research 2014;23:1093.

### 1.1.3 Quality of Life and Health-related Quality of Life

Quality of Life (QoL) is a frequently used concept, often in connection with health measurements in the field of dentistry and medicine. QoL has been described as synonymous with "life satisfaction," but there is no consensus regarding the definition (Moons et al., 2006). The concept of Health-Related Quality of Life (HRQoL) is described as a wider concept than health but subordinate to QoL, as it is used to describe quality of life within the area of medicine (Andersson & Buckhardt, 1999). Locker (1997) formulated the concept of QoL in a single question: "How good is your life for you," in contrast to the more attribute-based approaches of QoL, such as good income, social support and meaningful employment.

#### 1.1.4 Oral Health Related Quality of Life

Within dentistry, there is a corresponding concept to Quality of Life: Oral Health-Related Quality of Life (OHRQoL). This is a subjective concept, which is based on the assumption that aspects of oral health affect the individual's QoL. OHRQoL aims to measure individuals' subjective experiences of their quality of life in relation to their mouth and teeth. Gift et al. (1997) described OHRQoL as a multidimensional concept. Inglehart & Bagramian (2002) suggested that a person's OHRQoL is her or his

assessment of how the following four different groups of factors affect personal well-being: functional factors, psychological factors, social factors, and the experience of pain and discomfort (Figure 2). Further, this definition is considered to provide knowledge about how OHRQoL can be measured and used in clinical work and research. The four factors of OHRQoL described above are tied to the function of the person, the situation and the interaction between these. This means that an individual's cultural background, past and current experiences of oral health and care, state of mind and views on the future will influence the response to different situations. According to Gift et al. (1997), OHRQoL may be conceptualised as an integral part of general health, as it has an obvious overall impact on an individual's health and well-being.

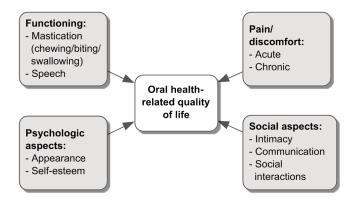


Figure 2. The main components of OHRQOL. Reproduced by permission of Quintessence Publishing. Inglehart & Bagramian. 2002. Oral Health-Related Quality of Life. p. 3. Quintessence Publishing Co, Inc.

## 1.1.5 Measures of Health-Related Quality of Life and Oral Health-Related Quality of Life

A large number of instruments for measuring both Quality of Life (QoL) and Oral Health-Related Quality of Life (OHRQoL) have been developed during the past decades. Frequently used generic instruments for measuring health are, for example, the SF-36 (the Short Form of medical outcomes studies) containing 36 items (Ware et al., 1981), and the EQ-5D (the EuroQuol-5D), a measure of health status from the EuroQol Group containing 16 items (Rabin and de Charro, 2001). However, instruments for the assessment of general

health do not discriminate well for oral health and disease (Brennan & Spencer, 2004).

Examples of OHRQoL measures that have been used and validated in many contexts are the General Oral Health Assessment Index (GOHAI), containing 12 items (Atchison & Dolan, 1990), the Oral Health Impact Profile (OHIP-49) containing 49 items (Slade and Spencer, 1994), the Oral Impacts on Daily Performances (OIDP), (Adulyanon and Sheiham, 1997) containing eight or nine items in alternative versions, and the Oral Health-Related Quality of Life-UK (OHQoL-UK), (McGrath et al., 2000) containing 16 items. In 1996, a conference was held at the University of North Carolina with the aim to "examine methods for measuring oral health-related quality of life, with the long-term objective of promoting the use of those measures in oral health outcomes research" (Slade, 1997). One aspect of the specific aims was to evaluate existing measures of Oral Health-Related Quality of Life on the basis of their theoretical framework. However, the measures were criticised for being too focused on disease, as many of them measure the negative aspects of oral disease rather than the positive effects of oral health as a resource for being able to live a good life. Locker (2007) questioned what OHRQoL instruments really measure. He stated that one problem is that OHRQoL is not clearly defined and therefore difficult to measure. Moreover, the definition may be modified over time due to changes in the societal context. Further, the difference between assessing oral health and OHROoL is not always clarified in the measures. Locker (2007) also suggested that a questionnaire assessing OHROoL should contain items dealing with aspects of daily life of importance to the target population.

Since the first measures for assessing OHRQoL were developed about 30 years ago, an array of different measures has been developed for this purpose. Over the years, the health concept as well as the view on quality of life, has developed. The OHRQoL measures originated in the actual view on how aspects of oral health could have impact on an individual's OHRQoL. The theory behind the first instruments was mainly disease-oriented. This theory originated from the World Health Organization (WHO) document "International classification of impairments, disabilities and handicaps: a manner of classification relating to the consequences of disease" (WHO, 1980). This perspective is based on sick-role theories (Juul Jensen, 1985) and thereby focused more on disease than on health. OHRQoL instruments developed in accordance with this theory have been described as holistic, as they deal with physical, mental and social aspects, but the focus is still on dental disease. Measures built on this theory are, for example, the OHIP-49 and the OIDP.

A few measures, like the GOHAI and the OHQoL-UK, contain items with both positive and negative aspects of oral health that may impact a person's OHRQoL. They have theoretical starting points that emanate from a synthesis of the literature in combination with expert judgements and results from qualitative studies. The existential model of oral health by MacEntee (2006) and Brodani and MacEntee (2014) could serve as a more relevant theoretical framework for OHRQoL measures. Some instruments, such as the GOHAI and the OHQoL-UK, are more in accordance with this theory, as items about the positive aspects of oral health are included in these measures. This is also the view of OHRQoL applied to this thesis.

Initially, these instruments were developed for adults and elderly individuals, but later on, measures were also developed for children and parents, like the Child Perceptions Questionnaire, CPQ 11-14, containing 36 items (Jokovic et al., 2001), the Family Impact Scale (FIS), containing eight items (Locker et al., 2002), and the Parental Caregivers Perceptions Questionnaires (P-CPQ) with 33 items (Jokovic et al., 2003), the Early Childhood Oral Health Impact Scale (ECHHIS) with 13 items (Thomson et al., 2014), and The Child Health Utility 9D (CHU9D), containing nine items (Page et al., 2014). There are no measures especially developed for adolescents over 14 years of age, or young and middle-aged adults, but the available instruments have been used for these age groups. Locker & Miller (1994) found that young adults as well as older people reported adverse OHQoL. However, during several decades there has been an improvement in self-reported oral health among young adults in Sweden (Nordenram, 2012). Epidemiological compilations of adults' clinical oral health in Sweden are scarce today.

Some of the existing measures, namely the GOHAI, the OHIP-49, the OIDP and the OHQoL-UK, have been translated into Swedish and adapted to Swedish conditions (Hägglin et al., 2005; Larsson et al., 2004; Östberg et al., 2008; Hakeberg, personal communication, 2010). The measures were all developed between 1990 and 2000 and have been commonly used and validated. In this thesis, three measures, the OHIP-49, the OIDP and the OHQoL-UK, were explored by young adults concerning their relevance to the age 21-29 years.

## 1.1.6 Public health, health promotion and oral public health

The concept of public health has been defined by Acheson (1998) as "the science and the art of preventing disease, prolonging life, and promoting health through the organised efforts of society." As a consequence of the

development of the health concept, the concept of public health has been broadened. One part of public health is health promotion, which comes from a positive salutogenic approach of health and well-being (Naidoo, Wills, 2009). In 1986, "The New Public Health" was described and defined as "the process of enabling people to increase control over and to improve their health." This definition emanates from the Ottawa Charter, which is a declaration from an international conference on health promotion (WHO, 1986). The development of the concept of health promotion brought about an expected active role for the individual in the process of attaining good health. The methods used are therefore empowering, which involves support for the individual to acquire knowledge and skills to make their own healthy choices. Another important goal for health promotion is to close the gap in health between individuals and to reach equity in health. Health promotion involves an individual lifestyle perspective, but also a structural perspective that includes social, environmental and political aspects.

A definition of oral public health made by Downer et al. (1994) was inspired by Acheson's definition of public health: "Oral health is the science and art of preventing oral disease, promoting oral health and improving the quality of life through the organised efforts of society." This means that clinical interventions are not enough to reach the goal of oral health. Social, environmental and political changes are also required, which means that knowledge from allied areas, like sociology and psychology, are needed to attain this goal.

#### 1.2 Young adults

#### 1.2.1 Young adults' living conditions

The living conditions for young adults have gradually changed in Western countries during recent decades. The rapid development in economy and technology has led to a change in the labour market that has resulted in unemployment or poor employment conditions, especially for young people without higher education (Lager et al., 2012). Because of their poor economy, more young adults continue to live with their parents for financial reasons. This has postponed the transition from childhood to adulthood (Arnett, 2007; Stone et al., 2011). The Swedish National Health Report found that the difficulty of finding a job has led to more young adults studying in higher education, but there are also more individuals who neither study, nor have a job (Lager et al., 2012). In parallel with these changes, poorer self-rated mental health has been reported among young adults in Sweden, especially by young women from early teens to the age of 25. The reasons for this are

unclear (Lager et al., 2012). However, an increasing level of individualisation (that emphasises individual well-being and self-realisation), together with fewer job opportunities, may have impacted the mental health and well-being of young adults. Worries about personal appearance and school performance are strong, especially among young females. These aspects were also considered as possible factors behind the increasing prevalence of ill health in this age group (Lager et al., 2012).

#### 1.2.2 Young adults in dentistry

Young adults in Sweden have to pay for their dental treatment from the year they turn 20; accordingly, dental care is free of charge until then. In one region, Västra Götaland, dental treatment is free of charge up to the end of the year the individual turns 24 (Västra Götalandsregionen, 2014), and such benefits are also introduced and/or planned in other counties. All adults in Sweden >19 years of age are offered a subsidy for dental costs once a year, a subsidy to be used mainly for check-ups and preventive care. The size of this subsidy is higher for individuals below 30 years of age and above 74 years. The structures of the oral health care systems are similar in the Nordic countries (Widström & Eaton, 2004; Widström et al., 2009).

A new capitation payment system, as a complement to the traditional fee-forservice payment system, has been implemented in the Swedish Public Dental Service. Since 2009, the terms are the same in all Swedish counties (SFS 1998:1337). Capitation payment means that the patient pays a fixed fee in advance for a fixed period of time. The patient's oral health and dental care needs determine the size of the fee (1997/98:112). The aim of the capitation system is to promote oral health and to reduce the expenses for dental care. It has been shown that the capitation system results in more preventive care and less need for restorative treatment than the fee-for-service system (Johansson et al., 2007; Andrén Andås et al., 2014). Subsidies for dental treatment for young adults (SOU 1998) and capitation payment may increase the use of dental care by young adults. Capitation may also increase the application of oral health promotion activities for this age group. It has been criticised as favouring young adults with established good oral health habits but, on the other hand, the objective is to encourage all patients to improve their oral hygiene and eating habits (Johansson, 2007).

The economy of a country and dental subsidies impact on dental attendance, which, in the long run, may influence oral health levels in the population. Middle-aged and older people in Sweden visit a dental clinic more often and more regularly than young adults (Försäkringskassan, 2012). In Sweden,

there has been a decrease in dental care attendance among young adults when they are no longer entitled to dental care free of charge (Nordenram, 2012). Other reasons, in addition to the economic ones, for less frequent attendance may be better oral health among young adults, and thereby less of a perceived need (Lundegren et al., 2004), or that young people have other priorities (Östberg et al., 2010).

## 1.3 Needs for research in the field and rationale for the thesis

According to Carr (2001), Health-Related Quality of Life is the gap between our expectations of health and our experience of health. In agreement with Carr's reasoning, the different expectations people have influence their views on OoL, regardless of their clinical status. In addition, patient satisfaction has been found to impact on an individual's QoL and to be more related to quality of life than clinical measures (Skaret et al., 2005). Therefore, it is important to explore young adults' expectations of future dental care, as well as their experience of received dental care to get a picture of their OHRQoL. Rapid changes in society have an impact on the situation of young adults, including their oral care habits, and without actual knowledge about their needs and priorities, it may be difficult to communicate and meet their needs (Bradshaw, 1972). Qualitative studies capture the perspectives of individuals, mirror their lives from inside and provide information that a quantitative approach might miss (Charmaz, 2006). Furthermore, qualitative studies have been recommended as a complement to quantitative methods for exploring individual OHROoL (Locker & Allen, 2007; MacEntee, 2006).

#### 2 AIMS

#### 2.1 General aim

The overall aim of the thesis was to explore young adults' views on dental care, oral health and Oral Health-Related Quality of Life (OHRQoL).

#### 2.2 Specific aims

- To determine young adults' views on dental care (Paper I)
- To describe and explore Swedish young adults' views on their oral health and their Oral Health-Related Quality of Life, OHRQoL (Paper II)
- To describe and analyse measures for Oral Health-Related Quality of Life (OHRQoL) from a public health perspective (Paper III)
- To explore the views of young adults on the relevance of three measures of Oral Health-Related Quality of Life (Paper IV)

#### 3 METHODS

#### 3.1 Design and methodological approach

This thesis is based on four scientific papers which all apply a qualitative approach with different theoretical frames and analytical methods.

#### 3.1.1 Paper I

The aim was to interview young adults' about their views on dental care, to deepen the understanding of their experiences and concern about dental care. The theoretical framework for the method used was the constant comparative method (Glaser & Strauss, 1967) which is an analytical process within the Grounded Theory methodology.

#### 3.1.2 Paper II

The aim was to describe and explore the views of Swedish young adults' views on their oral health and their Oral Health-Related Quality of Life (OHRQoL). The analysis was based on open-ended semi-structured interviews. The theoretical frame of reference was qualitative content analysis (Krippendorff, 2013; Graneheim & Lundman, 2004).

#### 3.1.3 Paper III

The aim was to describe and analyse multidimensional aspects of available measures for OHRQoL with respect to their theoretical origins. The method used was qualitative content analysis (Krippendorff, 2013) from a fixed theory framework. This framework was the principles for the evaluation of public health work, described by WHO (Rothman, 2001)

#### 3.1.4 Paper IV

The aim was to explore the views of young adults on the relevance of three measures of OHRQoL. The theoretical basis for the method used was qualitative content analysis (Krippendorff, 2013; Graneheim & Lundman, 2004).

#### 3.2 Material

#### 3.2.1 Qualitative interviews I

For Paper I, a strategic selection was made of young adults receiving regular dental care, with reference to age, sex, residence, education and use of private dental care or public dental service (PDS). This selection was made to obtain a broad and deep variation of the data. The study population consisted of eleven young adults aged 21 to 29 years (not having reached 30 years), six of whom were males and five females. Five were patients at a (PDS) clinic and the remaining six were treated at a private dental clinic. The head of the PDS clinic and the dentist at the private clinic gave permission to select informants from the patient registers.

#### 3.2.2 Qualitative interviews II

For Paper II and Paper IV, a strategic selection of informants was made with regard to age, sex, education, and use of private dental care or PDS. Most informants were regular dental attendees and the selection was made in cooperation with staff at the dental clinics. The sample comprised 16 young adults eight of whom were 21-25 years old and eight were 26-29 years. Nine informants were females and seven were males. Eight of the informants had completed grammar school and eight had a university degree or were students at a local university. Four of the informants attended one private clinic and ten were patients at one PDS clinic.

#### 3.2.3 Measures for OHROoL

The material used in Paper III was scientific papers presented in international peer reviewed journals concerning measures for Oral Health-Related Quality of Life.

#### 3.3 Data collection

#### 3.3.1 Qualitative interviews I

Data collection for Paper I was performed through open-ended semistructured interviews and was preceded by a pilot study in which five persons participated. The intended informants in the main study were contacted by phone and asked if they were willing to participate. Like in the pilot study the interviews were conducted by the author of this thesis. The interviews contained four direct questions viz.:

- What does a patient expect from a visit to a dental clinic?
- What does a patient deem as important in connection with a dental appointment?
- What has the patient experienced as positive or negative respectively in connection with a visit to a dental clinic?
- In which aspects of dental care does the patient desire change?

The informants were encouraged to give rich descriptions. Each interview lasted 20-40 minutes, was audiotaped and transcribed by the interviewer. The gathering of data was discontinued when nothing new could be gleaned from the interviews.

#### 3.3.2 Qualitative interviews II

Data collection for Paper II and Paper IV started after permission from the heads of the two dental clinics. The intended informants were initially contacted by mail and asked if they were willing to participate in the study. They were then all contacted by phone and asked again to participate in the study and for those who responded affirmatively, an appointment for an interview was arranged. They were asked to read and fill in two self-reported questionnaires at home (the OHIP-49 and the OHQoL-UK) and bring the filled-in questionnaires to the interview session. The third measure, the OIDP, which is constructed for personal interviews, was responded to orally during the interview. All three measures had been translated into Swedish and validated for Swedish conditions (Larsson et al., 2004; Östberg et al., 2008; Hakeberg, personal communication 2010). The purpose of asking the informants to complete the measures before the interview session was to introduce them to the measures that would be discussed during the interviews. The data collection was performed by the author of this thesis from June to December 2010 in undisturbed environments away from dental clinics. The interviews were based on interview guides and lasted altogether 25-50 minutes. In step 1, questions concerning the young adults' views on the concepts of oral health and QHRQoL were explored. Furthermore, their experiences of previously received dental care, their present oral health status and how their expectations of their future oral health-related life were explored. In Paper II the following entrance questions were asked:

- What does Oral Health-Related Quality of Life mean to you?
- What are your experiences from dental visits?
- What is your own opinion of your mouth and your teeth?

- Can you describe how your mouth and your teeth impact on your quality of life?
- How do you perceive the situation concerning your mouth and teeth in the future?

In step 2 on the same occasion, a second interview guide was used. This comprised questions about the young adults' opinions of the content of the three measures for OHRQoL and their feelings when responding to the items.

This interview guide was based on the OHIP-49, the OIDP and the OHQoL-UK and the main entry questions were as follows:

- What is your opinion of the content in the measures?
- What do you think about answering the questions?

#### 3.3.3 Measures for OHRQoL

The data collection in Paper III was carried out through a database search in the PubMed database (National Library of Medicine, 2006). The MeSH terms used were "dental health" and "oral health" in combination with "self-rated", "self-assessed", "subjective", "measures" and "Quality of Life" (Table 1). The search results produced 3009 papers but were reduced after removing duplicates and hits that did not meet the qualifications. Twenty-two measures of OHRQoL were identified. A complementary search was performed in the reference lists of obtained articles. Only papers written in English were included in the study. The search terms were broad and hits generating articles not covered by the aim were excluded, on the basis of their abstracts. The search for publications covered the time period January 1st 1990 to December 31st 2006.

Table 1. The results of search in PubMed database.

Search-terms and combinations	Number of hits
Oral health and self-rated	24
Oral health and self-assessed	21
Oral health and subjective	98
Oral health and measures	437
Oral health and Quality of Life	16

#### 3.4 Data analysis

#### 3.4.1 Paper I

In Paper I, data were analyzed using the constant comparative method that allows the researcher to generate a theory about a more or less unknown phenomenon from the gathered data and to describe and explain a situation or process. The method can be used to explain a situation through identifying a story line by linking concepts and processes. The data i.e. the informants' descriptions were analyzed, coded and categorized in order to finally emerge as core categories. The analysis started at the same time as the first interview was performed, so that the data analysis was carried out in parallel with the interviews. The analysis was performed in three steps. Firstly an open coding process was performed. Substantive codes (Starrin et al., 1991) that emerge by comparing data were then searched, identified and categorized. The next step was axial coding, which means that connections between different categories were sought. In the last step, selective coding, that is, the core content in the data was systematically sought for. Thus links between the categories were found and a theoretical model emerged.

