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

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ABSTRACT

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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 för- och 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.

I. 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).

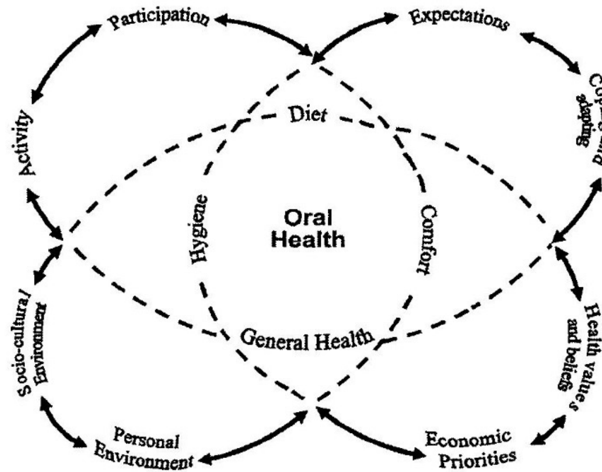

Figure 1. Refined model of oral health. Reproduced by permission from Springer. Brondani & MacEntee 2014. Quality of life research 2014;23:1093.

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.

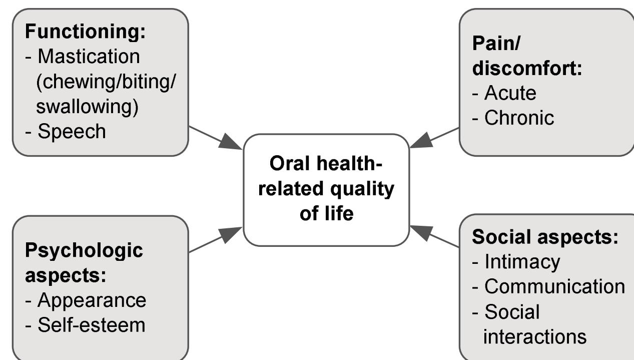

Figure 2. The main components of OHRQOL. Reproduced by permission of Quintessence Publishing. Inglehart & Bagramian. 2002. Oral Health-Related Quality of Life. p. 3. Quintessence Publishing Co, Inc.

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 OHRQoL is not always clarified in the measures. Locker (2007) also suggested that a questionnaire assessing OHRQoL 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. It may be a challenge for providers of dental service to meet needs and expectations of young adults.

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-for-service 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 QoL, 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 OHRQoL (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 public dental service (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 OHRQoL

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 semi-structured 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. Initially, the 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 QHRQoL 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.

Attitudes to dental care costs

Attitudes to given functions within dental care	Costs queried	Costs accepted
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.”*

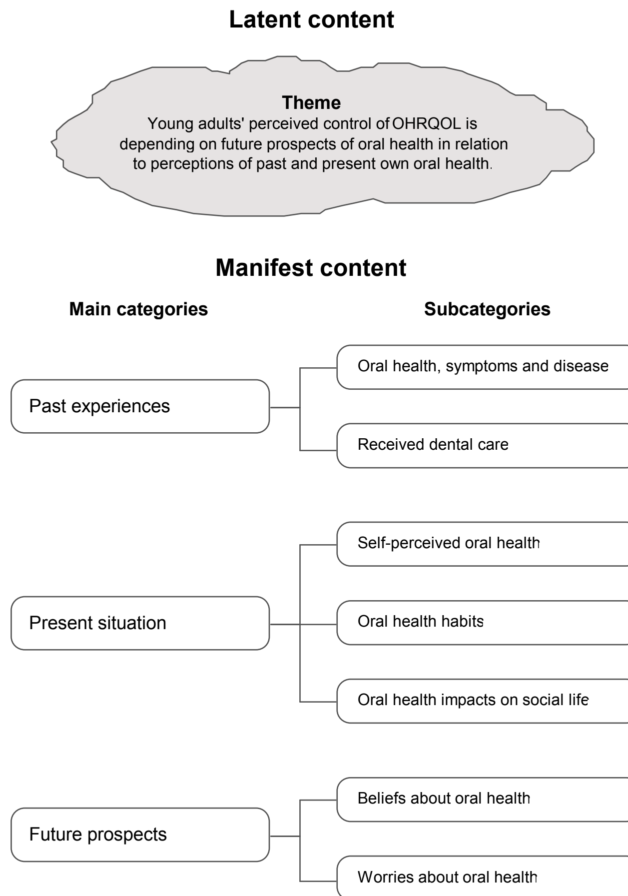

Figure 4. Latent and manifest content with categories and subcategories in Paper II.

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.

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	POH
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.

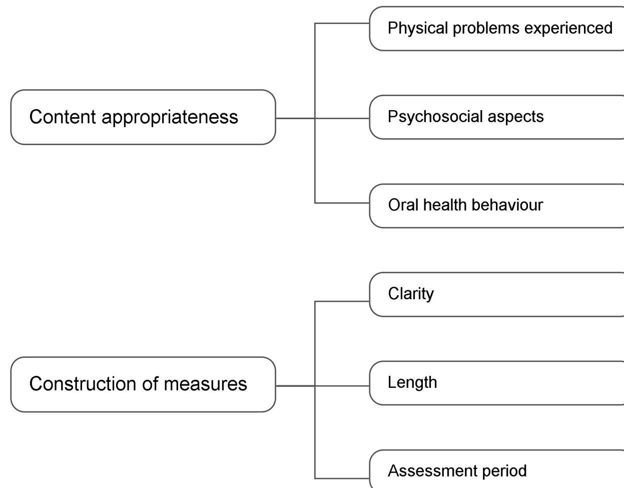

Figure 5. Themes and categories in Paper IV.

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 informants considered most often their own oral health as 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 socio-economic 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 all 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 open-ended 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 OHRQoL measures in Table 2

CHILD-OIDP
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CPQ 8 -11 – 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.