SOLGUN FOLKE

XEROSTOMIA

Views among health care professionals and the main concern among afflicted adults

ACADEMIA REGIA ODONTOLOGICA MALMOGIENSIS

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XEROSTOMIA

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PREFACE

This thesis is based on two original papers, which will be referred to in the text by their Roman numerals:

Paper I Folke, S., Fridlund, B., & Paulsson, G. (2009). Views of xerostomia among health care professionals: a qualitative study. *Journal of Clinical Nursing, 18*(6), 791-798.

Paper II Folke, S., Paulsson, G., Fridlund, B., & Söderfeldt, B. (2009). The subjective meaning of xerostomia – an aggravating misery. *International Journal of Qualitative Studies on Health and Well-being, 4*, 245-255.

ABSTRACT

The aims of the two studies were to survey and describe views of xerostomia among health care professionals and to explore, among afflicted adults the main concern associated with xerostomia and attempted remedies.

Two empirical studies of qualitative design were conducted. In Paper I, sixteen participants were interviewed representing health care professionals with various exposures to patients with xerostomia. The data were subjected to qualitative content analysis. In Paper II, fifteen participants with subjective complaints of dry mouth were subjected to qualitative, conversational style interviews. The grounded theory method was applied for data analysis.

The latent content of Paper I was formulated into a theme: *Xerostomia is a well-known problem yet, there is inadequate management of patients with xerostomia*. The findings identified three major categories expressing the manifest content: *awareness of xerostomia, indifferent attitude, and insufficient support*. Health care professionals recognised xerostomia as a common and escalating problem, particularly among elderly. Yet, the problem received little attention. In Paper II, a model was generated to elucidate the main concerns of xerostomia among afflicted individuals and how they handle various aspects of their condition. The core category was labelled *an aggravating misery*, meaning

that xerostomia has a devastating and debilitating impact on multiple domains of well-being. The model involves three different categories/remedial strategies, namely *professional consultation, search for affirmation, and social withdrawal*. All three categories express what the participants do to resolve their problems with xerostomia. In general, the participants perceived xerostomia as a burden and as a condition they were constantly reminded of. The participants also expressed a feeling of resignation due to lack of confirmation and support.

The findings underscore that xerostomia is not a trivial condition for those afflicted. Oral impairment as well as physical and psychosocial consequences of xerostomia had negative impact on the participants´ quality of life. Health care professionals felt that xerostomia was an underestimated problem and that clinical symptoms and subsequent treatment were often ignored. The findings revealed that xerostomia is not only a predicament of the oral cavity but affects the individual as a whole. This is of particular concern among elderly as the incidence of xerostomia increases with advancing age due to chronic diseases and adverse side effects of medications.

In summary, it is essential to adopt a holistic view, and to provide additional education and improved interdisciplinary collaboration to manage and care for individuals suffering from xerostomia.

SAMMANFATTNING

Syftet med de båda studierna var att undersöka och beskriva hälso- och sjukvårdspersonals syn på xerostomi och vad xerostomi innebär för drabbade vuxna samt vad de gör för att hantera sin situation.

Två empiriska studier med kvalitativ ansats genomfördes. I studie I intervjuades sexton personer verksamma inom hälso- och sjukvård och som hade varierande erfarenhet av att möta patienter med xerostomi. Insamlade data analyserades med hjälp av kvalitativ innehållsanalys. I studie II genomfördes kvalitativa intervjuer med femton personer i olika åldrar och som uttryckt subjektiva besvär med muntorrhet. Grounded theory användes som analysmetod.