#### 3.4.2 Paper II

The method for the data analysis in Paper II was qualitative content analysis in accordance with Graneheim & Lundman (2004). This method can be applied at different levels. The manifest part is what is visible and obvious, while the latent content mirrors the underlying meaning of the text. A deeper interpretation is thus required to retrieve the latent content. Manifest content as well as latent content was searched for in this study. interviews were transcribed by the author of the thesis and carefully read through to obtaining a sense of the whole. The data were then organized and notes were written in the margins in the interview protocols. Statements with similar content were reflected upon and compared in their respective context. The statements were grouped together into meaning units that is "words or sentences that are related to each other through their content or context" (Graneheim & Lundman, 2004, s 106). The meaning units were condensed into content categories. Condensation means shortening of text while preserving the core, and content categories express the manifest content of the text. The categories were discussed and reflected upon several times by the two authors. The latent content was sought and finally the authors agreed on an overall theme describing the main content of the data.

The categories were discussed and reflected upon several times between the two authors. The latent content was sought and finally the authors agreed of an overall theme describing the main content of the data.

#### 3.4.3 Paper III

The analysis in Paper III was initially made by searching for the theoretical starting-points in the different OHRQoL measures. Secondly, the measures were evaluated according to four basic principles for health promotion developed by a WHO working group (Rootman, 2001) on the basis of public health ideas. These principles were operationalized for measuring the instruments agreement with public health work (health promotion). The principles used were empowerment, participation, holism and equity. Thus, the measures were scrutinized in relation to whether they contained any element of health promotion. Empowerment was determined through the reading comprehension level and the context of the population where the measures were developed and applied. The reason for choosing reading comprehension was to assess health literacy (that is cognitive and social skills that motivate individuals to gain access to, understand use information that promotes and maintain health), which is a foundation for empowerment (Nutbeam, 2000). The establishment of participation was dependent on the influence of lay persons on the design of the different measures during their development. Whether the holism criteria were met was assessed on the basis of the extent to which a measure contained items about physical, mental, social and spiritual aspects. The equity perspective in the measures was assessed on the basis of whether the measures were validated and available for different populations. The equity aspect was also evaluated based on whether the measures were available for different populations irrespective of age, gender, ethnicity, and social class.

#### 3.4.4 Paper IV

The method for the analysis in Paper IV was qualitative content analysis guided by Graneheim & Lundman (2004). The manifest content as well as the latent content was searched for. Firstly, the interviews were transcribed and carefully read through by the authors and meaning units were marked in the interview protocols. This process aimed at obtaining and understanding the meaning of the data in their context. Thereafter, open coding followed, whereby the meaning units were condensed, abstracted and labelled with a code. The codes were reflected upon and categorized into two main categories and six sub-categories mirroring the manifest content. Finally, the underlying latent meaning was formulated in a theme agreed by all authors.

#### 3.5 Ethical considerations

When the study for Paper I was performed in 1996, the rules for ethical reviews required no application to an ethical board. However, ethics were given high priority and the informants were informed that the participation was voluntary and that the data would be treated confidentially. For Paper II and Paper IV, the Regional Ethical Review board in Lund approved the studies, Reg. no.2009/124. Information about the aims and the process of the studies was given to the informants and all participants provided written consent. The data in Paper III were collected from papers published in scientific journals. Most authors stated that the study protocols were ethically reviewed. A few papers did not bring up ethical issues; however, according to the descriptions of the methods, the ethical requirements were met. A careful database search aimed to include all relevant measures in the field of OHROOL so that no measures were left out.

#### 4 RESULTS

The results of the studies in the thesis captured the perspectives of young adults regarding dental care, oral health, Oral Health-Related Quality of Life (OHRQoL) and measures of OHRQoL.

#### 4.1.1 Paper I

Paper I explored young adults' views on dental care.

The results from the interviews about the views of the adults on dental care were summarized in a model showing four different functions of the care from the patients' perspective. These functions were: "information", "treatment", "service as a whole" and "check-ups" (Figure 3). The informants had different attitudes to these functions described in two core categories: "costs in relation to dental care" and "attitude to given functions within dental care". Cost, though considered high, was more or less accepted. Costs for check-ups and treatment were accepted and were seen as a responsibility of the dental staff. On the contrary, costs for information about oral hygiene were more contested and service as a whole was taken for granted. The attitudes to the four functions were found to be "active", which means that the informants wished to be informed and to participate, or "passive", that is when the informants did not want to influence the dental care and preferred to hand over the responsibility to the dental staff. Patients with an active attitude wanted to play an active role, both in terms of decision-making and information about what happened in their mouth during the treatment. Information about preventive actions were questioned especially when the patients had to pay for it and the information was perceived as routine or irrelevant.

# Active Information Treatment Active Information Treatment Passive Service as a whole Check-ups

Figure 3. Young adults' views on dental care in Paper I.

#### 4.1.2 Paper II

Paper II described and explored the views of Swedish young adults' on oral health and OHRQoL.

The findings from the interviews were organized in manifest and latent content (Figure 4). The manifest content was sorted into three main categories: "Past experiences", "Present situation" and "Future prospects". The young adults' past experiences mirrored the informants' former oral health, symptoms and oral disease. It was found that young adults without any experiences of oral health problems did not reflect much on their previous oral health. Nevertheless, an array of different oral health problems like caries, irregular teeth, bruxism and trauma were reported. Experienced symptoms like shooting pain, pain from wisdom teeth, blisters in the mouth and injuries were also considered as troublesome. Contacts between the dental staff and the informants were described as both positive and negative.

The current situation was captured by describing the informants' self-perceived oral health, health habits and how their oral health impacted their social life. The oral health at present was regarded as favorable and the informants considered their knowledge of how to promote oral health as good. To taking care of ones' teeth was considered to be important but the informants were not always convinced that their oral hygiene was good enough, and to keep up a good standard of oral hygiene was considered difficult. The most prominent oral health related factors that had an impact on the informants' social life were aesthetic aspects; fresh breath and the ability to speak clearly but also being able to eat and enjoy food.

Future prospects were described as "beliefs about future oral health" and "worries about future oral health". One challenge for the future was to maintain the level of good health and it was expressed as a hope that the oral health would remain the same as the present state of health. Some informants thought that oral problems were something to deal with at the moment they occurred instead of worrying about them in advance. The described worries were poor control of oral hygiene and consequently "poor oral health in the future". Severe caries problems and traumas in the past were other reasons for worries. Another matter was the costs of dental care in the future. According to the informants one way to avoid high dental care costs could be to keep up good oral hygiene.

The latent content was formulated in a theme: "The perceived control of OHRQOL of young adults is dependent on their future prospects of oral health, in relation to their perceptions of past and present own oral health."

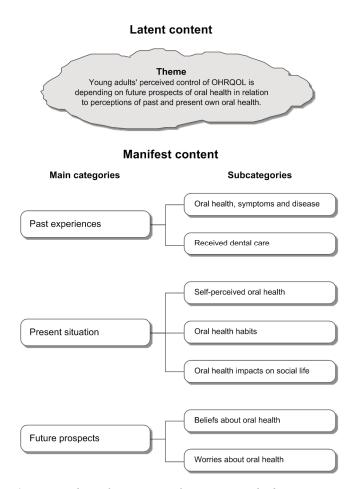


Figure 4. Latent and manifest content with categories and subcategories in Paper II.

#### 4.1.3 Paper III

Paper III aimed to describe various multidimensional measures for OHRQoL with respect to their theoretical starting-points and whether their application was in accordance with public health principles.

For six of the 22 scrutinized measurers the theoretical origins was Locker's theoretical framework on oral health (Locker 1988). The other 16 measures were based on literature reviews or/and on results from qualitative studies.

Some elements of the health promotion principles (empowerment, participation, holism and equity) were present in all the scrutinized measures (Table 2). Some aspects of empowerment and participation could be found in most measures, as they were based on interviews and consultations with patients or consumers.

If a measure was to be judged as holistic it had to incorporate physical and psychological as well as social and spiritual dimensions of health. The first three aspects were adequately covered by the measures, while the spiritual aspects were missing in all the measures. Another holistic aspect was well-being, which was present in four of the measures. Three of the measures, the GOHAI, the Dental Impact Profile (DIP, see Appendix) and the OHQoL-UK, included positive as well as negative aspects of oral health.

Equity aspects were present in all 22 measures. Most of the measures were initially developed for measuring impacts of oral diseases among older adults. However, a few were developed for younger patients. Three of the measures, the OIDP, the GOHAI and the OHIP-49 had been translated and validated for other cultural contexts and countries than those where they were originally developed.

 $\label{thm:continuous} \textit{Table 2. Empowerment, participation, holism and equity in measures for OHRQoL (see Appendix).}$ 

CRITERIA	MEASURES	
Empowerment		
Control	none	
Health literacy	GOHAI, OHIP	
Self-esteem	none	
Participation		
Lay perspective	SIDD, GOHAI, DIP, OHIP, DIDL, OIDP, OHQoLUK, CPQ8, CPQ11-14, FIS, P-CPQ, Child-OIDP	
Holism		
Physical aspects, Psychological well-being and Social well-being	SIDD, GOHAI, Dental Health Questions from the Rand Health Insurance Study, DIP, SOHSI, OHIP, DIDL, OIDP, OHQoL-UK, CPQ11-14, CPQ8-11, FIS, P-CPQ, Child OIDP	
Social aspects of health	OHQoL-UK	
Physical aspects of oral health	РОН	
Physical and Psychological aspects of oral health	OH-QoL	
Functional and Physical aspects of oral health	OHS	
Spiritual aspects	none	
Salutogenetic perspective	DIP, OHQoL-UK	
Equity		
Measure available and applicable for:		
Children, parents	POH, CPQ11-14, FIS, P-CPQ, CPQ8-10, Child-OIDP	
Elderly (65+)	GOHAI, DIP, SOHSI, OHIP, DIDL, OIDP, OH-QoL, OHQoL-UK, OHS	
Measure validated for:		
Ethnic minorities	GOHAI, DIP, SOSHI, OHIP, OH-QoL, OHQoL-UK	
Socio-economically deprived	SIDD, GOHAI, SOSHI, OHIP, DIDL, OHQoL-UK	
Measure available in different languages:	OHIP, GOHAI, OIDP, SOHSI, CPQ11-14, OHQoL-UK	

#### 4.1.4 Paper IV

The aim of Paper IV was to explore the views of young adults on the relevance of three measures of OHRQoL: the OHIP-49, the OIDP and the OHQoL-UK.

The three measures were all considered appropriate with regard to the relevance for measuring OHRQoL in young adults. The measures were considered to be fairly equal but to have different pros and cons. Clarity in the measures was found to be more important than other aspects, such as their length and the assessment period.

The results of Paper IV were described by a theme explaining the latent content: Young adults' own experiences were reflected in their views on the OHRQoL measures. This means that experiences of own oral problems and oral problems they considered as important for the age-group influenced the informants' views on the relevance of the measures. Two main categories emerged in the data: content appropriateness and construction of the measures. To have good self-perceived oral health without any experience of oral problems, so far, could make the informants deem the measures as being inappropriate and containing items dealing with problems that mostly occur later in life. On the other hand, some informants were worried about what might happen in the future especially when they were made aware of problems that were asked about in the measures (Figure 5).

Own experienced oral health problems, like pain in the mouth, eating problems or blurred speech, were represented in all three measures. Psychosocial aspects, like aesthetics, attracted a great deal of attention from the young adults. All three OHRQoL measures contained such items, but in the OHIP-49 and the OIDP, only negative aspects were asked for, while both positively and negatively formulated item could be ticked in the OHQoL-UK. The informants considered OHQoL to be related to self-confidence. There were items concerning the impact of oral health on social life in all three OHRQoL measures, but in the OHIP-49, the items were more detailed.

Three aspects of the construction of the measures emerged: clarity, length and assessment period. The measures were mostly regarded as easy to understand and fill in, but some respondents found the content to be complicated and difficult because of the wording and the extent of the measures. Another obstacle to completing the measures was the difficulty to understand items with positive aspects of health.

Irrespective of the varying numbers of items in the measures, the questionnaires were mostly regarded as easy and not too time-consuming to fill in. However, some informants stated the opposite – it took a long time to complete the measures. Some of the items required reflection and were therefore more burdensome to respond to.

The assessment period varied in the three measures from one year back in time (OHIP-49) to current status (OHQoL-UK), and there were different suggestions about the ideal length of the assessment period. However, remembrance of what happened one year ago was described as unreliable.

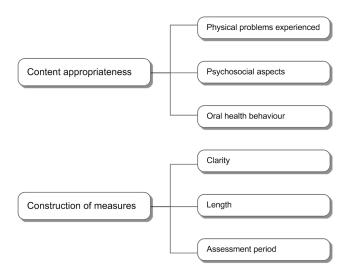


Figure 5. Themes and categories in Paper IV.

#### **5 DISCUSSION**

This thesis was undertaken to gain insight into how young adults view dental care, oral health and Oral Health-Related Quality of Life (OHRQoL). It was carried out in four studies with a qualitative approach. The importance and relevance of the subject for the target group have been confirmed in Paper I, II and IV. Paper III reflected the possibilities to describe the views of the target group in available measures of OHRQoL. The contribution from the studies to the understanding of the subject is summarised and discussed below.

#### 5.1 On the results

#### 5.1.1 Young adults and dental care

Young people's views on their dental care are mainly based on experiences from all their previous visits to dental clinics. In Paper I it was shown that the young adults were concerned about their influence in dental treatment and dental care costs. Further, the results indicated that the informants wished to participate in the decision-making regarding their dental care. This requires information and knowledge of possible treatment alternatives and preventive actions, and, for this, good communication between the dental staff and the patient is necessary. Likewise, Newsome & Wright (1999) stated that in addition to the patient's expectations, the caregivers' communication skills were important for making the dental patient satisfied with the dental care. Skaret et al. (2005) found that good personal relations between the patient and the dental staff were one of the most important factors for patient satisfaction. There is sparse new research about patient satisfaction with dental care, but changes to the relationships between staff and patients in dental care may have occurred since Paper I was published in 1996. For instance, nowadays, patient communication is generally included in the education of dentist and dental hygienist students (Donate-Bartfield, Lobb, Roucka, 2014). It was obvious from Paper II that the dental staff played an important role in giving patients support to adopt and retain favourable oral health habits. The wish for communication with the dental staff when visiting a dental clinic was also indicated in another Swedish study (Östberg et al., 2013). Contact with the dental staff was considered important in Paper I, but both positive and negative experiences were reported. Ericsson et al., (2012) found that the majority of 19-year-olds believed that they were taking good care of their teeth, but only three out of five regarded cleaning of the teeth as very important. This picture may persist into young adulthood, as many

attitudes and behaviour patterns originating in adolescence are further developed over the following years (Hendry & Kloep, 2002).

The opinions of the young adults about dental care costs were a recurring theme in the interviews in Paper I and in Paper II. The payment system for dental care has been changed since Paper I was published. In 1996, the patient had to pay for basic preventive care in relation to the required treatment, whereas nowadays in Sweden, preventive care is included in the basic examination (TLV, 2014). Although there are special subsidies for the dental care provided to young adults, they still consider dental care costs to be high and a cause of concern. This could be seen against the background of the changes in society that affect the economic situation of many young adults today. Aspects such as protracted study periods, the difficulty of finding employment and a high level of unemployment impact their economy (Lager et al., 2007). It was found that the young adults in Paper II considered that "taking care of" their teeth would reduce their dental need in the future and, by that, the cost of dental care.

Capitation payment has been introduced as a complement to the traditional fee-for-service payment system in Sweden (SFS 1998:1337), and has been shown to increase preventive care and reduce the need for restorative care (Johansson et al., 2007; Andrén Andås et al., 2014). The informants in Paper II mentioned this new payment system as a possibility to reduce dental care costs, but for individuals with large treatment needs, the fixed annual fee was considered to be too high. In a Swedish study (Östberg at al., 2013), it was found that perceived own oral health risks influenced the choice of payment system. Economic aspects were considered important and the informants weighed the benefits against the costs.

Most of the informants in this thesis were dental attendees. Richards & Armeen (2002) found that dental attendees have better oral health than non-attendees. This might have influenced their statements. Furthermore, socio-economic differences influence dental attendance and Listl (2012) concluded that inequalities in dental attendance are established already in childhood and remain throughout the person's life. However, the reasoning of the two informants who were non-attendees seemed to be about the same as that of the attendees.

#### 5.1.2 OHRQoL in young adults

It was found in this thesis that the views on OHRQoL among the informants were linked to experiences of previous dental care, which is in accordance

with the findings by Carr (2001) and Inglehart & Bagramian (2002). Moreover, the informants' perceptions of their present oral health and oral status, and views of their future oral health, were found to determine their OHRQoL. An array of components connected with the informants' OHRQoL was described in Paper II.

The own oral health was mostly considered by the informants to be good, although they reported different oral problems and symptoms. Some of the informants described previous severe caries problems, while others had no or little experience of the caries disease. The dental health in terms of dental caries is generally good among young adults in Sweden (Hugoson &Koch, 2008). However, oral health is differently distributed in different socioeconomic groups, where economically weak groups have poorer oral health (Molarius et al., 2014).

It was obvious from Paper II that aspects that impacted on the social life of young adults, like perceptions of appearance, were considered to play an important role. This was also regarded as impacting their self-confidence. The informants stated having "straight, white teeth" as the ideal. Malocclusion has been reported to have a negative impact on OHRQoL (Klages, 2004), and was one concern reported by the informants as compromising their appearance. The media and commercial advertising often stress the "ideal way of looking" (SOU 2006). The informants frequently discussed oral appearance, and one way to improve the appearance that has become popular in Sweden is dental bleaching. This can be performed by dental professionals but can also be done at home with self-care kits. However, the informants seemed to lack knowledge of the potential risks connected with bleaching (Kwon & Swift, 2014). Dental staff ought to give information on this issue. Moreover, the living conditions of young adults in Sweden and in other countries in the Western world have changed over the last decades with consequent effects, especially on the psychological health and economy of young adults (Lager et al., 2012).

The expectations of their future oral health differed among the young adults (Paper II). The informants who had experienced oral health problems had lower expectations than those with good self-rated oral health. This phenomenon may be related to adaptation. Adaptation, in this context, could mean that a person with poor oral health gets used to the situation and adjusts his/her expectations (Smith & Nolen-Hoeksema et al., 2008). This can be compared with the health theory of Nordenfelt (1995), in which health is dependent on whether a person can reach his/her vital personal goals. If the vital goals have been too ambitious and impossible to attain, it may be

necessary to reset the goals in order to achieve them. The model suggested by MacEntee (2006) and further developed by Brondani & MacEntee (2014) includes the aspect of adaptation and coping with impairment and disability in the field of oral health, and what that means for a person when assessing his or her oral health and OHRQoL. It is true that the theory of MacEntee (2006) and Brondani & MacEntee (2014) was developed on the basis of research among healthy old people, but the theory may be applied for younger ages as well.

Lack of control of oral hygiene was a reason for concern for the future among the young adults in Paper II. Although the informants considered that they knew how to take care of their teeth to avoid oral problems, they were unsure about their ability to manage oral hygiene in a proper way in the long run. Hugoson et al. (2007) found that individuals who received individual information and instruction about oral hygiene every second month improved their oral health more than those who received preventive treatment less frequently. This indicates that young people need to be empowered through knowledge and skills related to oral care. It may be of importance to consider the driving forces for young people, such as lower dental costs and improved appearance and freshness. In Paper I, the young adults queried information on oral hygiene matters, especially whether he/she considered it to be routine information or something that they had already been told.

# 5.1.3 OHRQoL measures for young adults

The use of OHRQoL measures has increased in recent years, according to the number of scientific publications on the topic. For example, a PubMed search in February 2015, using the search term "oral health and measures", generated 7414 hits, to be compared with 437 hits in 2006 when the data collection for Paper III was performed. Some new measures have been developed since then, but measures developed before the year 2000 still dominate the research in this field.

The principles of health promotion chosen for assessing the available measures for OHRQL in Paper III were empowerment and participation, holism and equity. They were chosen as they were considered to be applicable at an individual level. Originally, Rootman presented seven such principles (2001), but three of them (intersectorial, multi-strategic and sustainable) were omitted from the analysis as they mainly refer to the application of strategies for health promotion. Empowerment and participation were present to some degree in the analysed measures. These are goals that are considered important to attain in public health work

(Ottawa, 1996). Empowerment is "an approach that enables people to take charge of their lives" (Naidoo, Wills, 2009), which means to have enough knowledge and skills to control factors that affect health. If empowerment is ensured, it may strengthen the individuals' self-confidence and help them assume control of their situation. Aspects of equity, which were assessed as whether the measures were validated and available for different populations, were found in many of the measures. Equity in health is an important goal for health promotion (Ottawa, 1996). However, many new applications of the measures in different settings have been developed since the data collection for Paper III was carried out in the PubMed database.

Several of the measures analysed in Paper III have earlier been applied and validated among young adults, for instance by Skaret et al. (2004). Frequently used measures in research are the GOHAI (Atchison & Dolan, 1990), the OHIP-49 (Slade & Spencer, 1994) but also a short version of this measure, the OHIP-14 (Slade & Spencer, 1997), the OIDP (Adulyan & Sheiham, 1996) and the OHQoL-UK (McGrath & Bedi, 2000). Three of these measures were chosen in Paper IV to be explored with regard to their relevance for young adults (the OHIP-49, the OIDP and the OHQoL-UK), as they had been translated and validated for a Swedish context. The GOHAI has also been translated and validated for Swedish circumstances and could also have been used for this purpose. However, four measures might have been too burdensome for the informants to complete and familiarise themselves with.

While the OHIP-49 (Slade & Spencer, 1994) and the OIDP (Adulyanon & Sheiham, 1997) were based on a utilitarian disease-oriented theory of oral health, the OHQoL-UK (McGrath et al., 2000) was developed from openended qualitative interviews capturing both positive and negative aspects of OHRQoL. When assessing the measures (Paper IV), the young adults often had difficulties with the response options "positive" and "very positive". This created confusion, whereas the informants did not hesitate about items dealing with risk factors for oral disease. It was obvious that "positive health" was an unknown concept to the informants and that there was a need to explain that aspects of oral health may impact quality of life in a positive way. Previously, good oral health was primarily assessed as "having no cavities", which may have shaped young peoples' views and lead to the difficulties to relate to the positive aspects of oral health in this thesis (Östberg et al., 2002).

# 5.2 Methodological considerations

#### 5.2.1 Qualitative studies

In qualitative research, the researcher is interested in questioning and understanding the meaning and interpretation of phenomena (Guba & Lincoln, 1981). Further, qualitative research describes and interprets the nature of a phenomenon using words, while quantitative research measures "the numbers" of something and assesses, for instance, associations between variables (Berg, 2004). When considering a phenomenon from the informants' perspective, qualitative approaches may have several advantages over quantitative ones (Charmaz, 2006). The aim of qualitative studies is to deepen the understanding of human action (Dahlgren 2004). Qualitative research focuses on the experiences of individuals in everyday life, which, according to Berg (2004), are associated with emotions, motivation and empathy. Interviews in qualitative research are interactive and dependent on the communication between the interviewer and the informant (Krippendorff, 2013).

In Paper I, the method used aimed to generate a theory about how young adults regard the dental care that they have received. The constant comparative method that was used for the analysis is inspired by the method of Grounded Theory developed by Glaser and Strauss in the sixties (Glaser & Strauss, 1967). Theoretical sampling means that further data collection is based on concepts derived from already retrieved data, which decide what kind of data should be collected next and where to find them. This method of data collection is often used and recommended in grounded theory studies (Glaser & Strauss, 1967; Charmaz, 2006; Strauss & Corbin, 2008). However, in Paper I, the strategic sampling of informants aimed at providing a broad picture of young adults with regard to age, sex, education and the use of private dental care. Theoretical sampling may have provided greater variation of the data, but may also have been more difficult to perform for practical reasons.

There were some difficulties to recruit young adults for the interviews for Paper II and IV. Many of the regular dental attendees who were contacted and asked to participate were studying or working elsewhere in Sweden or abroad, while others reported being too busy or simply not interested. This may reflect the unstable situation of many young adults, which underlines the necessity to consider their needs in dentistry. However, those participating were interested in the subject and willing to share their experiences, thoughts and views. In epidemiological studies, reasons for non-participation have

been related, for instance, to lack of time in today's intense and fast everyday life (Galea & Tracy, 2007). However, in qualitative research, the understanding of a phenomenon is important, not how many people are interviewed.

Content analysis can, according to Krippendorff (2013), be both qualitative and quantitative, and "uncover patterns of human activity, action and meaning". Written documents (as in Paper III), as well as transcriptions of recorded verbal communication (as in Paper II and IV) can be used for data collection (Berg, 2004).

The data collection in Paper III was carried out through systematic sampling of scientific papers in the PubMed (National Library of Medicine, 2006) regarding measures of OHRQoL. PubMed is a comprehensive database including scientific publications from areas of medicine, public health and odontology. The search terms captured both previously used terms, like self-rated health, with their synonyms and the combination of "Oral health and Quality of Life". In addition, a search was performed in the reference lists of the obtained papers. This search can be compared with theoretical sampling, as the reference lists in the derived papers determined the next search. The search in the reference lists, therefore, focused more on "OHRQoL", as the findings from the first search indicated that this search term would be appropriate for finding relevant papers to answer the research questions. This may have reduced the risk of missing important papers.

In qualitative analysis, the researcher is a part of the process during the communication with the informants. In studies where texts constitute the data, as in Paper III, the interpretation depends on to what degree the researcher will be interested and motivated by the text (Krippendorff, 2013). Thus, the researchers were tools for the interpretation and the texts were thoroughly explored, as all six authors were involved at different stages of the process. Finally, consensus about the results was reached. This can be termed "observer triangulation", that is, two or more researchers participated in the analysis (Malterud, 2001).

It has been questioned whether standards for evaluating quantitative studies, like reliability and validity, can be applied to qualitative research. Strauss & Corbin (1998) considered that the usual standards for good research require redefinition to fit qualitative research. According to Strauss and Corbin (1998), it may be difficult, for instance, to reproduce social phenomena, as it is almost impossible to reproduce the context in which the data were collected. This means that the results from the qualitative studies in this

thesis cannot be generalised in the same way as the results from quantitative studies. However, the aim of qualitative studies is to describe variations in living experiences in their context, not to generalise.

Many different terms are used to evaluate and ascertain the trustworthiness of qualitative studies. A number of procedures have been proposed, and Ali & Yusof (2011) suggested strategies for achieving good quality in qualitative studies. One strategy that was cited was to clearly describe the selection of the informants. In this thesis, this demand was met through the strategic selection of informants, thus providing a broad picture of young adults who use dental care. Moreover, informants were selected from private clinics as well as from PDS clinics. Since only two of the informants were non-attendees, it would probably have given a broader picture of the age group if more non-attendees had got the opportunity for expressing their views.

Furthermore, another demand was to carefully reproduce the process of data collection (Ali &Yusof, 2011). The data collection in this thesis (Paper I, II and IV) was carried out by the main author. Interview guides, one for each study, were developed in collaboration with the authors of the papers. In Paper I, a pilot study was carried out to test the interview guide. The interviews were performed in quiet places away from dental clinics. Furthermore, the interviewer transcribed each interview shortly after the data collection. The main author's profession as a dental hygienist can be seen as an advantage, as she is familiar with the environment of dental care, but also as an obstacle as there is a risk of preconceived notions in the analysis. However, the experience of the author as a lecturer in public health during the last fifteen years may have reduced the risk of applying preconceived ideas to the analysis.

# 5.3 Implications of the findings in the thesis

The interviews in this thesis were performed among young adults who, with two exceptions, were dental attendees. Most regular attendees will probably continue to visit a dental clinic in the future. However, their living conditions may change, especially for the younger patients in this age group. Regular dental check-ups may be of great importance in order to maintain their frequently good clinical and self-reported oral health. For non-attendees, other ways must be found. Since oral health promotion and general health promotion in many areas face the same risk factors, and oral health and general health are distributed in similar ways among populations, collaboration with other health care professions could be a possible route (Watt & Sheiham, 2012). As there are no special instruments for measuring

the OHRQoL of young adults, one task should be either to develop a new OHRQoL measure or adapt already existing ones to this age group, taking their needs and wishes into account.

# **6 CONCLUSION**

The conclusions are that the OHRQoL of young adults is dependent on their earlier experience of dental care and their former and present oral health, as well as their future prospects regarding oral health. Elements of public health principles were, to a varying degree, present in all the OHRQoL measures. Young adults regarded the investigated measures of OHRQoL, with their pros and cons, as being equal. The measures were mainly disease-oriented and no specific measures had been developed for young adults.

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# **APPENDIX**

#### References for OHROoL measures in Table 2

#### **CHILD-OIDP**

Gherunpong S, Tsakos G, Sheiham A. Developing and evaluating an oral health - related quality of life index for children; The CHILD-OIDP. *Community Dent Health* 2004;21:161-169.

## **CPQ 8 -10 – Child Perceptions Questionnaire**

Jokovic A, Locker D, Stephens M, Kenny D, Tompson B, Guyatt G. Measuring Parental Perceptions of Child Oral Health-related Quality of Life. *J Public Health Dent* 2003;63:67-72.

#### **CPQ 11-14 – Child Perceptions Questionnaire**

Jokovic A, Locker D, Stephens M, Kenny D, Tompson B, Guyatt G. Validity and Reliability of a Questionnaire for Measuring Child Oral-health-related Quality of Life. *J Dent Res* 2002;81:459-463.

#### **Dental Health Questions from the Rand Health Insurance Study**

Dolan TA, Gooch BF, Bourque LB. Associations of self-reported dental health and general health measures in the Rand Health Insurance Experiment. *Community Dent Oral Epidemiol* 1991;19:1-8.

## **DIDL** – **Dental Impact Profile on Dental Living**

Leao A, Sheiham A. The development of a social-dental measure of dental impacts on daily living. *Community Dent Health* 1996;13:22-26.

#### **DIP – Dental Impact Profile**

Strauss R, Hunt R. Understanding the value of teeth to older adults: influences on the quality of life. *J Am Dent Assoc* 1993;124:105-110.

## **FIS – Family Impact Scale**

Locker D, Jokovic A, Stephens M, Kenny D, Tompson B, Guyatt G. Family impact of child oral and orofacial conditions. *Community Dent Oral Epidemiol* 2002;30:438-448.

#### **GOHAI – General Oral Health Assessment Index**

Atchison KA, Dolan TA. Development of the Geriatric Oral Health Assessment Index. *J Dent Educ* 1990;54:680-687.

#### **OHIP – Oral Health Impact Profile**

Slade GD, Spencer AJ. Development and evaluation of the Oral Health Impact Profile. *Community Dent Health* 1994;11:3-11.

#### OH-QoL – Oral Health Quality of Life Inventory

Cornell J, Saunders M, Paunovich E, Frisch M. Oral Health Quality of LifeInventory. In: Slade GD, editor. Measuring Oral Health and Quality of Life. *Proceedings of a conference June 13-14, 1996.* Chapel Hill: University of North Carolina. Department of Dental Ecology; 1997. p. 136-160.

#### OHQoL-UK – Oral Health-related Quality of life- UK

McGrath C, Bedi R, Gilthorpe M. Oral health related quality of life – views of the public in the United Kingdom. *Community Dent Health* 2000;17:3-7.

#### OHS – Oral Health Index

Burke FJT, Wilson NHF. Measuring oral health; an historical view and details of a contemporary oral health index (OHX). *Int Dent J* 1995;45:358-370.

#### **OIDP – Oral Impacts on Daily Performances**

Adulyanon S, Sheiham A. Oral Impacts on daily performance in: *Measuring oral health and quality of life. Proceedings of a conference June 13-14, 1996.* Chapel Hill: University of North Carolina, Department of Dental Ecology, 1997 p 152-159.

#### P-CPO – Parental Caregivers Perceptions Questionnaire

Jokovic A, Locker D, Stephens M, Kenny D, Tompson B, Guyatt G. Measuring Parental Perceptions of Child Oral Health-related Quality of Life. *J Public Health Dent* 2003;63:67-72.

#### POH – Self-perceived oral health

Östberg A, Halling A, Lindblad U. A gender perspective of self-perceived oral health in adolescents: associtaions with attitudes and behaviours. *Community Dent Health* 2001;18:110-116.

#### SIDD – Social Impact of Dental Disease

Cushing AM, Sheiham A, Maizels J. Developing socio-dental indicators – the social impact of dental disease. *Community Dent Health* 1986;3:3-17.

#### **SOSHI – Subjective Oral Health Status Indicators**

Locker D, Miller Y. Evaluation of Subjective Oral Health Status Indicators. *J Public Health Dent* 1994;54:167-176.

# Paper I

# Young Adults' Views on Dental Care—A Qualitative Analysis

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Seand J Caring Sci 1996; 10: 197-204

The aim of the present study was to determine young adults' views on dental care. The gathered data were gleaned from interviews and analysed in accordance with comparative method. It was possible to discern the views from two perspectives: the patients' opinions regarding costs in relation to given functions within dental care, and the attitudes to given functions in dental care per se. Costs for information and service were deemed questionable, whereas the costs for examination and treatment were accepted. The patients' stance was active with respect to information and treatment, whereas a greater degree of passivity prevailed within the areas of examination and service. According to this report, maintaining cheap dental care rates was deemed important. The patients questioned having to pay for information perceived as irrelevant to dental care. They expressed a hidden wish to assume an active role while being given more information, and to exercise greater influence with reference to own dental care, but were not in the habit of stating their views to dental staff. Thus, continuous patient satisfaction studies are vital in order to meet this group's needs. One suggestion for further research is to study how young adults regard dental care based on the theory presented.

Key words: adults, comparative method, dental care, patient satisfaction, quality of care.

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#### INTRODUCTION

The purpose of dental care, as described in the Swedish Dental Care Law (1), is to provide the entire population with wholly adequate dental health and dental care. Focus is on the patient, which means not least that a patient's every need is met during treatment and care. Dental care must also be built on respecting the will and integrity of a patient, in addition to establishing a positive link between patient and dental staff. Moreover, issues concerning care will, wherever feasible, be planned and carried out together with the patient. In order to guarantee the aims within dental care and patient safety requirements, the National Swedish Board of Health and Welfare (2) has designed a system of quality and safety for the patient whereby aims are based on patient needs. Questionnaires are frequently used to glean the views of patients in order to guarantee quality within dental care. It has been found from this type of questionnaire (3, 4) that young persons are less satisfied with dental care than older patients. One way to create understanding with respect to how young adult persons think and feel about their contact with dental care is to have them express and describe any views they may have. While such studies are rare, pinpointing young adults' preferences may be of use in future as they serve to meet the needs and requirements of young adults in matters relating to their own dental care. The aim of this study was to determine young adults' views on dental care.

#### Review of the literature

Hoppe (5) found that, as a rule, older patients displayed a greater degree of satisfaction concerning all aspects of care than younger patients. As a possible explanation, it was stated that older people compared modern care with the old days, counting themselves lucky. By contrast, younger patients only have experience of contemporary care within the National Dental Health Service. Given their different backgrounds, they can be more critical and expect more from dental care. In one study from Linköping University (6) showing the population's assessment of the quality in dental care, it was established that young National

Dental Health Service patients were to a greater degree dissatisfied with service as a whole than older patients. The majority of the patients dissatisfied with information pertaining to examination and treatment were to be found among the National Dental Health Service's young patients. Almost 5% of these young patients regarded the information they received as either inadequate or very bad. Patients between the ages of 16 and 39 felt they only exercised a modicum of influence on their own dental care. This was the case with both private and National Dental Health Service patients. In a study on consumer satisfaction, in which three types of care were examined, Williams and Calnan (7) ascertained that young patients in health and medical care are to a greater degree than older patients prone to criticize. However, younger and older patients displayed similar attitudes with respect to dental care. In a survey designed to describe the quality shaping aspects of adult dental care valued most by dental care users, Danielsson (8) ascertained that younger adults appreciated more than older adults the flexibility of longer opening hours at the clinics. Agreeable premises met with greater appreciation from the youngest in the study, but are also appreciated by older patients. The same is true with regard to courtesy and kindness exhibited by staff. For young adults aged between 21 and 30 years, information concerning planned treatment was of great importance. Cost played an important role for both young adults and individuals between the ages of 30 and 40, in addition to being deemed important by older patients. In response to a direct question as to what caused the greatest irritation, staff incompetence ranked highest. Again, young patients were in a majority here. Courtesy and kindness from staff members together with information concerning planned treatment, in addition to feeling safe in the hands of the dentist, were valued most across all age groups. Forsberg (3) found that young adult patients at National Dental Health Service clinics were clearly less satisfied with the care provided than older patients. A mere 26% of the young patients placed a great deal of confidence in dental clinics. Corresponding figures for older and middle-aged patients were 56% and 45%, respectively. Rönnberg (9) felt that meeting patients' expectations is an integrated aspect of quality within dental care. Where the patient may find difficulty in assessing the technical side of treatment, the patient's own views are to a greater degree based on the experiences of care as a whole and what occurs during the actual treatment process. Thus, a patient's perception of care may differ substantially from the objective, professional view. The interaction between patient and the dentist or dental hygienist is considered vital in meeting patient expectations. A patient's expectations are decisive in how he/she perceives the treatment provided. Expectations are dependent on previous experiences of dental care and a patient's dental care habits.

#### METHOD

The method applied was the constant comparative method which is inductive and the approach qualitative (10). This method was chosen because it allows the researcher to ascertain informants' opinions and experiences and from this data to generate a theory about a more or less unknown area; i.e. to describe and to explain a given situation through identifying the story line linking concepts and processes.

#### Informants

The selection of informants was strategic and the criteria laid down in order to provide a comprehensive study with reference to the informants' age, sex, domicile, education, civil status, and use of private dental care or National Dental Health Service. Eleven young adults—six males and five females aged between 21 and 30 years-participated in this study. All the patients were listed in their respective clinic's recall system, and were summoned for regular check-ups and treatment. Given that a substantial number of 20-year-olds have yet to take advantage of adult dental care, i.e have neither been summoned for nor sought dental care themselves, we decided to set a 21-year age-limit to those studied. Five of the informants were patients at a National Dental Health Service clinic in a small town in southwest Sweden. The remaining six were treated at a private clinic in a medium-sized town also in southwest Sweden.

#### Data collection

Data collection was preceded by a pilot study in which five persons of both sexes aged between 21 and 30 were interviewed. The interviews were conducted similarly to the pilot study and required no major changes. The informants were contacted by phone and asked if they would be willing to participate in the study. The data gathered were gleaned from thematic interviews conducted by the main author. The interviews took the form of direct questions, viz.:

- What does a patient expect from a visit to a dental clinic?
- What does a patient deem important in connection with a dental appointment?
- What has the patient experienced as positive or negative, respectively, in connection with a visit to a dental clinic?
- In which aspects of dental care does the patient desire change?

# Attitudes to given functions within dental care Costs queried Costs accepted Information Treatment Costs accepted Costs accepted Costs accepted Costs accepted Costs accepted

Attitudes to dental care costs

Fig. 1. Young adults' views on dental care.

The interviews were conducted in treatment or classrooms and on office premises. The interviews between informants and the researcher were to be carried out undisturbed. The informants were called exclusively for the study. The premises were also chosen in order to facilitate transport for the patients to and from the interviews, always bearing in mind the time element. Each interview lasting 20–40 minutes was audiotaped and written out verbatim. The gathering and analysis of data were partially done at the same time, and the gathering of data was discontinued when nothing new could be gleaned from the interviews.

#### Ethics

The go-ahead was given by both the Head of the non-private clinic and the dentist at the private clinic to select informants from the patient index for the main study. The patients were informed that any participation in the study was entirely optional and that the interviews would exclude personal details such as name and home address, as well as the name of the dentist and clinic in question. As those investigated were examined as a group, the patients were guaranteed anonymity.

#### Data analysis

The minutes from the interviews were analyzed applying the constant comparative method (10). Initially, the interviews were analysed by means of an open coding process whereby substantive codes were identified and documented. The substantive codes were definitions such as: 'query about information' and 'dont want to pay for information'. The material was analysed again and reorganized. For example quotations such as 'they state the obvious' and 'don't want more information' were related to 'query about information'. These indications were transferred to 'don't want to pay for the information' because the costs of the information seemed to be the problem for the patient, especially paying for information already known to the patients. In the next step of axial coding analysis connections between categories were sought. For example: 'I appreciate preventive dentristry like information about how to clean my teeth, but when

they state the obvious, I don't want to pay for this kind of information, but I avoid complaining to the staff'. In the final step of the analysis process during the so-called selective coding, we carried out a more systematic search for principal variables whereby links between the variables were sought and a tentative theoretical model was derived.