Resultatet i studie I sammanfattades i temat: *Xerostomi är ett välkänt problem, trots detta är omhändertagandet av patienter med xerostomi otillräckligt,* vilket uttrycker den underliggande meningen i den samlade texten. Det konkreta innehållet beskrevs i tre kategorier; *kännedom om xerostomi, likgiltig attityd* samt *otillräckligt stöd*. Hälso- och sjukvårdspersonalen ansåg xerostomi vara ett vanligt och ökande problem, speciellt bland äldre men trots det ägnades liten uppmärksamhet åt patienternas symtom. I studie II, utvecklades en modell som belyser den huvudsakliga innebörden av xerostomi hos de drabbade. Kärnkategorin betecknades: *ett tilltagande elände*, vilket innebär att xerostomi hade en destruktiv och negativ inverkan på många aspekter av de drabbades välbefinnande. Modellen innehåller tre olika kategorier/underlättande strategier: *professionell konsultation,*

sökande av bekräftelse och *socialt tillbakadragande* vilka förklarar vad deltagarna i studien gjorde för att hantera sina problem med xerostomi. Xerostomi upplevdes vara en börda och ett symtom de ständigt påmindes om. Vidare, uttryckte de drabbade en känsla av uppgivienhet till följd av brist på bekräftelse och stöd.

Resultaten understryker att xerostomi inte är ett banalt problem för den som drabbats. Problem från munhålan och psykosociala konsekvenser av xerostomi hade negativ inverkan på deltagarnas välbefinnande och livskvalitet. Hälso- och sjukvårdspersonalen ansåg att problemet underskattades och ignorerades samt att patienternas symtom ofta negligerades. Resultaten avslöjar komplexiteten med xerostomi, vilket vidgar fokus från munhålan till individen som en helhet. Antalet personer som drabbas av xerostomi ökar med stigande ålder beroende på kroniska sjukdomar och ogynsamma bieffekter från medicinering. Således är ett holistiskt synsätt, en förbättrad utbildning och ett utökat interdisciplinärt samarbete väsentligt för att öka insikten om xerostomi samt stödet för och omhändertagandet av individer som drabbats.

INTRODUCTION

Xerostomia

The definition of xerostomia varies in epidemiological studies. The most commonly accepted definition is that xerostomia is an individual, subjective feeling of dry mouth which can exist in the presence of a normal or an abnormal salivary flow rate (Fox, *et al.,* 1985; 1987; Närhi, 1994; Nederfors, 2000; Kaplan, *et al.,* 2008).

The prevalence of xerostomia in population-based samples has been reported to vary from 0.9 percent to 64.8 percent, maybe explained by definitional variations (Thomson, *et al.,* 1999; Guggenheimer & Moore, 2003; Orellana, *et al.,* 2006). Although xerostomia may occur at any age, (Bergdahl, 2000; Bågesund, *et al.,* 2000; Ikebe, *et al.,* 2001; Thomson, *et al.,* 2006a,b) the condition is more frequent with increasing age (Ship, *et al.,* 2002). More than 25 percent of elderly complain of daily recurring mouth dryness (Orrelana, *et al.,* 2006). Johansson, *et al.,* (2009) found the prevalence of subjective mouth dryness to increase almost linearly among 4,714 individuals when studied longitudinally from age 50 to 65. It is also known that women report mouth dryness more often than men (Johansson, *et al.,* 2008; 2009). However, one should be conscious of the fact that xerostomia is not a result of aging *per se*. It may also occur in association with certain diseases (Pajukoski, *et al.,* 2001; von Bultzinglöwen, *et al.,* 2007; Cho, *et al.,* 2009) or as a drug related side effect (Nagler & Hershkovich, 2004; Shinkai, *et al.,* 2006). The latter is more common among elderly.

Saliva

Saliva plays a crucial role in oral health (Screebny, 1992) by forming a protein derived surface coating of the oral mucosa, teeth and oral appliances. This salivary film is important for oral health and for oral comfort (Lindh, 2003). Salivary components serve to maintain a neutral oral pH at 6.5-7.4 and to remineralize lost tooth structure from early dental decay. Further, salivary antibodies protect the oral hard and soft tissues against virulent microorganisms invading the oral cavity. Among saliva enzymes, amylase is particularly important during digestion as it breaks down complex carbohydrates entering the gastrointestinal tract (Screebny, 2000). Saliva also acts as a solvent for and a carrier of flavoured substances which facilitate and augment the perception of taste (Mese & Matsuo, 2007). Further, saliva performs the important function of diluting substances introduced into the oral cavity, a process referred to as salivary clearance or oral clearance (Sreebny, 2000).