#### RESULT

#### The emergency theory

The expectations and views on dental care of a great many young adult patients' are based on their experiences of all previous visits to dental clinics. While the older patients have gained more experience of adult dental care, the youngest have experiences almost exclusively from the organized child and youth side of dental care. From the patients' perspective, dental care is considered to fill numerous functions relating to each other, together constituting a whole. The contents of these given functions are seen from perspectives identified as principal variables. The main variables constitute the patients' views on dental care costs, and their attitude to given functions within dental care per se. The patients' views respecting dental care costs are ambivalent. Costs that are queried and costs acceptable to the patient. The patients' attitude to dental care was both active and passive; that the patients' stance was active is evident when they expressed a secret wish to assume a more active role while exercising greater influence both in terms of decision-making and on what actually occurs in their own dental care. Passivity prevails when the patients do not wish to influence the course of events leading up to and during treatment, but instead to hand over all responsibility to the staff member concerned, while at the same time taking for granted that all components in the process are an integrated part of treatment. Young adult patients' expectations and views on dental care may be described with reference to four areas within dental care: Information, Treatment, Service as a whole and Check-ups (Fig. 1).

#### Information

The informants referred to information regarding a patient's state of oral and dental health, information and recommendations regarding prophylactic measures available to the patient, as well as information on treatment. Being provided with information on prophylactic measures was perceived positively, as is illustrated by the following interview quotations from the informants: 'It means prophylactic treatment to prevent cavities in your teeth'; Informants: 'As I've only had 3 or 4 cavities, I feel it's adequate preventive treatment'; 'You know just what to do, and the same

applies to my children'. On the other hand, the information was queried if it was perceived as routine or irrelevant, or if the patient felt he/she had already acquired the specific knowledge pertinent to the information. Below are some extracts from the interviews: . . . that they state the obvious, you know'; 'they should tell us the most important things, and not waffle on about numerous other things'; 'providing you've been to the dentist every year, it doesn't need to be repeated'. As not all information offered was perceived as relevant, the patient was not inclined to pay for it. Below are some sample quotations from the interviews: '... if they feel they need a bit more money, they can just keep on nattering about it'; '... then she showed me how to use dental floss. I mean, I already knew that, and she adds another 50 kronor to the bill'; '... I was told I had to pay a certain amount because they told me to rinse with fluoride, which is something I don't think I should have to pay for.' It was clearly important for the patient to be informed prior to treatment, though continuous information during the various stages of treatment was also deemed important. Such examples of quotations are: 'it's good if the dentist explains all the time what he's doing'; 'yes, when you go in and he talks about the treatment, explaining what he's going to do and why'; 'it's really important that they tell you what they're doing, so that you can follow what's going on'.

#### Treatment

The various forms of treatment mentioned by the informants in the interviews were prophylactic, for example, fluoride treatment and oral hygiene instructions, treatment of cavities and gingivitis, as well as taking x-rays and scaling. Check-ups and treatment were both considered expensive, although ultimately worthwhile. The following quotations reflect informants' opinions on costs: 'as with everything else, it's a money thing, it mustn't be expensive'; 'I have friends who go to the dentist only every other year just to save money'; 'if you have to fork out a thousand kronor every year just to have your teeth fixed, it's probably in your best interest to look after them to prevent cavities'. A desire to influence during the actual treatment is prevalent in the following examples: 'not all dentists stop to ask if you require an anaesthetic'; 'if you can choose and say, no I don't want to be x-rayed'; 'some dentists give you a breather every now and then, others just don't bother'. Being asked questions or having to listen to ongoing conversations in the treatment room while the patient cannot respond or participate in the conversation because of instruments in his/her mouth is needless to say extremely awkward for the patient. The following statements exemplify this: 'they

shouldn't ask so many questions when you've got a mouth full of instruments'; 'it's fairly difficult to talk once you're stuck there with instruments in your mouth'; 'perhaps they don't really want you to know, so they ask when they know full well that it's impossible to respond'. The consequences of this, combined with an absence of information during treatment, were best described as a powerlessness leading to passivity. The following interview quotations from the informants exemplify this: 'it was, you know, as though you were totally at their mercy'; 'sometimes they drill, and then you glance in the mirror and half a tooth's gone'; 'you can neither say nor do anything. I mean, you're just stuck in the chair until . . .'

#### Service as a whole

Service as a whole referred to how the patient experienced being taken care of by dental staff. An excellent dentist and dental hygienist-patient relationship right from the word go was vital. Those studied had views on how the staff concerned should conduct themselves in relation to themselves in their capacity as patients, but were not in the habit of stating their views to the dental staff. It was evident that the informants were mostly content with the service as a whole at the clinic where they are currently receiving treatment. Below are additional quotations from the interviews: 'it's more like going to see a friend'; 'should you meet in town she might say hello, as well as knowing who you are'; 'well, she recognizes me both as a person and client they take care of'. Personal service ranked high, and was something more of the informants felt they had received. Patients occasionally felt that the treatment offered lacked an individual touch. Examples from the interviews are: 'there it was like being a product on the assembly line'; 'that the people in question are treated routinely'; 'you go through some standard things'. Having criticism levelled at you by dental staff had a negative ring to it. Quotations that exemplify this are: 'now it's the same old grumbling about having tartar from having smoked'; 'I thought I knew exactly how to brush my teeth'; 'thought he'd tell me off the whole time because I hadn't been careful'. In this instance, service refers to factors such as pain relief, clinic opening-hours, waiting-times, being treated by the same dentist and dental hygienist during each visit, and staff competence. Below are some interview extracts: 'there's this feeling that they're good at what they're doing'; 'if only they could have longer opening-hours every now and then'; 'I think it's important you're treated by the same dentist whenever you have a dental appointment'. Patients were not in the habit of displaying discontentment to the dental staff treating them. The following statements shed light on this: 'a lot of people complain,

though I never have'; 'really I should phone and tell them, but I haven't'; 'when I go to the dentist, you go there because you take for granted everything's in order, good in other words'. It was taken for granted that service as a whole should be an integrated part of care, at no extra cost. Discussions were held regarding increasing costs in connection with longer opening-hours at the clinics.

#### Check-ups

An item that kept cropping up in the interviews was check-ups, i.e. examination. Receiving a thorough check-up was an expected part of treatment and also the most important and sometimes only reason for making a dental appointment. Examinations mainly entailed checking for cavities, but also paradontal conditions and oral hygiene examination. The following informants' quotations were extracted from the interviews: 'I see a dental hygienist to make sure there are no problems"; 'not having any cavities was most important'; 'so that they monitor everything within their specific field'. During check-ups trust was placed in the staff member in question and it was taken for granted that the patient be given all examination results. Paying for this service was acceptable to the patient provided rates were not unreasonably high.

#### DISCUSSION

#### Methodological issues

When gathering information from qualitative studies, Patel & Tebelius (11) point out that safety is based on applicability, security, credibility and accuracy. Applicability sheds light on choice of technique for the gathering of data and study group in relation both to given questions and the study's format. The informants in this study were selected in order to provide a clear picture of young adults who utilize dental care. Sex, age, education, civil status, domicile and use of private dental care or National Dental Health Service varied. As the number of informants was limited to eleven individuals selected from two dental clinic patient indexes, no general conclusion can be drawn from this study regarding young adults' views on dental care. Choosing interviews as the method from which to glean data coincided with the study's aim to pinpoint, from a patient perspective, young adults' views on dental care. Thus, it seemed important to avail the patients of the possibility of expressing freely and in their own words their views on matters previously described in this study. When designing a questionnaire to assess quality in dental care as perceived by patients, Runsten (12) believed that the gathering of data should partially concern a specific treatment occasion; i.e. the questions should specify exactly the

time and place in order better to reflect patients' immediate experiences of care and treatment. In contrast, Danielsson's (8) questions were based on the informants collective experiences of dental care. With reference to Rönnberg's (9) description of consumer satisfaction as being dependent on both patients' expectations and previous experiences of dental care, the patients' collective experiences of dental appointments formed a basis for the interviews. Security as to the gathering of data in relation to the subject matter under examination was determined when the themes which formed the interview basis were discussed between the authors as well as two colleagues. The pilot study covered both test questions and interview methodology. As the person conducting the interviews is active within dental care, there existed prior knowledge of dental care, which facilitated understanding of what the informants described. However, there exists a very real risk that certain aspects were given insufficient attention, or simply taken for granted. The process of collecting and interpreting data was given credibility when the authors collaborated in making an assessment. In order to ensure that accuracy was maintained during the process of analysis, the authors switched constantly between data, codes and categories. Once the principal variables had been identified, they made sure that theory and data tallied.

#### Patients' attitudes to dental care costs

Dental care costs were a recurring theme in the interviews. The prevailing feeling among both the youngest patients in the study, who had only just started paying for their own dental care, and the mature adults was that dental care rates should be kept low. In select material concerning every third patient at a private clinic, Wickholm and Halling (4) ascertained that only 55% of the young persons between 20 and 39 years old felt they could afford dental costs. In Forsberg's study (3), 38% of young adult patients considered dental care rates, in relation to other items pertaining to personal hygiene and recreation, as too steep. In another study Danielsson (8) was able to glean that dental care costs are vital to young adults, which agrees well with the evidence presented in this study. One way to keep dental care costs low for this patient category still paying current dental care rates is to provide the appropriate level of competence at the lowest possible price. Paying for information perceived as irrelevant by patients was problematic and resulted in a lack of confidence in the staff member concerned. Patients were not always in the habit of stating dissatisfaction, making it difficult for dental staff to meet a patient's needs if they remain unspoken. Check-ups and treatment were those measures most frequently expected by the patients to be carried

out during dental appointments. As a consequence, customers were to a greater degree prepared to pay for these aspects of treatment if the provided costs were kept relatively low. Service, together with an agreeable personal touch are viewed as part and parcel of dental care. It was only in connection with longer clinic opening-hours that service costs were brought up. It was confirmed that prophylactic treatment results in a general improvement in dental health, which subsequently leads to lower dental care rates. This was described as an incentive to look after one's teeth and to have them checked. If changes in dental care rates are carried out in accordance with a proposition from the Ministry of Health and Social Affairs in 1993 (13) concerning bonuses in dental care, patients may be rewarded immediately by receiving a slot in a low risk group, which also entails lower dental care costs.

Patients' attitudes to given functions within dental care

Rönnberg (9) writes, inter alia, that the patient's role in dental care is undergoing change. The passive patient is becoming an active one. In future it will be increasingly normal for patients to state their own requirements and put forward their own suggestions. Expectations and requirements to be met by dental care will increase despite of the fact that, to all intents and purposes, the basic needs of the population have been met. Data presented here verify Rönnberg's description of the patient role in future dental care. The patients express a wish to assume a more active role in their own dental care. In a report concerning quality assurance Ordell (14) describes how the traditional view of dental care as something to relieve pain has gradually waned in favour of a belief today that dental care exists to help people stay healthy. In future, patients will have greater need for up-to-date information. With an increase in awareness and curiosity pertaining to these matters, quick and simple answers will be in demand. Those interviewed in this study expressed a desire to be provided with information on how to maintain adequate oral health. The patients themselves felt they had adequate knowledge, especially with regard to prophylactic treatment. This influenced patients' preferences in terms of content from information provided. As some information was scarcely newsworthy, it was occasionally deemed uninteresting. In order that this group of patients comes to appreciate information on prophylactic measures, a better adjustment to each individual will be required. Put simply, patients' desires and needs will govern the information content. Given the wide range of views reflecting patients' willingness and ability to express their views, it is vital that all dental staff listen very carefully. As shown in Danielsson's study (8), patients are greatly appreciative of information concerning what treatment is planned for them.

From the study concerning quality of care in Linköping (6), it was revealed that young non-private patients were least happy with the lack of information provided concerning examination and treatment. Runsten (15) found that patients were less satisfied with information pertaining to health and their own roles in any decision-making than with how they were welcomed and treated by staff. Information as to treatment were considered to be important aspects by the patients in this study too. It was clear from the interviews that this type of information tended to be lacking. Being able to influence the actual process of treatment, as well as receiving information about the various stages of treatment, was considered important by the patients, especially those who felt discomfort, even fear, when subject to dental treatment. Corah (16), inter alia, indicated 10 factors governing a dentist's professional conduct which might relieve classical fear of dental treatment, and went as far as to compare factors which were important for patient satisfaction. Important factors on both counts were calm professionalism from the dentist and the availability of pain relief. A steady stream of information was not deemed a vital factor in terms of minimizing dental fear. This was equally true regarding consumer satisfaction, in stark contrast to what patients in this study related. One consequence of a lack of information during treatment is that patients will find it difficult to exercise influence on their own treatment. There is evidence in the interviews that the patients have views and wishes concerning dental care which they keep silent on, which in turn makes it more difficult for the dentist or dental hygienist to offer individual care. Being and feeling welcome was considered important in both Danielsson's (8) and this current study. It was not common to express complaints, for instance about waiting-times which sometimes caused problems. Patients still have inhibitions which prevent them from voicing opinions and wishes concerning the dental care provided, despite their described free and open relationship with dental staff. This study seems to confirm that passive patients are becoming more active in putting forward their requirements and wishes in matters concerning dental care. By contrast, patient interviewees in this study still show some hesitancy, particularly in expressing views on service as a whole when going to the dentist. This may to some extent be because patients are, by and large, content with the treatment offered and are thus reluctant to voice any complaint to the dentist or dental hygienist.

Forsberg's (3) and the current study reveal that some young adults are not entirely satisfied with the service offered. He found that younger patients were more critical than older patients about the staff's ability to understand and show empathy. Young adults voice legitimate claims in matters of treatment and a say in how this is shaped in full agreement with the Swedish Dental Care Law (1), but as the young adult patients in this study seem to keep some of their views to themselves, it is important that studies concerning consumer satisfaction are an ongoing feature. If dental staff are made aware of the requirements patients have, the staff will be better equipped to meet them at the dental clinic. Kress (17) and Rönnberg (9) are of the opinion that patient satisfaction studies are good for both patients and dental staff. Rönnberg (9) describes the connection between good service and consumer satisfaction thus: good service creates consumer satisfaction, which in turn results in positive feedback from the patients, thereby giving dental staff the energy to maintain a high level of service.

Patients in the present study form a select group in that they are all regular patients of dental care. Tolpin (18) discusses two categories of consumer in dental care: first, those who are part of the dental care system, as in the case of the patients in this study; and, secondly, the category currently not receiving and not demanding dental care. The first category is described as satisfied patients who stick to their own dentist and show full appreciation of the care they receive. Between the second category and dental staff, by contrast, the very reverse of a meeting of minds was discovered. There may well be cause to fear that the future may see ever more young adults feeling cut off from regular dental care, for reasons of cost or because they no longer see its benefits. In the only qualitative study identified, Jensen & Tegelberg (19) found that the two young adult patients interviewed regarded dental care as of marginal importance for crass economic reasons. Dental care was generally regarded as very expensive. Thus, the potential dental patient remained passive, expecting instead to be summoned. It is thus vital to catch young adults when their dental care as children and teenagers ceases, which is precisely when dental care for adults must assume responsibility for this category of patients.

#### Conclusion

The conclusion to be drawn from this study is that young adults' attitudes differ in respect to given functions such as costs and influence within dental care. Dental care costs were deemed important. In addition, patients' views on dental care, but not being in the habit of stating them to the staff member in question, were also regarded as important. The implications of this are that dental staff must listen carefully to patients in order to meet their needs, and that additional consumer satisfaction investigations be carried out.

Clinical and research related implications

In order better to meet the needs of this patient group, it is vital for dental staff to acquire knowledge of what young individuals perceive as important aspects of dental care. The theory generated in this study may well form the basis for research into how young adults currently not claiming it, regard dental care. Knowledge of this specific category's viewpoints ought to be of significance in order to prevent them from being excluded from dental care and thus, in the process, jeopardizing their dental health.

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# Paper II

# Submitted for publication

Oral health-related of	quality of	life in Swedish	young adults
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#### Abstract

The living conditions of young adults in Sweden have changed during the last decades, due to the economic and employment situation in society. Although oral health is mainly considered to be good in this age group, their use of dental care has decreased and their priorities and opportunities regarding oral health are little known. The purpose of this study was to describe and explore the views of Swedish young adults on their oral health and oral health-related quality of life (OHRQoL). The design of the study was qualitative, using content analysis. Sixteen young adults, aged 21 to 29 years, were interviewed. The findings from the interviews were summarized under the theme "The perceived control of OHRQOL of young adults is dependent on their future prospects of oral health, in relation to their perceptions of past and present own oral health," consisting of three categories: Past experience, Present situation and Future prospects. The OHRQoL of young adults is dependent on their experiences of own oral health during childhood and their received dental care, but also on their present self-perceived oral health, oral health habits and social life together with their expectations of future oral health. The findings in the study indicate that the oral health awareness and needs of young adults, as well as their expectations of oral care, merit further follow-up.

#### Introduction

Oral health-related quality of life (OHRQoL) has been defined as an individual's perception of how functional, psychological and social aspects, together with pain and discomfort, affect personal well-being (Inglehart & Bagramian, 2002). Accordingly, OHRQoL has been described as a multidimensional concept including subjective evaluations of own oral health, as well as expectations of and satisfaction with dental care. The concept of OHRQoL has also been described as "an integral part of general health and well-being" (Sischo & Broder, 2011). Thus, OHRQoL can be seen as measuring both dental care needs and efficacy of care. Psychosocial factors, like negative life events involving social readjustment, were found to impact the OHRQoL of young Australian adults (Brennan & Spencer, 2009). Positive aspects, such as optimism, resilience and coping ability, have likewise been described as having an impact on a person's general quality of life (Broder, 2001; Strauss, 2001).

Oral diseases, specifically dental caries and periodontal disease, are still a major problem worldwide (WHO, 2014). The caries situation has improved during the past decades, but signs of stagnation in young people have been reported in recent years (Haugejorden & Birkeland, 2006; Tanner et al., 2013). Periodontal diseases are less investigated in young people, but Ericsson et al. (2009) found high levels of plaque and gingivitis among 19-year-olds in Sweden, and poor oral hygiene was found especially in male subjects. The prevalence of dental caries as well as periodontal disease varies both between and within countries (Petersen, 2003). In Sweden, epidemiological data on caries in children and adolescents have been available for many years, but not for young adults (National Board of Health and Welfare, 2011). The self-reported oral health is generally good among young people in Sweden and continues to be good, but is poorer in socioeconomically week groups (Nordenram, 2012). Another oral problem is dental trauma. The consequences of a dental injury in childhood may persist throughout the individual's life and may therefore cause problems in young adulthood (Glendor, 2008). Temporomandibular problems are also of concern. Nilsson et al. (2005) found in a Swedish study that over four per cent of adolescents (more girls) reported such pain.

In Sweden, dental care is offered through the Public Dental Service and at private clinics. Dental care in Sweden is free of charge for individuals below 20 years of age. Thereafter, an annual subsidy of SEK 300 is offered until the year a person turns thirty. A decrease in dental care use has been seen among young adults, especially among men (Nordenram, 2012), for several decades. When young people no longer receive dental care free of charge, there may be a risk that they do not seek dental care until they experience oral problems. Reasons given by young Swedish people for not having regular dental visits were strained economy (Johansson et al., 1996; Östberg et al., 2002, 2010), but also little perceived need based on good self-rated oral health (Nordenram, 2012). In a Swedish study, 41 per cent of male and 30 per cent of female 19-year-olds were found not to plan for future dental visits when they have to pay for the care (Östberg et al., 2010).

The life situation for young adults in the industrialized world has changed over time during the past fifty years. Their economic situation has become more insecure due to the uncertain labour market, leading to high levels of unemployment and also prolonged education (Arnett, 2007; Stone et al., 2011; Lager et al., 2012). Moreover, these circumstances often entail delayed settling into adult roles like marriage and parenthood (Arnett, 2007; Stone et al., 2011). Quite a few young adults still live with their parents, mainly for economic reasons (Hendry & Kloep, 2010; Stone et al., 2011). However, the life situation for young adults differs considerably depending on their employment and/or educational status.