About ninety percent of mixed, whole saliva is derived from the parotid, submandibular, and sublingual glands. Minor salivary glands which are scattered throughout the oral mucosa contribute to the remaining ten percent of the mixed fluid. The submandibular glands are the major contributors to resting (unstimulated) saliva, and the parotid glands are the major producers of stimulated saliva (van Nieuw Amerongen, *et al.,* 2002). Saliva originates primarily from acinar serous and mucous cells. The minor salivary glands contribute only small quantities to whole saliva, but their mucous secretions play a significant role in the lubrication and protection of the oral mucosa (Tabak, *et al.,* 2006). Their mucin component is also important for swallowing and speech (Navazesh, 1994).

Salivary gland hypofunction (SGH) results in a decreased amount of produced saliva as well as an alteration of its composition. SGH is defined to exist when whole unstimulated saliva production or whole chewing stimulated saliva production is <0.1ml/minute or <0.7ml/minute, respectively (Navazesh & Kumar, 2008). The unstimulated flow rate of <0.1ml/minute is also used as a diagnostic criterion for Sjögren´s syndrome, a systemic autoimmune disease,

which also impairs the salivary glands and causes xerostomia (Vitali, *et al.,* 2002). When salivary secretion is reduced in volume and becomes highly concentrated, it loses its ability to lubricate, moisten and protect both teeth and oral soft tissues. This loss of the antimicrobial, buffering, remineralizing and cleansing properties of saliva may cause rapid colonization of oral microorganisms (Almståhl, 2008) and subsequently result in severe dental caries (Fox, 2004) and extensive candida infections, both intra- and extraorally (angular cheilitis), (Leung, *et al.,* 2007; Campisi, *et al.,* 2008).

The flow of saliva does not always correlate with a sensation of oral dryness (Fox, *et al.,* 1987; Hay, *et al.,* 1998; Field, *et al.,* 2001a; Baker, *et al.,* 2007; Wiener, *et al.,* 2010). Wolff and Kleinberg (1998) observed that individuals with dry mouth exhibited reduced salivary fluid thickness on their lips and hard palate. More recent studies (Eliasson, *et al.,* 2009) have corroborated these observations which seem to indicate that saliva from minor labial glands influence the perception of dry mouth regardless of normal or reduced whole saliva flow. Further, individuals, regardless of age and gender, who have smaller salivary glands and less secretion seem to be at greater risk for developing xerostomia (Lee, *et al.,* 2002; Ono, *et al.,* 2009). It seems therefore prudent, as Thomson (2005) has emphasized, to clearly define which aspect of dry mouth is being investigated, SGH or xerostomia.

Xerostomia - causes

The most common causes of xerostomia are conditions or circumstances that result in alterations of salivary gland function, either quantitatively or qualitatively (Guggenheimer & Moore, 2003; Tabak, *et al.,* 2006). The most frequent cause of salivary alterations relate to medications (Porter, *et al.,* 2004; Shinkai, *et al.,* 2006). A wide variety of prescription and over-the-counter drugs are known to induce hyposalivation and result in complaints of dry mouth (Guggenheimer & Moore, 2003; Thomson, *et al.,* 2006b, 2006c). An association between transient xerostomia and the total number of various drugs has also been reported (Nederfors, *et al.,*1997; Field, *et al.,* 2001b). Radiation therapy of head and neck

malignancies causes transient or irreversible damage to salivary gland tissue, which in turn changes salivary composition, decreases or in some cases, permanently cease saliva production (Wijers, *et al.,* 2002; Jensen, *et al.,* 2003*;* Bruce, 2004; Dirix, *et al.,* 2006; 2008; Jham, *et al.,* 2008). Another major cause of xerostomia is systemic disease. A large number of health conditions have adverse effects on salivary gland function which subsequently yield complaints of oral dryness. Diabetes, thyroid conditions, cystic fibrosis, HIV and connective tissue diseases like Sjögren´s syndrome represent such disorders (Fox, *et al.,* 2000; Navazesh, *et al.,* 2000; Moore, *et al.,* 2001; von Bultzinglöwen, *et al.,* 2007; Gubois, *et al.,* 2008; Stewart, *et al.,* 2008; Busato, *et al.,* 2009; Nittayananta, *et al.,* 2010). Further, changes in patient cognitive state, psychological distress, mouth breathing and sensory alterations in the oral cavity are often associated with an awareness of oral dryness (Locker, 1993; Anttila, *et al.,* 1998; Bergdahl & Bergdahl, 2000).