Åström &Wold (2012) followed a cohort of young Norwegian people and found that early sociobehavioural circumstances at age 15 had a great impact on adult oral health at age 30. Oral health awareness was described as poor, in general, among adolescents and their beliefs in changing their oral health by themselves were limited. In a Swedish study, personal and professional care, social support and impact as well as external aspects like appearance and economy were important for the adolescents' self-perceived oral health (Östberg et al., 2002). However, less is known about young people's views on their oral health during the transition to adulthood. The aim of this study was therefore to describe and explore the views of young adults on their oral health and Oral Health-Related Quality of Life.

#### Design and methodological approach

A qualitative approach was chosen and data collected through qualitative interviews were analysed according to content analysis. Content analysis is a method for the systematic analysis of written, verbal or visual communication. The method may have an inductive as well as a deductive approach (Krippendorff, 2012). Qualitative content analysis has been defined "as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns" (Hsieh & Shannon, 2005, p. 1278). In qualitative content analysis, both manifest content and latent content are sought. The manifest content can be described as the visible, obvious components in the text, while the latent content deals with a relationship between different parts of the manifest content and an interpretation of the underlying meaning of the text. Both perspectives demand interpretation but of different depth and on different levels. This study focuses on both manifest and latent content.

#### Sampling of informants

The study was performed in south-western Sweden. Strategic sampling according to age, sex and education was carried out to represent the age cohort of 21-29 years. About half of the invited individuals chose not to participate. The reasons given were often studies or work away from home, but some stated that they were busy or simply "not interested". Sixteen young adults, eight of whom were 21-25 years old and eight 26-29 years, participated. Of these, nine were females and seven were males. Eight of the informants had either a university degree or were students at a university and eight had completed grammar school. Fourteen received dental care on a regular basis and two were non-attendees. Ten were patients at one Public Dental Service clinic and four of the informants attended one private clinic. A staff member from each clinic and the interviewer selected patients from the clinics' recall systems. Two non-attendees were recruited from the local university. This sampling was intended to provide data with adequate depth and breadth to fulfil the aim of the study.

#### Interview guide

The interview guide covered issues of OHRQoL and the main entry question was: What does Oral Health-Related Quality of Life mean to you? Other areas were introduced by the following questions: What is your experience from dental visits? What is your own opinion about your mouth and your teeth? Can you describe how your mouth and your teeth impact your quality of life? How do you perceive the situation concerning your mouth and teeth in the future? The informants were encouraged to elaborate on their answers during the interviews. Probing questions were asked, like: Can you tell me more about that? How did it happen? How did you feel then? Can you give an example? Anything else you want to say?

#### Data collection

The informants were initially contacted by ordinary mail and asked if they were willing to participate in the study. After about one week they were contacted by phone and for those who were interested in participating, an appointment for an interview was arranged. Sixteen open-ended thematic interviews were carried out from June to December 2010 by the first author (GJ), who is an experienced, registered dental hygienist and public health lecturer. The interviews were conducted outside of the dental clinics in peaceful environments, like a parish house or a school office. The current study was the first step in an interview session about OHRQoL measures reported on elsewhere (Johansson et al., 2014).

#### Data analysis

The interviews were transcribed verbatim by the interviewer shortly after they were conducted. The data were systematically analysed by both authors. The second author (ALÖ) is a dentist and researcher. A qualitative content analysis, guided by Graneheim & Lundman (2004), was made. Initially, the interviews were carefully read through several times, line by line, to obtain a sense of the whole and to

get an overview of the text before rearranging it into units for analysis. As a first step of organizing the data, notes were written in the margin while the interview protocols were read through. The next step was searching for statements that represented each informant's perception of her/his OHRQoL. Statements with similar content were then discussed and reflected upon by the research team. The statements were compared in their context and with each other. Thereafter, statements with similar meaning were grouped together to meaning units. Further, the meaning units were condensed to content categories with the core still preserved. Overall agreement on the interpretation was reached between the two authors. The latent content was sought in a similar way and describes the underlying meaning in the interviews, and was formulated as a theme.

#### Ethics

The heads of the dental clinics allowed access to the patient databases for the selection of informants. Written and verbal information about the aim of the study, assurance of privacy, confidentiality in the presentation of results, and contact information for the responsible author was sent to the intended informants. It was emphasized that participation was voluntary and could be interrupted at any time without a stated reason. The risk of ethical problems may be difficult to predict, as interviews may cause discomfort or negative emotions, although clear information before the interviews may contribute to minimizing those problems. The study was approved by The Regional Ethics Board in Lund (Reg. no.: 2009/124).

#### **Results**

The results were organized in manifest and latent content. Three main categories containing seven subcategories constituted the manifest content (Figure 1). The main categories in the manifest content were "Past experiences", "Present situation" and "Future prospects". The latent content was formulated as a theme: "The perceived control of OHRQOL of young adults is dependent on their future prospects of oral health, in relation to their perceptions of past and present own oral health". The quotations illustrating the results are chosen to represent all interview protocols.

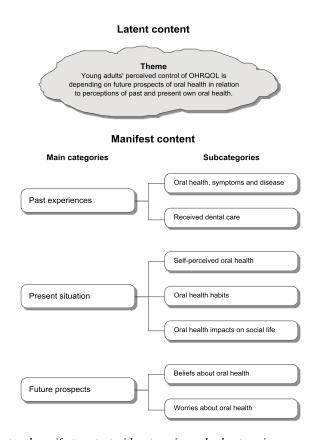


Figure 1. Latent and manifest content with categories and subcategories.

#### Past experiences

Oral health, symptoms and disease

The informants had experienced good oral health during their childhood and adolescence. No experience of oral health problems was described as causing less reflection on their former or present oral health, compared with others of the same age or of older persons. Informants expressed satisfaction with their teeth in the past from different points of view:

Since I haven't really had any immediate problems, I haven't thought about it much, but it's been more of a natural thing for me, but then, at the same time, you think that this is important.

However, the informants reported an array of former oral health problems like caries, irregular teeth (often corrected by orthodontic treatment), trauma, pain from blisters in the mouth, problems with wisdom teeth and bruxism. Some informants had no own experience of caries; however, they were aware of the problem and this was frequently brought up, irrespective of their own oral health. Severe caries lesions in early childhood were described as leading to mental stress, numerous dental visits and a great deal of fuss surrounding their dental health:

I've had cavities in almost every single tooth since I was a child, when I was little... It wasn't as if my teeth bothered me... I can't remember having problems, except that it was a pain to go to the dentist because I always had to have fillings.

Some informants had experiences of orthodontic need and treatment. This was common and often commented on. The need for treatment was reported to be related to irregular teeth, gaps between the teeth and "teeth growing on top of each other".

Also, the informants reported dental traumas. Accidents had occurred during sports activities, gameplaying and physical activities, for instance, at school, but also under the influence of alcohol. The consequences differed, from minor injuries, like losing a small part of a tooth to more serious consequences like losing a whole tooth. However, such minor fillings were often repeatedly fractured or lost and therefore seen as a problem. Some informants reported more severe injuries resulting in prosthetic treatment, such as a crown or an implant. The treatment caused pain and discomfort, but the results were satisfying:

As I said, I got this implant, too, when I was in upper secondary school. I went to the dentist a lot then and had a lot of pain and that wasn't a whole lot of fun... When I was in fifth grade, I was on my bike and fell and had my tooth knocked out.

Some informants reported problems with shooting pain in their teeth, pain or irritation from the gums, and from carious lesions. Impacted wisdom teeth had also caused problems with possible need for surgical removal. This was considered to be an expensive treatment:

...and I've had problems with my wisdom teeth when they came out all awry. They grew all over the place

Blisters in the mouth or aphthous lesions could be frequent and some females related these to the menstrual cycle. Grinding of teeth (bruxism) was another source of pain, mostly headache, and was described by a few informants. This had also caused fractures of fillings and teeth.

#### Received dental care

The dental care that had been received from the Public Dental Service during childhood was considered as a "good basis", also in adulthood, for keeping the teeth in a healthy state. Oral problems in childhood

were regarded to influence present oral health. For example, severe caries in childhood resulted in a lot of fillings:

Well, you know, I have lots of old fillings and that may not be all that positive later in life... But it's not something that I keep thinking about, because now I have no problems at all

Contacts with the dental staff during childhood and adolescence were described as both positive and negative. Some of the informants emphasized that a good relationship with the dental staff was very important and sometimes even crucial for the decision to continue with the dental treatment. Dentists and dental hygienists, as well as dental assistants, had given information about oral health and oral hygiene. One informant considered it easier to talk to the dental hygienist or a dental assistant than to talk to a dentist because, "when you see the dentist you only get things done and leave". Information given about oral hygiene was considered as important and useful in order to attain oral health. There were examples in the data of how health education had influenced informants to better oral health habits. On the other hand, less successful, one-way information was also reported. One informant reported that the dental staff had made clear the importance of flossing aggressively. Strict advice from dental staff to avoid soft drinks was not always successful, as it sometimes led to obstinate behaviour, i.e., increased consumption. However, the informants often expressed satisfaction with the information they had received about "how to take care of the teeth" and to preserve and promote oral health:

When I got a new dentist – she was really angry that I hadn't used dental floss – but after that, my dental hygiene has become much better, too. Now I'm almost addicted to it, 2-3 times a week.

Dental staff and parents seemed to influence the actual oral hygiene habits of the young adults. Support from dental staff was considered to be important for oral health habits in adolescence and adulthood. In early childhood, parents seemed to have been important as role models with regard to oral hygiene:

I think that... I grew up with fluoride rinsing at school and that, so I suppose I've grown up with taking good care of my teeth. My parents always made sure that I looked after my teeth, brushed twice a day, and I've used a lot of dental floss and things like that.

The informants were generally satisfied with the reception at the dental clinics. However, some complained that the dental visits could sometimes be unnecessarily time-consuming:

Yes, but I don't know if I'll go to the public dental service or privately... because they messed up last time, changed my appointments and that – and then they couldn't do it (remove tartar) at the same time as they examined me.

Orthodontic treatment was considered as important, also by those who had not received that kind of care. One informant had been offered orthodontic treatment, but felt that he was expected to decline the treatment, due to the dental staff's attitude to his needs, and today he regrets the decision. Some informants reported that they wished they had been offered orthodontic treatment during childhood to get straight teeth as adults. Satisfaction with orthodontic treatment was reported, as it could "boost (the person's) confidence" to have straight teeth, and some informants said that they were "grateful for the treatment", since, without it, "I would not have been so happy". The reverse situation, where the treatment had failed, was also reported, for example, when retainers were removed prematurely and a relapse occurred:

I had braces before, but then I had that stuff that was on the inside, the steel wire, removed, and then it was a complete mess again. You've had braces all these years and then they say that it's ok and we can take them away now, so I've been annoyed and irritated with that...

Dental treatment, including anaesthetics and drilling, could be painful according to the informants. Injection of a local anaesthetic could entail anxiety and even fear, especially among those having severe problems or trauma treatment:

Well, I had some fillings as a child and they drilled and drilled quite a lot so they hit the nerve and it comes from that, it was a pretty unpleasant experience.

# Present situation

Self-perceived oral health

The informants perceived their oral health as being favourable at present and considered themselves as being aware of how to promote oral health and how to avoid risk factors for oral disease. Satisfaction with oral health was expressed in different ways. Absence of caries or new lesions in the teeth seemed to be important. A more comprehensive description was to be satisfied with their teeth and to have a positive view on their teeth and their mouth as a whole.

I think so, I have a good relationship with my mouth -I think we are good friends.

Problems like pain from blisters and shooting pain in the mouth persisted into adulthood. Few informants reported recently diagnosed caries lesions. Still, oral health problems did not always entail worse self-perceived oral health. It could also be a matter of ability to cope with the situation and the state of the mouth, even if it was not regarded as perfect. One informant stated that it was "necessary to accept the situation as it is", concerning oral conditions.

...you have the mouth you have... it works.

# Oral health habits

The awareness of good food habits to prevent caries lesions differed. "Sugar addiction" could be noted among the informants and it was thoroughly described how frequent use of sweetened beverages had led to severe pain in a tooth.

I had a wisdom tooth at the back of my mouth that was so incredibly painful that I more or less wanted to kill myself, and then my mother forced me to go to the dentist—she had to drive me—"just get in there". It turned out that I had drunk so much Coke that the tooth was completely eaten away.

It was felt that dental staff had not always explained possible reasons why some individuals are more affected by caries than others. Some informants thought they had good knowledge and took good care of their teeth, while others were aware of their poor food habits and poor oral hygiene.

Yes, I changed dentists and when I saw him I had cavities, really big ones in some places, and I don't really know why I'd got them.

Informants were hesitant about whether their oral hygiene was good enough, even if they tried to take care of their teeth. Quite a few reported modified oral hygiene habits over time, either for the better or for the worse. The ambition was mostly to keep up a high level of oral hygiene, but this was considered difficult. Being caries-free was often regarded as "evidence of good oral hygiene". Some considered that they "should be more careful and use fluoride and dental floss". Bad conscience could lead to spending a lot of money buying dental oral hygiene equipment (whether used or not):

And I buy all sorts of special toothpaste for a lot of money. Fancy toothbrush, 'cause I imagine that it will get better then. But at the same time I'm doing this because I have a bad conscience about smoking and drinking Coke.

Control over oral health habits was described as a requirement for good oral health. The informants wanted more information from dental staff about food habits and tobacco use, but also general recommendations about how to take care of the teeth. Informants stated that oral health matters or oral hygiene were seldom discussed with their peers.

Oral health impacts on social life

Factors impacting social life were fresh breath and the ability to speak clearly. Further, to look good was also considered important for a positive OHRQoL. On the contrary, bad breath or fear of having bad breath was frequently described as causing insecurity and interfering with social situations. One informant using snuff considered this a reason for bad breath, which compromised activities like kissing. On the whole, a fresh mouth was described as being very important:

Mm, what we haven't talked about at all is bad breath. I work as a teacher so I come into contact with a lot of people, and sometimes up close. So that's something I think about quite a bit—and it affects me quite a bit, too.

Concern about how oral health can impact a person's speech was also discussed, even if the informants were uncertain about whether the teeth or something else had caused the problems. "Big teeth" and difficulty of closing the mouth were suggested as possible reasons for articulation problems that could impact encounters with other people:

If my dental health affects my speech, it means that it affects how I'm perceived.

Aesthetics was a frequently stated aspect with an impact on the OHRQoL. Informants expressed great concern with their appearance. The colour of the teeth and whether the teeth are straight and perceived as beautiful was reflected upon. Some mentioned aplasia of permanent teeth; however, this was not a reason for aesthetic concerns.

It's probably important throughout your whole life, but especially when you're young, if you... other things that influence your health, with all the ideals and that, I think it would be a good idea to talk about appearance a bit more.

Moist snuff usage was also regarded as possibly compromising the aesthetics of the teeth, as well as creating gingival retractions. The informants were satisfied with the appearance of their teeth, even if they were not considered to be perfect (while others were less satisfied). Orthodontic treatment was discussed as a way to improve the appearance. Another suggestion for getting nice teeth was to bleach them:

Then there's bleaching and that, I used to bleach my teeth... seven or eight years ago. I thought the result was great and it's lasted until almost now.

Aphthous lesions caused pain and were an obstacle to cleaning the teeth, eating and socializing with others, and could lead to withdrawal behaviour. Thus, it was considered to cause social problems and to impact on quality of life:

... the fact that my mouth hurts means that I don't want to talk because it hurts and I don't want to eat because that hurts, too, and it's obvious that it impacts everything—I can get annoyed with my partner and my sisters and then they can tell straightaway—now her mouth hurts.

The informants often stated that the ability to eat and enjoy food was dependent on oral health and this was considered important for well-being. Pain in the mouth was seen as leading to eating problems, loss of appetite and, consequently, lack of nourishment. It was important to feel comfortable while eating with others and to enjoy the conversation. Taste sensations were also regarded as being of great value.

# Future prospects

Beliefs about future oral health

As long as the oral health was perceived to be good, the informants did not think about possible future oral problems. The main challenge for the future seemed to be to maintain their present oral health. The hope for the future was that it would stay the same, provided that nothing unexpected happened. Some stated that "oral health problems are something I can deal with when they come". To take care of your teeth was considered as a way of assuring good short-term oral health, but it was also stated that luck was the reason for good health but that this might change in the future.

Actually, I haven't thought a lot about what will happen to my teeth. I hope they will stay as good as they have so far.

With regard to future expectations, the meaning of good oral health differed a great deal depending on earlier experiences. Some had high demands, including white, straight teeth and no caries, to be satisfied. Others who had received more dental care had lower expectations:

In the future, I will have ... good teeth, but I will have to pull some of them out or, yes—remove them and put in a porcelain tooth or whatever they call it.

The planning of future dental visits was considered very important, both by dental attendees and non-attendees. Among the reasons given was the belief that oral problems and large expenses for dental care could be avoided in that way. Although some informants associated dental care with pain and inconvenience and also "something necessarily painful", this was not generally considered as a reason to refrain from dental visits. However, for some, pain in connection with dental treatment was seen as a cause of dental fear, which could lead to avoiding further dental visits in the long run. The informants considered it risky to avoid dental care, as this could possibly lead to future oral problems.

Actually, I haven't seen a dentist since I got the crown. I think that was five years ago. I suppose I have some kind of deep-rooted fear of dentists, and the longer it's been since I last saw a dentist, the more I shy away from going. I suppose I'm a bit worried that there will be a lot of problems with my teeth.

# Worries about oral health

Worries about future oral health problems, as a consequence of the lack of control of oral hygiene habits, were reported. Informants with present or former caries problems and with old fillings stated that this led to a feeling of uneasiness that was more severe for some informants. For some of the informants, who had experienced severe caries, it had led to a constant awareness of being at risk of new lesions or fillings that might have to be replaced. Severe caries problems in early childhood were discussed by those who had been very caries-active as children. Even if the caries problems had come to an end in adulthood, the memories were reported to remain and lead to insecurity about the informant's oral health situation. However, the uneasiness did not always persist in adult life, if the caries situation was stabilized

I have some problems every now and again. I've had cavities, for instance, and I feel that that's been bugging me for a long time.

The informants with experience of dental traumas described these as a source of anxiety, as it was difficult to know what would happen in the future with the restorations (filling, crown or implant). Injuries seemed to be associated with insecurity about the future oral health of the informants, irrespective of the extent or the cause of the injury. New injuries might also occur:

Well, since... everything has been rolling along really well for so many years, so I haven't really thought about what to do in the future, but I still play hockey.

There were some worries about how to avoid chewing problems or dentures in the future, sometimes despite good self-rated oral hygiene and dental care. Relatives with severe caries problems or other oral problems causing bad oral health led to thoughts about possible heredity. Furthermore, it raised questions about what could be done in addition to good oral hygiene to keep the teeth and the mouth healthy in the long run:

My granny, for instance, she's had cancer of the gums. My granddad had some prosthetic teeth in his mouth—so, of course, I think about it and I think a lot about looking after my teeth now.

The informants mentioned that the cost of dental care was a cause for concern, especially for non-attendees.

It's not cheap to see a dentist—then, on the other hand, I suppose you have to look at it as an investment, to avoid cavities and suchlike before it's too late.

In contrast to those who were anxious to take care of their teeth, it was said that "some other" young people do not feel responsible for their teeth, they "live for the day" and do not "invest" in dental care, because they think it is too expensive. Dental care insurance was discussed as a possibility to avoid high dental costs in the future. However, insurance was hardly seen as an alternative by those who were in great need of dental care because the insurance premium would be too high. The cost of orthodontic treatment in adulthood was perceived as being too high and prevented them from seeking such care.

The informants asserted that if one takes care of the teeth, dental care will be cheap. But if a person gets a caries lesion, the cost of treatment was thought to be extremely high. Only those in gainful employment were considered to be able to afford dental care. It was also a question of priorities; some informants did not want to spend their money on dental care even if they could afford it:

Yes, but right now, it's a question of money—unfortunately, it's like that. Well, you think—yes, it's a lot of money. Then, the fact that I haven't really done anything about it—I suppose laziness comes into the picture—and finding a good dentist—this thing about changing dentists, like, all the time, it's like finding a new hairdresser. I think it's a big bother.

# **Discussion**

The aim of this study was to explore and describe OHRQoL of young adults. The results of the analysis were summarized in a theme: The perceived control of OHRQOL of young adults is dependent on their future prospects of oral health, in relation to their perceptions of past and present own oral health. Three main categories emerged from the analyses: Past experiences, Present situation and Future prospects. The category of "Past experiences" contained experiences of Oral health, symptoms and disease during childhood and adolescence but also views on Received dental care. The second category, "Present situation", contained three subcategories: Self-perceived oral health, Oral health habits and Oral health impacts on social life. Two sub-categories emerged under the third category, "Future prospects": Beliefs about oral health and Worries about oral health.

Inglehart & Bagramian (2002) concluded that when assessing OHRQoL, it is important to find out about the individuals' past experience. When the informants in our study described their oral health experience it was often associated with caries or the absence of dental caries. Caries seemed to be of great concern, although many Swedish young adults have no personal experience of the disease. The majority of children and adolescents in Sweden have no caries lesions where fillings are needed (Nordenram, 2012). The informants in our study did not particularly reflect on gingivitis as a consequence of bad oral hygiene, and comments about possible tooth loss in the future were sparse. However, Ericsson et al. (2009) reported poor oral hygiene in a study of 19-year-old Swedes. Experiences of other, more obvious problems, like trauma and aesthetic matters, caused a lot of concern among the informants. Surprisingly, a large number of the informants in this study had experienced trauma. This is in agreement with findings by Glendor (2009), who described traumatic injuries as an increasing problem that is mainly related to the environment and activity of the individual.

Social support from dental staff and parents emerged in the study as being most important during childhood and adolescence. The importance of social support found in our study confirmed the results from a study of Australian young adults (Brennan, 2009), while an American study among adults found that lack of financial support, but not social support, reduced OHRQoL (Maida, 2012).

The awareness of risk factors for caries seemed to be good in this group, compared with the findings by Östberg et al. (2002), which indicated that oral health awareness among Swedish adolescents was poor. Although the informants in our study had knowledge of the causal connection between oral hygiene, sugar consumption and caries, they often failed to perform proper daily oral hygiene. Periodically, lack of motivation led to concern and, sometimes, to bad conscience. If dental visits are limited to once a year or every second year, the patients have to keep up their level of oral hygiene for quite a long time without feedback, which might lead to poor oral hygiene. Hugoson et al. (2007) found that an oral hygiene prevention programme for young adults with follow-up every second month was more successful than programmes where the patients visited the dentist for information and instruction less often. Renewed information or more frequent follow-ups than regular check-ups might be useful but costly and difficult to organize. Choo et al. (2001) argued that oral health promotion should be integrated in general public health programmes. Likewise, Watt & Sheiham (2012) concluded that the best way to reduce oral disease in the long run is to integrate oral health promotion in general health improvement strategies. It was suggested by Choo et al. (2001) and Mårtensson et al. (2004), that media campaigns might enhance the awareness of oral health. There is a large commercial market for oral hygiene products, which may sometimes lead to confusion about what to use rather than to better oral hygiene habits.

In an American study (Kiyak, 2008), fear of bad breath, blurred speech, concern about appearance and pain, were reported to impact young adults' social life, which is in agreement with what we found in our study. Adolescence and young adulthood is a period of establishing new social contacts and romantic relationships (Hendry & Kloep, 2002). This could probably be one reason why the appearance of the orofacial area is of great concern to young adults. In a Swedish population survey, one out of four in the age group 20-39 years was dissatisfied with the condition of his/her teeth (Nordenram, 2012). Similarly,

minor aesthetic concerns among German university students had significant effects on the perceived OHRQoL, according to Klages et al. (2004).

In this study, the informants believed that three main factors were the most important for oral health: good oral hygiene, avoidance of sugar and regular visits to a dentist. Regular dental care was also seen as protection against high dental costs in the future. However, dental anxiety and pain in connection with dental treatment were not seen as main obstacles to dental visits. Broadbent et al. (2006) concluded that oral health beliefs were associated with dental health behaviour, which was indicated also in our study. Some of our informants had not reflected much on their future oral health but hoped for the best. Likewise, Östberg & Abrahamsson (2013) found that those who believed oral health to be a matter of chance experienced poor self-perceived oral health.

Some informants in the study who had experienced oral problems seemed to have low expectations on their oral health in the future. This is in agreement with what Carr (2001) proposed, namely that expectations are the result of experiences. Thus, poor health could lead to low expectations on health in the future. One way to improve health for people with low expectations would, according to Carr (2001), be to make them aware of the situation and to help them "take control over and improve their own health".

The uncertain economic situation of young people depends, in part, on the employment situation and the fact that many of them study longer than was usual before (Hendry & Kloep, 2002; Arnett, 2007). A subsidy of SEK 300 per year may not be enough to encourage dental care use among young adults. Being employed was regarded by the informants as a requirement for being able to afford dental care. Young people may have other priorities than dental care (Östberg et al., 2010). One way to reduce the cost of dental care might be to join a capitation plan, where the patients pay a fixed fee for dental care. Furthermore, Johansson et al. (2007) and Andrén Andås et al. (2014) found that patients in a capitation plan received more preventive care than patients in the fee-for-service system.

# Methodological considerations

The design chosen for this study was a qualitative method with the aim to obtain broad as well as deep knowledge of how young adults express their concerns about their OHRQOL. In a qualitative analysis, the reliability should be scrutinized through evaluation of *credibility*, *dependability* and *transferability* (Graneheim & Lundman, 2004; Krippendorff, 2012).

In our study, *credibility* was established by transcription of the interviews, shortly after data collection by one of the authors (GJ). The text was read and analysed independently by the two authors. Furthermore, the sample was strategic to get a representative selection of young adults with regard to age, sex, education and dental attendance as well as dental care regime (PDS or private care). The socioeconomic level was described with reference to education, but other criteria, like ethnicity, might have broadened the scope of the findings. Still, different socioeconomic factors are often correlated (Nordenram, 2012). The informants were interviewed away from the dental clinic in calm and quiet settings, which enhanced the possibilities of relaxed communication. One matter that could possibly have influenced the results was that the informants knew that they were later going to discuss some existing OHRQoL measures (Johansson et al., 2014). This may have increased their awareness of their OHRQoL.

Those declining to participate are, as always, a concern. They may have had divergent perspectives or less interest in the research in question, which might have generated other aspects. The reasons given were plausible, for example that they had moved to other places for studying or to find a job.

Dependability in a qualitative study measures to what extent the results can be confirmed by others and in a similar context. In this study, dependability was established by consensus between the two authors at the second step of the analysis. Thorough detailed descriptions of the analysis process in combination with quotations from the data can be considered to strengthen the *transferability* of the study.

# Conclusion

The OHRQoL of young adults is dependent on their experiences of their own oral health in childhood and received dental care, but also on their present self-perceived oral health, oral health habits and social life, together with their expectations of their future oral health. The findings in this study indicate that the oral health awareness and needs of young adults, as well as their expectations of oral care, merit further follow-up.

# Acknowledgements

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# Paper III

# Measuring oral health from a public health perspective

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# Abstract

The paper aims to analyse measures of oral health-related quality of life (OHQOL) from a Public Health perspective. Twenty-two measures were analysed conceptually as to their mirroring of the Public Health principles: empowerment, participation, holism and equity. Elements of empowerment were found in connection with application of the measures. Participation was found in using lay opinions during development in 12 measures. All measures analysed had elements of a holistic approach so far that they were not wholly biological. Two measures captured positive health effects. Measures were available for all ages, various languages and populations, an element of equity. No measure was wholly compatible with Public Health. They were based on a utilitarian theory not in full accordance with modern health promotion. There is a need to develop measures that more obviously capture the positive aspects of health and health as a process, as well as the personal perspective of oral health.

# Key words

Measures, oral health, oral health-related quality of life, public health

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# Mätning av oral hälsa ur ett folkhälsoperspektiv

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# Sammanfattning

Syftet med studien var att analysera m\u00e4tinstrument f\u00f6r sj\u00e4lvrapporterad munh\u00e4lsorelaterad livskvalitet ur ett folkh\u00e4lsoperspektiv. H\u00e4lsorelaterad livskvalitet har kommit i fokus under senare \u00e4r och innefattar en helhetssyn p\u00e4 m\u00e4nniskan. Detta syns\u00e4tt p\u00e4 h\u00e4lsa ligger till grund f\u00f6r modernt folkh\u00e4lsoarbete. Tjugotv\u00e4 m\u00e4tinstrument analyserades med utg\u00e4ngspunkt fr\u00e4n de teorier de baserats p\u00e4 och p\u00e4 vilket s\u00e4tt de speglade n\u00e4gra av de principer som praktiskt folkh\u00e4lsoarbete bygger p\u00e4: empowerment, "klientdeltagande", holism och j\u00e4mlikhet.

Resultatet visade att empowerment i viss utsträckning kunde identifieras vid användning av mätinstrumenten. Klientdeltagande förekom i 12 av mätinstrumenten då utformningen av frågeställningarna i mätinstrumenten baserades på intervjuer med målgruppen. Samtliga analyserade mätinstrument hade en holistisk ansats i bemärkelsen att de inkluderade psykologiska och sociala aspekter av välbefinnande. Endast två mätinstrument innehöll frågeställningar om positiva effekter av munhälsa. Jämlikhetsaspekten tillgodosågs genom att mätinstrumenten var anpassade för individer i alla åldrar, till olika språk och till olika populationer.

Inga mätinstrument var helt utformade i enlighet med principerna för folkhälsoarbete då de baseras på en utilitaristisk teori som beskriver nedsatt förmåga som oacceptabel och som därmed inte är i överensstämmelse med modernt folkhälsoarbete. Det finns behov av att utveckla mätinstrument som tydligare omfattar positiva aspekter av munhälsa och beskriver hälsa som en process, och som i större omfattning innefattar individens syn på munhälsa.

### Introduction

The general the health concept, as well as the idea of public health, have both developed gradually. Since the WHO definition in 1948, health is no longer considered as something that a person simply has got, but it is created over time as a process, without any starting or final point (82). Public health has been described as "a social and political concept aimed at improving health, prolonging life and improving the quality of life among whole populations through health promotion, disease prevention and other forms of health intervention" (80, p 3). Public health covers a multitude of ways of working for the best of the public. A widening of the concept of public health has been made though health promotion - sometimes called "the new public health" (58). Health promotion is defined as the process of enabling people to increase control over, and to improve their health (82, p.1). Health promotion is also described as a social and political process that aims to strengthen the individual's skills and capabilities but also to change social, environmental and economic circumstances on a community level for improving health (82). Schou & Locker (60, p.182) consider health promotion as the modern equivalent of the public health movement of the 19th century.

A part of both health and health promotion concerns the oral cavity. Oral health like general health has traditionally been defined as the absence of disease. However, the view of oral health has also gradually changed, especially during the last decades. Focus has shifted from a biologically defined disease view to a holistic multidimensional perspective, and oral health is now considered necessary for obtaining an essential part of general health in terms of well-being and quality of life (34). This can be illustrated by the definition of dental (oral) public health as "the science and art of preventing oral disease, promoting oral health and improving the quality of life through the organised efforts of society" (18, p. 9). The widening concept of oral health emphasises the importance of connecting the mouth with the rest of the body and with the person to whom the body belongs (72). Sheiham (63) suggests that oral health promotion should be integrated with health promotion in general, since oral health is also influenced by socio-political factors. The promoting factors as well as the risk factors are to a large extent the same. There is consensus nowadays on this multidimensional and dynamic perspective on health as well as on oral health. There has been an intense theoretical development opening new conceptual dimensions.

Still, theory is not enough – for creation of empirical knowledge, measurement is essential. There is however, no non-theoretical measurement. All measuring presupposes a theoretical and conceptual understanding of what should be measured (9). This is, indeed the gist of measurement validity, the measuring of what is intended to be measured.

Running parallel to the described development, several new indices have been developed. They were initially designated as socio-dental indicators or subjective oral health indicators but are nowadays more usually referred to as measures of oral healthrelated quality of life, in this paper called OHRQOL. The shift of term is based on the assumption that the functional and psychosocial impacts they document must, of necessity, affect the quality of life. This assumption has not been subject to any critical scrutiny in dentistry, which, according to Locker & Allen (37) makes it somewhat unclear what exactly is being measured by indexes of OHQOL. This terminological change could be seen as a consequence of the growing concern among members of the health care system, as well as among the public, that the ultimate goal of medicine and health care must be quality of life and not simply the cure of disease and the forestalling of death (51). In the light of this it would be relevant to study if, in the field of oral health promotion, the theoretical development of the concepts also can be traced in other ways in the measures that have been used. More specifically, the question becomes: do the available measures for OHRQOL, reflect any of the principles of health promotion, though they were not developed for this specific purpose?

Based upon the WHO Working Group's development of basic principles for health promotion, Rootman (58) presented seven principles for practical health promoting work, according to Public Health ideas. Four of these principles; empowerment, participation, holism and equity may be possible to connect with the measures for OHRQOL found in this study. Health Promotion initiatives should also, related to Roothman be: intersectorial, multi-strategic and sustainable (58). These aspects of health promotion are not part of this study because they refer more to application strategies of health promotion projects. The four principles empowerment, participation, holism and equity were chosen, because they were considered as more appropriate on an individual level than the three more comprehensive ones (intersectorial, multistrategic and sustainable). The measures were analysed with a theoretical and conceptual approach in the meaning that the content

of the measures has been interpreted considering their theoretical starting-points for oral health and OHRQOL, and in accordance with the Public Health ideas

Thus, health promotion initiatives should be empowering, meaning that they should enable individuals and communities to assume more power over the personal, socio-economic and environmental factors that affect their health (58). Empowerment is rare to find as a fully operational principle, but it has been described in a more practical manner as including factors like control, competence and self-esteem (55).

Practical work in health promotion should also be participatory, a consequence of achieved empowerment. Participation in health promotion implies that those who have a direct interest should also have the opportunity to participate in all stages of planning and evaluation of a health promotion initiative (58). The operational question then may be if such participation can be found in the construction of the measure.

The third principle, holism, means that physical, mental, social and even spiritual aspects of health and not only disease and disability, should be considered (58). Traditionally, mainly negative aspects like disease and illness have been connected with the health concept and the broader more positive aspects have been neglected. A pathogenetic, not a salutogenetic perspective, has been dominant. Positive health has been described as psychological well-being, physical health and the ability to cope with stressful situations (7). Antonovsky (4) considered the dynamics of well-being as a complement to the medical perspective, oriented towards treating a special disease.

The fourth principle of health promotion addressed is equity. It can be achieved through a fair distribution of power and resources and by removing unfair inequalities that are avoidable (58). One way to reach equity is to enable people to take action in health promotion actions like planning, intervention and evaluation of health promotion (48). Equity also involves asking how accessible to public health different interventions are and an identification of the socio-economic composition of the population reached (57).

Operationally, measures should be available and applicable for all, irrespective of nationality, race, sex, age or socio-economic level.

The aim was to describe measures of OHRQOL, their definition of the concept, dimensions and applications in accordance with the health promotion principles and thereby with the Public Health approach. Operationally the following questions emerge:

- Do the measures focus conditions for empowerment and own activity?
- Can participation be found in construction and application of the measures?
- Do the measures contain physical, psychological, social, or spiritual aspects and do they focus positive health or do they just address degrees of symptoms and problems?
- Are the measures available and applicable for all?

# Material and methods

Study selection

Papers concerning OHRQOL measures were identified by a search of the literature covering January 1st 1990 to December 31st, 2006. This search period was selected because it was primarily during the last decade of the twentieth century that the development of OHRQOL measures emerged (67). The search was done by applying the Medline database (EntrezPubMed www.nebi.nlm.nih.gov/entrez/query. fcgi) and the MeSH terms used were dental health and oral health in combination with self-rated, selfassessed, subjective, measures and quality of life. The search terms were broad to capture both the measures which headings contained the formerly used terms self-rated oral health with its synonyms and the more recently used concept OHRQOL. Moreover, a second search was performed by scrutinising the obtained articles' reference lists for additional studies, also searching for the measures and authors that evolved from the articles. Papers that contained multidimensional measures of self-rated oral health or OHROOL, were written in English, and presented with an abstract, were included in the study. Exclusion criteria were papers not containing OHRQOL measures, papers written in languages other than English and papers without abstracts.

# Search results

The initial literature search produced 3009 papers reporting 22 measures for self-rated oral health and OHRQOL. The hits in the search are shown in Table 1. After removing duplicates and applying the exclusion criteria, the number of the papers was reduced. The main reason for not including some of the remaining papers was that the initial search was very broad, yielding hits that, for example, captured purely clinical variables, risk factors of disease, single

symptoms and functions, dental fear, dry mouth, dental attendance, dental health behaviour and oral hygiene. Data from the conference in Chapel Hill 1996 (63) were also used to get information beyond that presented in the available papers.

Table 1. The results of search in PubMed database.

Search-terms and combinations	Number of hits
Oral health and self-rated	24
Oral health and self-assessed	21
Oral health and subjective	98
Oral health and measures	437
QOL and oral health	16

Basis for classification

Twenty-two of the identified OHRQOL measures were analysed as to their reflection of the four principles of health promotion as described above: empowerment, participation, holism and equity.

There are four issues in the aim for operationalization in the classification of the measures. First, the judgement if a measure contained an element of empowerment was determined by how the reading comprehension level was reported during the development of the particular measure. This is only one, although necessary, of the aspects that create empowerment. The reason to choose it was that it was possible to assess in terms of health literacy levels reported when the measures were used. Other aspects of empowerment refer more to the context where the measure is used.

Second, the participation was estimated through lay people's participation in the development of an OHRQOL measure, as an element of capturing the client's perspective on OHRQOL. The lay perspective can be considered as an aspect of public health, enabling individuals and groups to state how their health is to be promoted and recognising the value of their perspective (46). The degree of lay perspective during the development of the OHRQOL measures was therefore one of the questions in the present study.

Third, the holistic perspective was judged in terms of whether the measures favour a generic approach of oral health and therefore also incorporate aspects related to the environment, like physical, mental, social and spiritual factors. The holistic aspects of the analysed measures were judged in relation to the domains of each measure. Another aspect that was considered was whether the measures captured possible salutogenic aspects of oral health. The holistic character of the measures was thus decided through their content of different dimensions in the measures.

Fourth, the measures were evaluated with respect to equity. One question in this study was accordingly if there are suitable OHRQOL measures available for all kinds of individuals and populations irrespective of age, gender, ethnicity, and social class to make empowerment and participation possible for all stakeholders.

# Quality assessment

The analysis was carried out by one of the authors (GJ) under the head-guidance of one of the co-authors (BS). All authors were involved in the analysis and writing process which imply that the analyses also were judged relevant by another four persons.

# Results

A list of the measures is shown in Table 2. One of the measures was composite, including both the perspectives of the professional and the patient; the Oral Health Index, OHX (10) more recently called the Oral Health Score, OHS (11). The DELTA measure (31) was excluded from the analysis since no information could be found concerning the development of the measure. Some measures analysed in this study were parts of more extensive measures: Oral Health Quality of Life Inventory, OH-QoL (12), Dental Health Questions from the Rand Health Insurance Study (16) and Oral Health-Related Quality of Life, OHQOL (32).

The measures for OHRQOL were analysed from two perspectives, on one hand in relation to the development process and on the other hand in relation to their contents. Concerning theoretical startingpoints, seven of the measures were based on a theoretical framework, emerging from the WHO classification of Impairments, Disability and Handicap (81), as presented by Locker (35). The seven measures were: The Dental Impact on Daily Living, DIDL (33), Oral Health Impact Profile, and OHIP 49 (66) including three short versions of OHIP (65, 2, 36), Subjective Oral Health Status Indicators, SOHSI (40) and Oral Impact on Daily Performances, OIDP (1). The OIDP was later modified in some studies (62, 42, 43). The aims of these indices were to measure the impact of dental disease on an individual level.