Health and quality of life

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO, 1948). Health can also be understood as peoples´ happiness, their fitness, and their ability to work or just the absence of obvious physical and mental pathology. The biomedical perspective of health, (Boorse, 1977) is the most predominant in medicine and dentistry. It requires scientific observations and knowledge to ascertain health or to discover disease. During the last decades, there has, however, been a shift from a disease-centred, biomedical approach to a holistic perspective. The latter pertains to the whole person within his or her context and not to whether an organ is diagnosed as healthy or diseased. According to the holistic theory, Nordenfelt (2007) characterizes an individual as completely healthy if, and only if, he or she has the ability, under a given standard of circumstances, to reach all his or her vital goals. Vital goals are a person's most essential aspirations in life and health is seen as an essential prerequisite to reach them. Illness, on the other hand, represents perceived problems such as pain, suffering or disability, irrespectively of diagnoses (Nordenfelt, 2007).

The factors that influence a person's sense of well-being are called conditions for quality of life (QoL). These refer to a general perception of pleasure, joy and satisfaction (Nordenfelt, 1993). QoL is dynamic and influenced by our personal and sociocultural environments. Health is seen as a relevant aspect of QoL but not entirely by itself (Brülde & Tengland, 2003). QoL is also influenced by psychological state of mind, functional capacity and coping mechanisms while environmental factors such as work, housing conditions and social networks are examples of external conditions. The debate on issues like these continues with many aspects brought in, like in the existentialist paradigm on quality of life (MacEntee, 2006).

Oral health

Whether the oral hard and soft tissues are healthy or diseased is usually confirmed by the dental profession while the subjective perception of oral health can only be perceived and expressed by the individual (Folke & Paulsson, 2010). Previously, oral health has been regarded as being of biomedical character and has often been referred to as the absence of oral disease From a holistic perspective, oral health is a part of general health and has been described as: *a standard of health of the oral and related tissues which enables an individual to eat, speak and socialise without active disease, discomfort or embarrassment and which contributes to well-being* (Kay & Locker, 1997 p.8).

The existentialist model of oral health by MacEntee (2006), later refined by Brondani, *et al.* (2007), focuses on positive oral health. In this context, oral impairment and disorders neither are, nor necessarily associate with, restrictions, dysfunctions or illness. Comfort, general health, diet and hygiene are major components of oral health which in turn are strongly influenced by personal and sociocultural environments, participation as well as coping and adaptation. MacEntee and Prosth (2007) suggested that humans over time may develop a capacity to adapt to and endure oral ill health and oral impairments and thereby modify their expectations and activities.

Oral health related quality of life and xerostomia

Oral health related quality of life (OHRQoL) is a multidimensional construct that refers to the extent to which oral disorders disrupt an individual's normal functions (Gift, *et al.,* 1997; Inglehart & Bargamain, 2002). Oral diseases and associated disorders may affect physical and psychosocial functions which in turn can lead to negative health perceptions, dissatisfaction with oral health and diminished quality of life (Hay, *et al.,* 2001; Rydholm & Strang, 2002; Locker, 2003; Baker, *et al.,* 2007). Recently, the relationship between xerostomia and well-being has systematically been investigated using different health related quality of life scales (Wärnberg-Gerdin, *et al.,* 2005; Matear, *et al.,* 2006; Tomson, *et al.,* 2006a; Ikebe, *et al.,* 2007; Dirix, *et al.,* 2008). Their studies clearly indicate a correlation between quality of life and oral health among individuals with xerostomia.