The Oral Health Quality of Life Inventory, OH-QoL (12) was developed to measure a person's subjective well-being in relation to his or her oral health and functional status. The measure was based on works by Gerin et al. (22), Frisch et al. (21) and Frisch (20).

The Social Impact of Dental Disease, SIDD (14) was one of the first socio-dental indicators. It was

Table 2. An overview of oral health-related specific measures (OHRQOL).

Author/ Year	Index	Aims to describe	Dimensions
Cushing et al., 1986	SIDD Social Impact of Dental Disease	social and psychological impact of dental disease	functional, social interaction, comfort and well-being, self-image
Atchison & Dolan, 1990	GOHAI General Oral Health Assessment Index	psychosocial impacts of dental disease	physical function, psychosocial function, pain or discomfort
Dolan et al., 1991	Dental Health Questions from the Rand Health Insurance Study	pain, worry and concern with social interaction from problems with teeth and gums	pain, worry, concern with social interactions
Strauss & Hunt, 1993	DIP The Dental Impact Profile	how natural teeth or dentures positively or negatively affects social, psychological and biological well-being and QOL	eating, health/well-being, social relations, romance
Locker & Miller, 1994	SOHSI Subjective Oral Health Status Indicators	the functional, social and psychological outcomes of oral disorders	chewing ability, speaking ability, oral and facial pain, eating impact, problems in communication and social relations, limitations in daily activities, worry and concern
Slade & Spencer, 1994	OHIP (49) Oral Impact Profile	self-reported dysfunction discomfort and disability, attributed to oral conditions	functional limitation, physical pain psychological discomfort, physical disability, social disability
Slade & Spencer, 1997	OHIP (14)	a sub-sets of items from OHIP (49)	see OHIP (49)
Locker & Allen, 2002	OHIP (14)	an alternative short form of OHIP with minimal floor effect	see OHIP (49)
Allen & Locker, 2002	OHIP 20 (OHIP-Edent) for edentulous people	a short form of OHIP appropriate for edentulous people	see OHIP (49)
Leao & Sheiham, 1996	DIDL, The Dental Impact Profile on Daily Living	a socio-dental method that measures the impacts of oral health status on the quality of daily living	comfort, appearance, pain, performance and eating restriction
Adulyan & Sheiham, 1996	OIDP, Oral Impacts on Daily Performances	the serious oral impact on the person's ability to perform daily activities	eating and enjoying food, speaking and pronouncing clearly, cleaning teeth, sleeping and relaxing, smiling and laughing without embarrasment, maintain usual emotional state, carrying out work and social role, enjoying contact with people
Kressin et al., 1996	OHQOL, Oral Health Related Quality of Life	the impact of oral health on quality of life	if problems with teeth and gums affected daily life and social activities, if appearance caused avoidance of communications
Cornell et al., 1997	OH-QoL, Oral Health Quality of Life Inventory	satisfaction and importance of oral health and functional status	performance and satisfaction
Östberg et al., 1999	POH, Self-perceived Oral Health	self-perception of oral and functional status	single-item rating of oral health, bleeding gums and dental appearance
McGrath & Bedi, 2000	OHQoL-UK, Oral Health- related Quality of Life	the impact of oral health on quality of life	physical, social and psychological aspect
Jokovic et al., 2002	CPQ 11-14 Child Perceptions Questionnaire	the impact of oral and oro-facial conditions	oral symptoms, functional limitations, emotional well-being and social well- being

# Table 2. Continuation...

Author/ Year	Index	Aims to describe	Dimensions
Locker et al., 2002	FIS, Family Impact Scale	the family impact of oral and oro-facial disorders	parental/family activities, parental, emotions, family conflict
Jokovic et al., 2003	P-CPQ, Parental- Caregivers Perceptions Questionnaire	parental/care-givers perception perception of the oral health-related quality of life for children	oral symptoms, functional limitations, emotional well-being, social well-being
Burke et al., 2003	OHS, Oral Health Index	to provide numerical measure of the overall state of patient's oral health	comfort, aesthetics and functional combined with clinical data
Jokovic et al., 2004	CPQ 8-10, Child Perception Questionnaire	the impact of oral and oro-facial conditions	oral symptoms, functional limitations, emotional and social well-being
Gherunpong et al., 2004	Child-OIDP	the serious oral impact on childrens ability to perform daily activities	eating, speaking, cleaning mouth, doing activity, sleeping, emotion, smiling, study, social contact
Jocovic et al., 2006	Child Perceptions Questionnaire for 11- 14 year old children	oral symptoms, functional limitations. emotional well-being, social well- being	see CPQ 11-14

structed in accordance with a health status model of Wolinsky & Wolinsky (78) and focused on how dental disease impacted on three major aspects of health status: physical, social, and psychological aspects (61).

The Oral Health Related Quality of Life – United Kingdom, OHQoL-UK was developed in UK (33-34), based on the results of a study with a qualitative approach. Data were collected through open-ended question interviews, capturing aspects that reduce as well as add to quality of life. The effect on, as well as the impact of, quality of life is measured by the 16 items in OHQoL-UK.

Some measures were partly built on literature reviews. The items in the Child Perceptions Questionnaire, CPQ 11-14 (29), Family Impact Scale, FIS (39) and CPQ 8-10 (28) were for example based on existing oral health and child health status measures, assessed by an expert panel and further adjusted after in depth interviews with parents and child patients. The theoretical base for the Parental-Caregivers Perceptions, P-CPQ index (27) was similar to that of CPQ 11-14. The items in the General Oral Health Assessment Index, the GOHAI (6) and OH-QoL were also partly based on synthesis of the literature in combination with expert judgement.

Dental Questions from the Rand Health Insurance Study were based on the WHO definition on health from 1948 (83), on a paper by Ware et al. (76), and on the Oral Health-Related Quality of Life measure, OHQOL which had its theoretical foundation in an earlier work by Stewart & Ware (69). The Self-perceived Oral Health index, POH (84) was based on

a model used by Hamp & Nilsson (24). Theoretical starting-points were not described in the Dental Impact Profile, DIP (70), and in the Oral Health Score, OHS (11).

# Empowerment

Elements of empowerment are shown in Table 3. Aspects of health literacy were not present in any of the measures. Neither were control, nor self-esteem. However, the level of education among the respondents was measured as a part of the socio-demographic data in some studies where GOHAI (75,79,53), OHIP (79,59) and OHIP 14 (15,49) were applied. In connection with the application of OHIP in Brazil, De Olivera (15) assessed the level of education of the mothers of adolescents and in a study in Brazil (11) interviews were used instead of questionnaire because some of the participants were illiterate. With a somewhat stretched interpretation, this could be considered as a concern for health literacy.

Table 3. Empowerment and participation

Empowerment criteria	Measures
Control	none
Health literacy	GOHAI, OHIP 49, OHIP 14
Self-esteem	none
Participation criteria	Measures
Lay perspective	SIDD, GOHAI, DIP, OHIP, DIDL, OIDP, OHQoLUK, CPQ8, CPQ11-14, Family impact Scale, P-CPQ, Child- OIDP

# Participation

Lay people's perspectives on oral health, shown in Table 3, were used for the development of some measures. CPQ11-14, CPQ 8-10 and FIS were for instance based on a selection of items in reviews of available oral health status measures, in combination with interviews with children and in P-CPQ with parents of child patients. An open-ended interview study was also performed during the development of OHIP 49, where patients were asked about statements of experiences of dental disorders. The foundation for items when developing the GOHAI was a combination of already existing items in reviews of available oral health status measures, and results of consultations with health providers and patients.

The DIP items were based on qualitative interviews with dentists, social scientists and consumers, while the items in the OHQoL-UK were developed using open-ended interviews with a large sample of United Kingdom residents. When developing the SIDD and the DIDL interviews with lay people were also used. The translation of OIDP to Greek was tested through lay peoples' perspective in interviews (74). In the measures Dental Health Questions from the Rand Health Study, OH-QoL, OHQOL, POH, and OHS contained no intentions to collect information of lay people.

# Equity

Aspects connected with equity are shown in Table 4. OHRQOL measures are nowadays available appropriate for all ages. Some of the indices are developed for special target groups. Many of the existing measures, like GOHAI and OHIP 49, were primarily developed to measure impact of oral disease among older adults, but have been further validated and tested in populations where younger adults were included (5,8). Recently, there has been a development of measures especially adjusted for children: CPQ 11-14 (23), a short version, CPQ 8-10 (28), Child OIPD (56) and for parents P-CPO, and family FIS (39).

OIDP, GOHAI, and OHIP have all been applied and validated in populations with different ethnicity. For instance, OIDP and OHIP 14 have been tested in a study in the UK where 19 ethnic groups were represented (3), while GOHAI was used for measuring self-reported oral health among Hispanics and African-Americans (5). OHIP 49 has also been used to make cross-cultural comparisons between two Canadian populations and an Australian population (50). OIDP (including modified versions) has been frequently used outside English-speaking countries (43,74,68,13,47,52). During the develop-

ment of OHRQoL-UK, it was tested among a general UK population representing different ethnic groups, and among South-east Asian and Chinese people. Newton et al. (50) used SOHSI for measuring self-assessed health in four different ethnic groups in England, while OH-QoL was used in three ethnic language groups in Texas, of which one was Spanish-speaking (12). DIP (70) and OHIP 20 (2) are other measures that were evaluated in different ethnic groups during their development.

As some of the measures have been applied in populations in other countries they have been translated into other languages. GOHAI, OHIP and OIDP are, for example, available in a number of different languages (Table 4).

# Table 4. Equity

Equity criteria	Measures
Measures available and a	pplicable for:
Children, parents	POH, CPQ 11-14, Family Impact scale, P-CPQ, CPQ 8-10, Child-OIDP
Elderly (65+)	GOHAI, DIP, SOHSI, OHIP, DIDL; OIDP, OH-QoL, OHQoL-UK, OHS
Measures validated for:	
Ethnic minorities	GOHAI, DIP, SOSHI, OHIP, OH-Qol OHQoL-UK
Socio-economically deprived	SIDD, GOHAI, SOSHI, OHIP 14, DIDL, OHQoL-UK
Measures available in dif	ferent
Languages:	OHIP 14, OHIP 49, GOHAI, OIDP, SOHSI, CPQ 11-14, OHQoL-UK

The use of OHRQOL measures in different socioeconomic groups was less widespread but GOHAI has been tested in a population of disadvantaged people with mainly unemployed, less educated Hispanic- and Afro-Americans (5). SOHSI was used for determining the relationship between self-assessed oral health status and age, gender, employment status and educational level (50). During the development of OHRQOL-UK the instrument was tested on groups with different socio-economic backgrounds and among employed as well as unemployed people (34). Hyde et al (38) used OHIP 14 to measure OHRQOL after an intervention for welfare recipients.

# Holism

The holistic approach of the measures is presented in Table 5. Environmental aspects as well as physical, psychological and social dimensions were captured in most of the measures while spiritual dimensions were absent. Physical, psychological and social dimensions were present in GOHAI, Dental Health Questions from the RAND Health Study, SOSHI, OHIP 49, OHIP 14 (65), OHIP 14 (36), OHIP 20, DIDL and OIDP. OHQOL contains social aspects of oral health, and POH captures physical aspects and appearance. Appearance is a dimension present in POH and in OHS.

Well-being aspects were present in the SIDD index, the DIP index, and in the more recently developed measures CPQ 11-14 and P-CPQ. OHQoL-UK measures positive as well as negative effects and impacts of oral health on the quality of life. The Dental Impact Profile DIP (70), measures how natural teeth and dentures positively and negatively affect quality of life.

# Table 5. Holism

Holism criteria	Measures
Physical aspects, Psychological well-being and Social well-being	SIDD, GOHAI; Dental Health Questions from the Rand Health Insurance Study, DIP, SOHSI, OHIP, DIDL, OIDP, OHQol-UK, CPQ 11-14, CPQ 8-11, Family Impact Scale, P-CPQ, Child OIDP
Social aspects of health	OHQOL
Physical aspects of oral health	POH
Physical and Psychological aspects of oral health Functional and Physical	OH-QoL
aspects of oral Health	OHS
Spiritual aspects	none
Salutogenetic perspective	DIP, OHQoL-UK

# Discussion

There has been much effort devoted to the area of oral health measures the last fifteen years. A great deal of this work has focused on further applications of some of the measures developed in the middle of the 1990's, on different settings and populations. There has been a lack of measures for children and adolescents, but four new indices have been developed for this group during recent years. Still a main result of the present analysis is that the analysed measures to some extent are in agreement with the Public Health. A few traces, which can be interpreted as reflections of empowerment, participation, holism and equity were found in the development and use of the measures of OHRQOL.

Different aspects of public health were analysed in

relation to the development of available OHRQOL measures. These principles were to some extent influencing and overlapping each other. Health literacy for example is connected both to empowerment and equity.

The lay peoples' perspective during the development of the measures was considered in some measures through qualitative interviews as far as could be documented. Most of the measures covered the physical, psychological and social aspects of oral health. Many of the OHRQOL measures were also equitable in that they were available for different age groups. Equity is a somewhat problematic concept in this circumstance since it cannot be secured though participation from samples of populations. To validate the measures among different populations can nevertheless be important because it is known that there might be differences between how people themselves define their needs and how professionals define them (57, p 215). Especially four of the measures, GOHAI, OHIP 49, OHIP 14 (61) and OIDP were tested among many groups. One limitation in this study was that only English language papers were assessed which can be misleading when judging the aspects of equity, since such aspects might be incorporated to a larger extent in papers written in other languages.

The development of different measures for selfrated oral health and later OHRQOL has to some extent followed the change in the health concept from WHO 1948, but the most frequently used indices have their theoretical starting-points in the WHO: International Classification of Impairments Disabilities and Handicap from 1980 (81). Based on this theoretical framework, they rather measure the negative aspects of oral disease than the oral health of an individual regarded as a resource for well-being and the possibility to live a good life. The more recently developed measure OHRQoL-UK, as well as the DIP, have a broader perspective and are also focused on well-being aspects of oral health and not only on negative consequences of oral disease.

Locker & Gibson (38) concluded that there was no consensus on how the concept positive health should be defined and that most definitions were lacking empirical referents or indicators. Positive aspects of health have been described as psychological wellbeing, life satisfaction and physical health. Salutogenic aspects can be captured by assessing the ability to cope with stressful situations (7). Values differ depending on the society people live in. A shift from survival values to self-expression values is evident,

following the economic development in the rich part of the world (26). Self-expression values are connected with human choices and autonomy emphasizing the well-being and promotive perspectives. However, the health concept and health promotion still develop and new OHRQOL measures will be following. Measures with their origins in ICDIH are based on social role theory and utilitarian tradition describing disability as a negative and unacceptable consequence of impairment (41).

Some authors' report lay participation with interview studies during the development of their measures. Since oral health is based on individual judgement (25), the perspective of the concept may differ between people, which make it difficult to establish an ideal measure. There might be other aspects that can be valuable to estimate. Trulson (73) for instance, found in interviews that orthodontic treatment could improve self-esteem and self-image. There is an on-going development of measures for children, but there is only one measure available for adolescents and no measure especially developed for young adults. Dental appearance, present among the items in some of the measures, can be considered valuable, especially among young people. Peoples' opinion of aspects being important when measuring OHRQOL might also change over time and other dimensions in the measures can then be demanded (44). Extensive longitudinal studies where processes can be estimated are also needed. GOHAI, OHIP and SOSHI have been used in longitudinal studies. Methodological problems have, however, been reported while using OHRQOL measures for that purpose (17, 64).

The analysed measures are to some extent in agreement with the Public Health. There are some elements that can be interpreted as a reflection of empowering, participatory, holistic and equitable content. The purposes for the measures were only slightly related to health promotion. Still, they are often used in such contexts, and the present analysis has shown that the anchoring of the measures in that discourse is very weak (71).

It might be possible to use the OHRQOL indices for measuring the outcome of health promotion activities. However, the indices may be rather insensitive for changes in the process of public health. Weintraub (77) recommended development of measures for health promotion programmes. That recommendation is still valid, as none of the currently available OHRQOL measures are compatible with the four aspects of Public Health that are assessed in this study.

# Conclusion

The theoretical basis of the health concept is mirrored in its measurement. Concerning the development in the use of measures for oral health, the perspectives are still predominantly disease-oriented, while there are only a few measures available including positive or salutogenic aspects of oral health. It is an urgent task to develop measures that more obviously capture the positive aspects of health as well as the personal perspective of oral health. Measuring health in a public health perspective assumes longitudinal studies, as health is regarded as a dynamic process that cannot be measured only at one point of time. Fulfilling such tasks could be an important step towards a Public Health approach in dentistry.

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# Paper IV

# ORIGINAL ARTICLE

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# Young adults' views on the relevance of three measures for oral health-related quality of life

Abstract: Objective: The aim of this study was to explore the views of young adults on the relevance of three measures of oral healthrelated quality of life (OHRQoL). Methods: Sixteen young adults aged 21-29 years were interviewed. The selection was strategic with reference to age (21-25 years.; 26-30 years), sex and education (university degree; upper secondary school). The interview guide covered areas on the content and construction of the measures: The Oral Health Impact Profile (OHIP), the Oral Impacts on Daily Performances (OIDP) and the Oral Health-Related Quality of Life UK (OHRQoL-UK). The data were analysed using qualitative content analysis. Results: A theme expressing the latent content was formulated during the data analysis: 'young adults' own experiences were reflected in their views on the OHRQoL measures'; that is, the experiences of young adults of own oral problems and aspects that were found to be especially important for their age group influenced their view on the measures. The self-reported ability to understand and answer the questions varied and the perceived advantages and disadvantages were almost equally distributed among the three measures. Conclusions: The OHIP, OIDP and OHRQoL-UK were evaluated as being equal by the young adults in this study, with regard both to their pros and cons. The clarity of the measures was regarded as the most important factor, while the length and assessment period were less significant.

Key words: oral health; quality of life; questionnaires; young adult

# Introduction

Oral health-related quality of life (OHRQoL) is affected by functional and psychosocial effects of oral conditions and, in turn, the way they affect health, well-being and quality of life (1). Inglehart and Bagramian defined OHRQoL as a person's own assessment of his or her well-being in connection with functional, psychological and social aspects, as well as pain and discomfort when these are related to orofacial concerns (2). Locker & Miller (3) found that younger adults were as likely as older adults to report oral health-related problems, such as dry mouth and problems with speaking. Furthermore, younger subjects were more likely to report pain and other oral symptoms than older adults (3, 4). Östberg et al. (5) observed that young adults and older people who were affected by physical, psychological or social impacts of poor oral health considered the impact to be greater than did middle-aged individuals. On the other hand, Maida et al. (6) showed that both the youngest and the oldest patients rated their OHRQoL more positively than middleaged people and suggested that this was due to the mostly good oral health in younger people and that the oldest compared their health with their peers. Reports show that young adults are profoundly concerned about aesthetic aspects (7), and dental aesthetics has also been found to have a significant effect on young adults' OHRQoL (8).

The economic and technological changes in Western society are rapid since recent decades. Many choices are available to young people today but the changes have also led to destabilization of the authority of traditional institutions and to insecurity, as their future may be perceived as more insecure than before. Factors such as a fluctuating and uncertain employment market and the demands for higher education and qualifications have led to a delayed transition into adulthood among young people in Western society of today (9). Furthermore, unemployment is high among young adults (10). The share of young adults in Sweden who neither work, nor study, is increasing, which may result, in the long run, in an impaired financial situation for the individual (11). Ostberg et al. (12) found that 35% of 19-year-olds did not plan for regular dental visits after the age of 20, when they will be charged for the care. However, self-perceived oral health among young Swedish adults was reported as good in one study (13).