Xerostomia can have devastating consequences with regard to oral health, well-being and quality of life. The condition causes continuous oral discomfort, and patients generally report a sore, painful mouth, reoccurring dental caries and often express difficulties eating, articulating words and wearing a denture (Rostron, *et al.,* 2002; Cassolato & Turnbull, 2003; Ikebe, *et al.,* 2005; Jong-Lyel, *et al.,* 2006; Turner, *et al.,* 2007, 2008; Folke, *et al.,* 2009b). Altered taste perception and eating difficulties often result in nutritional problems (Budtz-Jörgensen, *et al.,* 2001). Sparse, viscous saliva contributes to halitosis (Nally, 1990; Nalcaci & Baran, 2007), and increases problems with taste (Mese & Matsuo, 2007).

There is a connect how we experience QoL and how we perceive our oral health (Benyamini, *et al.,* 2004). Locker and Gibson (2006), point out that there is a lack of consensus how to define positive health which consequently explains the difficulties to construct measures and indicators of oral health. As a result, the OHRQoL concept is very complex and therefore difficult to assess and measure (MacEntee & Prosth, 2007). Thus, oral health is best understood through clinical observations and self-reported indicators, symptoms and perceptions (Gift, *et al.* 1997).

Besides augmenting detrimental oral conditions, xerostomia impairs quality of life (Napenas, *et al.* 2009). Yet, it is considered to be one of the most inadequately diagnosed and managed oral health conditions (Friedman & Isfeld, 2008). Health care professionals tend to underestimate the severity of xerostomia compared to patient self-reported symptoms (Sreebny, 2000; Meirovitz, *et al.,* 2006; Folke, *et al.,* 2009a,b) while there also are reports that providers overestimate impairments of QoL for other conditions (Sampogna, 2010). These shortcomings call for health care providers to improve recognition and alleviation of symptoms and to minimize potential complications.

AIMS

The general aim was to survey and describe views of xerostomia among health care professionals and to explore, among afflicted adults, the main concern associated with xerostomia and attempted remedies.

The specific aims were:

I: to explore and describe views of xerostomia among health care professionals

II: to explore, among afflicted adults, the main concern of xerostomia and attempted remedies

MATERIAL AND METHODS

Design and methodological approach

The thesis consists of two empirical studies of qualitative design. Associated methods are considered appropriate when pursuing information about individual opinions, assessment and personal experiences (Kvale, 2009).

Paper I

A qualitative design was chosen to explore and describe views of xerostomia among health care professionals. Data, based on qualitative interviews and subsequently transcribed text, were examined using qualitative content analysis which is a process of collecting and organizing data to facilitate its systematic interpretation (Berg, 2004). It has been used differently in quantitative versus qualitative studies. The process in qualitative studies systematically analyzes and codes messages in any type of conversation (Kondracki, *et al.,* 2002). In addition, the content of the text may be categorized as manifest or latent. (Graneheim & Lundman, 2004). In Paper I, the analysis focused on both manifest and latent content of the transcribed text following interviews. The manifest content was identified when unambiguous statements existed, while the latent content was based on interpretation of the underlying meaning of the text.

Paper II

The inductive, comparative research method of "classical" grounded theory was chosen (Glaser & Strauss, 1967). Grounded theory is suitable for gaining a more profound understanding

of a phenomenon or to gain further knowledge of an area already explored. The method was originally developed by two sociologists, Glaser and Strauss (1967), and later modified by Strauss and Corbin (1998) and Charmaz (2006). Grounded theory aims at revealing the participants´ perspectives on the central issue under study and at conceptualizing patterns of human behaviour. Further, the aim is to generate substantive or formal theories, models or concepts from empirical data rather than to test existing hypotheses or theories (Glaser & Strauss, 1967). A substantive theory is applicable to a defined specific area, i.e. living with, or caring for patients with xerostomia whereas a formal theory is more general and has broader applications (Glaser & Strauss, 1967; Glaser, 1978). Systematic abstraction, constant comparison, and conceptualization of empirical data constitute the theory-generating process of a grounded theory study (Glaser & Strauss, 1967; Glaser, 1978; Hallberg, 2006).