A large number of measures have been developed to estimate the impact of oral health-related quality of life (OHRQoL). Three often used measures are the Oral Health Impact Profile, OHIP (14), translated into Swedish and validated by Larsson et al. (15), the Oral Impacts on Daily Performances, OIDP (16), translated into Swedish and validated by Östberg et al. (5), and the Oral Health-Related Quality of Life UK, OHRQoL-UK (17), translated by Hakeberg (personal communication). The theoretical starting point for OHIP and OIDP was the WHO document 'Classification of Impairments, Disability and Handicap' which brought about a main focus on negative aspects of oral status while OHRQoL-UK has a broader perspective that also captures positive aspects of oral health. These, as well as other similar measures, were developed for middle-aged or older adults. However, no measure has been especially developed for the age group of young adults (18).

Hence, it is unclear whether young adults consider the content of the OHRQoL instruments to be significant for their oral health and oral health-related quality of life. When using such instruments in dental care and scientific studies, the views of the target group are important and should be considered. The aim of this study was to explore the views of young adults on the relevance of three commonly used measures of OHRQoL.

# Methods

# Design and informants

For this study, a qualitative approach using interviews for data collection was chosen to describe and explore the views of young adults on three available measures for OHRQoL. The study was conducted in the south-west of Sweden, and the sampling of informants was made to represent the age cohort 21–29 years. The selection was strategic with reference to age, sex and education. The sample comprised 16 participants (eight 21–25 years; eight 26–30 years). Nine informants were females and seven were males. Half of the informants had completed upper secondary school, and the rest were studying at the local university or had a university degree.

Fourteen informants were regular attendees at a dental clinic (10 at a PDS clinic, four at a private clinic) and two were non-attendees. Staff at the clinics and the interviewer selected patients from the clinics' recall systems in relation to the criteria. The two non-attendees were recruited from the local university.

# Interview guide

The interview guide covered areas in the following three OHRQoL measures: the OHIP, OIDP and OHRQoL-UK (14, 16, 17). The questions about the instruments were based on the dimensions in each instrument.

The OHIP contains 49 items with seven dimensions: functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability and social handicap (14). Each dimension contains seven items about the frequency of the experienced problems.

The original version of the OIDP contained eight items on daily performances (16), later expanded to nine items in some studies (19). The Swedish version comprises nine items about the frequency of and to what extent the experienced oral problems affect physical, social and psychological performance in daily life (5).

The OHRQoL-UK contains three dimensions: physical, social and psychological aspects of oral health-related quality of life; altogether, 16 items inquiring about positive or negative effects of oral health on quality of life (17).

The main entry questions in the interviews were as follows: 'What is your opinion of the content of the measures'? and 'What did you think about answering the questions'?

# Data collection

The interviews were carried out during June to December 2010 by the main author GJ (a registered dental hygienist and public health lecturer). The participants were initially contacted by ordinary mail and asked if they were willing to participate in the study. They were then contacted by phone and an appointment for an interview was arranged with those who were willing to participate. By way of introduction, the participants were asked to read and fill out the two self-reported questionnaires at home (the OHIP-S and the OHRQoL-UK) and bring the filled-out questionnaires to the interview session. The third measure – the OIDP – was responded to orally in connection with the interview. The purpose of asking the participants to respond to the items in the three measures was to introduce them to the measures to be discussed later during

Table 1. An example of a meaning unit, a condensed meaning unit and a code

Meaning unit	Condensed meaning unit	Code
It is difficult to answer as I feel I have so few (oral) problems	Difficult to answer due to few oral problems	Few oral problems

the interviews. During the interviews, the participants were encouraged to describe their understanding and interpretation of the content of the three measures. The interviews took place in neutral environments outside dental clinics and lasted between 25 and 50 min. They were audiotaped and transcribed verbatim by the interviewer shortly after the interview.

# Data analysis

The data analysis was carried out using qualitative content analysis in accordance with Graneheim and Lundman (20). Content analysis can be qualitative as well as quantitative (21). The characteristic of a qualitative content analysis is that the manifest as well as the latent content is sought. The manifest content can be described as the visible, obvious components in the text, while the latent content deals with relationships between different parts of the manifest content and an interpretation of the underlying meaning of the text (20). This study focused on both the manifest and the latent content. The data were systematically analysed by two persons in the research team (GJ and ALÖ). After transcription of the interviews, the next step was to carefully read through all the interviews several times, line by line, to obtain a sense of the whole and to get an overview of the text. The interviews were then analysed to identify statements that represented each participant's perception of the measures. Statements with the same main content were discussed and reflected upon by the researchers and grouped into meaning units. The meaning units were then condensed and labelled with codes. One example is shown in Table 1. The codes were compared and reflected upon and through comparing them with respect to similarities and dissimilarities they were sorted into categories with shared content, further subdivided into subcategories. These constitute the manifest content. The underlying meaning of the study, the latent content, was discussed and formulated into a theme by the researchers.

# Ethics

Information concerning the aim of the study, voluntary participation and confidentiality was given to the participants. Written informed consent was obtained. The Regional Ethical Review Board in Lund (Reg. no. 2009/124) approved the study.

# Results

The latent content was formulated into a theme: 'Young adults' own experiences were reflected in their views on OHRQoL measures'. Two main categories with subcategories constituted the manifest content (Fig. 1). The main categories were 'Content appropriateness' and 'Construction of measures'. The quotations chosen to illustrate the results represent a diversity of interview protocols.

# Content appropriateness

The experience of their own oral health had an impact on how the informants evaluated the content of the measures. One reason for considering the content or parts of the measures as inappropriate was good self-rated oral health and no experience of severe oral problems. For young adults with good selfrated oral health, oral problems were seen as something that occurs later in life or something that others of the same age might have. The participants could, nevertheless, be anxious about what might happen to their teeth in the future; however, it was stated that 'if you don't have problems, you don't reflect on your mouth at all', or that a possible impact was not even considered until the problem was made obvious by the questions in the measures.

The informants consequently regarded own oral problems as important. Despite the stated lack of oral problems, many informants suffered from a number of physically and psychosocially related oral problems. For instance, worries about caries (former or active) and problems with wisdom teeth were reported.

# Physical problems experienced in relation to the measures

Pain in the mouth was experienced quite often by some participants; for instance, shooting pain from gingival recessions,

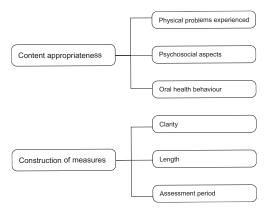


Fig. 1. Themes and categories in the study.

sometimes occurring when eating or brushing the teeth or when using snuff. Pain was also reported from wisdom teeth and when undergoing dental treatment. Aphthous ulcers were reported as being very painful and the source of much suffering. Such aspects made items about pain relevant to the participants. Pain in the mouth was, however, directly inquired about only in the OHIP:

When I have pain in my mouth I don't want to talk or eat because it hurts and affects everything...

Eating problems, such as being unable to feel the taste of the food or experiencing pain during food intake, were thus considered to have an impact on OHRQoL. All three measures (OHIP, OIDP and OHRQoL-UK) contained items inquiring whether oral health problems had entailed blurred speech. Such problems were mentioned merely by one participant. On the other hand, it was described as an important aspect of oral function. These aspects were present in all three measures to a varying extent and degree.

### Psychosocial aspects experienced in relation to the measures

Anxiety about having bad breath could influence the wellbeing of the young adults and was regarded as an obstacle to social relations with others. It was also seen as a possible consequence of snuff use that was completely contrary to the desire of having a fresh mouth. Items concerning bad breath were present in two of the measures, the OHIP and the OHR-QoL-UK.

What we haven't talked about at all is bad breath – I am in contact with people a lot, sometimes close contact – so that's something I think about a lot – and I think it (breath) has a great impact...

Aesthetics was regarded as one of the most important aspects of OHRQoL, especially by individuals without other oral problems. Those having experienced caries, shooting pain or other dental problems often seemed to focus on these problems more than on aesthetics. However, oral aesthetics was considered very important in general for young people, not least for their social life:

Yes, appearance – I think so. It has to do with daring to smile and laugh and to feel comfortable with your oral health and your teeth. Since you're young and social life and that is important, I think it makes a difference. So, yes, appearance is definitely important.

Aesthetic disadvantages mentioned were worries about 'yellow teeth', caused, for example by coffee or snuff. Bleaching of the teeth was described as an available but expensive method to get whiter teeth. To have white, straight teeth without too much space between them was considered ideal. Many informants had had orthodontic treatment and the majority was satisfied with the treatment. All three OHRQoL measures contained items concerning aesthetic matters. In the OHIP and the OIDP, these aspects are negatively formulated,

while in the OHRQoL-UK, positive as well as negative experiences of aesthetics can be indicated. Consequences of dental traumas – which could also affect the aesthetics of the teeth – were also a concern to some informants.

Oral health-related quality of life was related to self-confidence, according to the informants. Daring to smile without embarrassment and being able to eat with others were considered most important to their social life. Items on socializing with others are present in all three OHRQoL instruments; more detailed in the OHIP and more general in the OIDP and the OHRQoL-UK.

...how much you smile and laugh – if you have nice teeth and very good oral health......it affects your confidence

Thus, questions about whether you have been upset or irritated with others because of oral health problems were relevant to the target group. Some informants sometimes felt miserable and insecure because of their teeth. For example, pain from aphthae was said to cause irritation with immediate friends and relations. Items about irritation with others in connection with oral problems as described above are found in the OHIP and the OIDP. Worries about perceived poor own oral health could also cause sleeping problems, according to some informants. This was inquired about in all three instruments.

# Oral health behaviour in relation to the measures

The OHIP and OIDP ask about oral problems preventing proper oral hygiene, a matter frequently brought up by the participants themselves. The consequences of poor oral hygiene may affect the well-being of young adults:

I haven't always brushed my teeth properly – I've sort of brushed but not perfectly. I've swept over them for a few seconds and then gone to bed...

Thus, it was obvious that the informants were aware of the importance of good oral hygiene; however, they often found it difficult to maintain. Parents and dental staff in clinics and schools were often cited as having influenced oral hygiene habits from an early age.

Oral health habits could be influenced by economic circumstances, according to some participants. Dental care was described as expensive, and sometimes as an obstacle to regular dental visits. Asking about economic matters seems to be important; however, this was not performed to any greater extent in the measures:

I think that your economic situation...has a great impact on your quality of life

To summarize, the informants were familiar with the content of the three OHRQoL measures to a varying degree. Parts of the measures were regarded as appropriate, whereas other parts were more questionable. One commonly expressed view was that the measures mainly captured negative aspects and were too disease-oriented and probably more suitable for

older people, as many items concerned symptoms and problems that many of the participants had no experience of (such as items concerning prostheses and inability to chew). Nevertheless, many of the items seemed to be relevant to the target group. If a particular item was irrelevant to one person, there might be others in his/her age group with such symptoms.

# Construction of the measures

In general, the items in all three OHRQoL measures were considered easy to understand. The ability to fill out the selfreported questionnaires varied among the informants but the advantages and disadvantages were almost equally distributed among the three different instruments. The views on the OHIP were mostly that it was clear and easy to fill out. The OHRQoL-UK questionnaire was considered to mirror the positive aspects of the OHRQoL, containing more questions about health, and was also regarded as more suitable for younger individuals. However, it was obvious that the informants had problems with interpreting the meaning of positive aspects of health. Finally, the strength of the OIDP was expressed as being the depth of the items and how problems impact daily life, but a drawback is that it is mainly limited to respondents with oral problems.

Furthermore, one participant suggested digital information and instructions about how to fill out the questionnaires and to use a combination of the OHRQoL-UK and the OIDP measures in digital form.

# Clarity

The most important issue for the informants appeared to be the clarity of the items. The majority considered the items in all three measures to be easy to understand and answer; however, some regarded them as complicated and difficult to understand. The OHIP was appreciated and considered easy to understand. It was also regarded as more concrete than the other measures:

I think the questions were clear and distinct ... to me, the wording was clear and I felt that I could answer clearly, there was no real hesitation (OHIP)

However, some informants found the OHIP difficult to follow, because it contained too many questions, and they also felt that the wording did not appeal to them.

The OHRQoL-UK measure had to be explained because of the experienced lack of clarity about what was meant by positive aspects. However, some subjects found it too easy to reply 'no impact'. Instead of deciding on the negative or positive impacts, they simply chose the alternative 'no impact':

I got a little confused afterwards - I can't really figure out what I mean - this with positive and negative... (OHRQoL-UK)

The OIDP was considered to be more detailed and more profound than the other measures, as it takes the impact of oral health on a person's daily living into account, and this was

regarded as important. The possibility to elaborate further on a specific problem, by breaking it down and asking how often and how much it really impacted on the person's daily life, was considered to be of great value:

It is more complete as it has more questions in every question - what can you say - you have all those different... so then you can include more and get more detailed answers

Another view was that answering the questions in the OIDP made the informants realize the importance of the mouth in social situations. The OIDP was also seen as dealing more with what was outside of the mouth, such as social life and self-confidence, while the content of the OHIP was more focused on what was inside the mouth.

# Length

The number of items varies in the three measures, with the OHIP containing the largest number of items (49). The informants did not consider it particularly burdensome to fill out the self-reported questionnaires, even though some of questions required more reflection, which could be demanding. However, the questions could mostly be answered quite fast and were easy to understand.

Right, even if there were 49 questions I don't think it was hard work or difficult to get through, I thought it was clear enough, so it was, like, full steam ahead

On the contrary, some participants considered the questionnaires to be too comprehensive and too time-consuming to fill out. There could be a risk of incorrect answers, resulting in unreflective marking with a cross:

Yeah, then I felt sometimes that I'll just put a cross somewhere, because there are so many questions so I'll just cross something... there are so many questions so you just put a cross anywhere...

The OIDP was considered as short and easy to respond to when orally presented.

# Assessment period

The time perspective for the assessment period is different in the three measures. In the OHIP, the respondents are asked to remember 1 year back in time and in the OIDP 6 months, while the items in the OHRQoL-UK concern the current status of the subject's OHRQoL. Remembering what happened as long ago as 1 year was seen as somewhat doubtful. It could also be a problem to remember and think about the assessment period while answering the questions:

I think it could be a disadvantage that you have to remember what happened last year - not everybody remembers what last year was like - if they have had pain or problems with pronouncing words or with eating - or think about it when they fill out the forms

A fixed assessment period was considered by some as making it more difficult to answer the questions in the measures. There was no consensus as to whether 6 months or 1 year was preferable; some even thought that experiences from a person's whole life should be inquired about.

# Discussion

In this qualitative study, young adults reflected on three measures of oral health-related quality of life (OHRQoL). The measures were considered as more or less relevant, depending on the participants' own views of QoL and the impact they considered that oral health had on their QoL. Experiences of own oral problems and aspects of special importance to their age group were found to influence their view on the content of the measures. Furthermore, the construction of the measure, with regard to its clarity, length and assessment period, seemed to be of importance.

The people studied in a qualitative study have a life and a culture of their own, and to understand them and the context of which they are a part, we must be able to appreciate and describe their culture. One way to do that might be to uncover their way of communicating and their unique problems (22). Qualitative studies concerning young adults' views on oral health or OHRQoL are lacking. Likewise, young adults' views on existing measures of OHRQoL have been sparsely explored from a qualitative point of view. However, in-depth interviews have been used in the development of some of the available OHRQoL measures; for instance, the OHIP (14, 18).

The trustworthiness of this study is best described using the terms credibility, dependability and transferability (20). It was attempted to ensure trustworthiness of the data collection using a well-established dental hygienist and lecturer in public health to conduct the interviews. The interviewer transcribed the interviews soon after conducting them, to minimize the risk of misunderstanding. Furthermore, the data collection method was chosen with the aim of letting the young adults express freely, using their own words, their views on the three measures, which resulted in variations in the responses. Credibility in the study was reached through selecting participants to provide a good representation of young adults. Sex, age, education and use of dental care varied. Two of the authors read all the transcripts and analysed the text independently, as a first step. Discussions were held and a negotiated consensus completed the final step of the analysis to strengthen the dependability of the study. Quotations chosen to illustrate the findings strengthened the transferability of the study (20). However, the living conditions for young adults differ between and within countries today. In an international perspective, many countries undergo similar economical, technological and social progress (9); therefore, the results might be transferred to most Western countries.

The design of this study aimed to encourage the participants to consider and value the three measures in relation to their own situation and to the age group to which they belonged. It may have been difficult for the participants to discuss the measures immediately after responding to the items, but it was obvious that some had made a great effort to read and understand the content, while others put less effort into the task. This can be seen as a limitation of the study. To prevent this problem, two of the measures (OHIP and OHRQOL-UK) were sent in advance, together with an information letter, before the interview (23).

The life situation for young adults concerning employment and economy varies considerably. Due to Arnett (24), the transition from childhood to adulthood has been increasingly prolonged for young people in recent years. As a result of economic changes and difficulties of finding a job and a place to live on their own, young people stay longer in education and live with their parents longer than before. Their economic situation differs considerably, depending on their employment or educational status. It is characteristic for this age group to have different interests and to establish social settings and leisure activities (9). For this reason, it may be difficult to identify and appraise their priorities; for example, with regard to their oral health, as was shown in this study.

Self-reported oral health during young adulthood has been reported as good, in general (6, 13), but in the current study, oral problems were fairly frequently reported. This is similar to what Cohen-Carneiro et al. (4) and Locker and Miller (3) described. As mentioned above, Östberg et al. (12) found that young people often did not plan regular dental visits when they will be charged for the care. This may put into question the attitudes of young adults to their self-rated oral health-related quality of life and to the dental service offered.

Aesthetic aspects seemed to be of great importance in this study, in concordance with findings in 20- to 25-year-old Swedes by Stenberg et al. (7). Having white, straight teeth were described as being important for socialization; for example, finding new friends and meeting a partner. It seemed that filling out the questionnaires (OHIP and OHRQoL-UK) and answering the questions in the OIDP raised the level of consciousness about oral problems that could occur even among those who had no such experiences. Good oral health and good-looking teeth were also considered to contribute to a better QoL. It is a key issue to empower young people to be aware of oral health, not least considering the decreasing dental care use among young adults (25). One possible way of making young adults pay attention to oral health matters, especially young non-attendees, would be to incorporate questions about OHRQoL in population studies on self-reported general health. Patients being asked a few simple questions about their OHRQoL in connection with dental visits could also potentially raise their awareness of oral health. Answering questions in routine dental care might not, however, result in the same depth of reflection as in a study.

The informants observed that two of the question batteries only reflected negative aspects of health. It might have been an eye-opener to them that oral health could have a broader meaning than merely the absence of symptoms. This would probably have occurred in connection with answering the questions about OHRQoL. Nevertheless, trying to understand the meaning of positive aspects of health and filling out the

OHRQoL-UK without an explanation of the concept seemed to cause problems to the informants. This might reflect the focus on prevention and treating of disease in dentistry and that the definition of oral health traditionally has been 'absence of disease' rather than well-being. Positive health in itself is a somewhat vague concept, without an agreed definition, containing aspects as well-being, life satisfaction and physical health (26). Huppert & Whittington (27) and MacEntee (28) concluded that it was important to measure the positive as well as the negative aspects of well-being in connection with QoL. More attention should be paid to lack of enjoyment and satisfaction, as these experiences may be even worse for health than the presence of negative aspects. In this context, a potential challenge is to increase the knowledge of the determinants of health and quality of life.

Concerning the construction of the measures, only one participant mentioned the possibility to computerize the measures. This is somewhat surprising, as young adults are frequent computer and Internet users. Bhinder et al. (29) found that the willingness to complete an online health-related quality-of-life questionnaire (HRQoL) was associated with young age, employment and school enrolment. The demand for personal support when filling out the questionnaires in this study may be due to the young individuals' lack of practice of communicating oral health and life quality matters.

From our findings, it is difficult to conclude that one of the three measures would be the preferred measure for young adults. The length of the measures was not considered as particularly important. It was rather the clarity of the measures that seemed to be the most important issue for the participants. Thus, the choice of instrument should be guided by purpose and circumstances, whether for research or clinical use. Further investigations of young adults' attitudes to their OHRQoL might provide a basis for specific measures for this age group.

# Conclusions

The OHIP, OIDP and OHRQoL-UK were evaluated as being equal by the young adults in this study, with regard both to their pros and cons. The clarity of the measures was regarded as the most important factor, while the length and assessment period were of less significance.

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