Collection and analysis of each data set occur in close sequence during continuous processes. Initial open sampling aims at maximizing variations of descriptions. Subsequent theoretical sampling is guided by concepts generated from data analysis of previous interviews and written notes. Data collection continues until theoretical saturation is achieved, meaning that additional data do not contribute any new information. Grounded theory is built on symbolic interactionism and a meaning is constructed, developed and modified through social processes and social interactions between people. Thus, the intent of a grounded theory study is to envision a "reality", based on interactions between the researcher and the information provided by the informants (Glaser & Strauss, 1967; Glaser, 1978). As such, the grounded theory may be a valuable complement to clinical practice to promote both a better understanding of and a greater empathy for individuals suffering from xerostomia.

Participants

Paper I

Sixteen participants were selected representing a broad range of health care professionals with various exposures to patients with

xerostomia. The participants were strategically selected in reference to gender, age, occupation and years of professional experience. The cohort consisted of thirteen women and three men with a mean age of fifty-two years. They served as district nurses, physicians, dentists or dental hygienists. The interviewed participants had been professionally active between three to thirty-five years and were still associated with either private or public health care, including medical home care.

Paper II

The study group consisted of fifteen persons with subjective complaints of dry mouth, five men and ten women, nineteen to eighty-one years of age. These individuals were recruited from a heterogeneous group with contrasting milieu and background in accordance with the principles for grounded theory (Glaser & Strauss, 1967). The participants were strategically identified based on the following variables: complaints and duration of xerostomia, gender, age and family status. Upon consent, eleven participants with subjective xerostomia problems were recruited from patient pools of four dental hygienists. In addition, and with the assistance of a local patient organization (Laryngföreningen), two men and two women were included having developed dry mouth following radiation treatment of head and neck cancer.

Data collection

Paper I

Prior to data collection, two test interviews were conducted (SF) to assess and validate each interview question addressing various aspects of xerostomia. Necessary adjustments or omissions of questions were made to minimize misconceptions or irrelevancies. The selected participants were approached by telephone or e-mail, informed about the aim of the study and reassured that obtained information would be kept confidential. Signed, informed consent was procured from each participant prior to interviews. These were conducted by SF who is familiar with qualitative methods and has professional experience as a dental hygienist. Each individual interview was performed following informal conversation about the informants´ previous education and professional experiences.

The subsequent interview commenced with introductory questions to facilitate a more profound, extended conversation about the participant's personal views of xerostomia. During the interview, the participants were encouraged to provide more detailed statements relating to their experiences by responding to follow-up questions. The interviews were conducted at the participants´ work place, tape-recorded and lasted twenty to thirty minutes. Each interview was subsequently transcribed verbatim (SF).

Paper II

All chosen individuals were initially contacted over the telephone by SF. The aim of the study and related procedures were described. Information was provided about the confidentiality of personal interviews as well as the prerequisite of a signed informed consent. The conversational style interviews were conducted by SF at the home of the informants or in a neutral setting at Halmstad University. A few broad introductory questions were used to capture the main concern of xerostomia. Throughout the dialogue, the participants themselves brought up various aspects of xerostomia and were encouraged to elaborate or become more specific with follow-up questions such as: "In what way?", "How does that feel?" "Can you describe such a situation?" "What do you do in a situation like that?" The face-to-face dialogue varied from forty-five to sixty minutes, was tape-recorded and later transcribed verbatim by SF.

The initial open sampling process was aimed at maximizing variations of data. It started by interviewing two persons who had suffered from xerostomia for a long time and who felt comfortable articulating their various experiences. Collection and subsequent analysis of data were simultaneous processes and further theoretical sampling was guided by concepts and categories emerging from new interviews (snowball effect) and concomitant data processing. SF also recorded thoughts, possible interpretations and additional questions which seemed valuable for extended data collection and analytical integration. Theoretical sampling continued until saturation was reached, meaning that additional data did not bring any new information to the developed categories.

Ethical considerations

Paper I, Necessary permissions were given by the Ethics Committee of Lund University, Lund, Sweden (LU 296-02).
Paper II, The study design was approved by the Research Ethics Committee at Halmstad University (90-2007-646).

Data analysis

Paper I

The data analysis was carried out using qualitative content analyses in accordance with Graneheim and Lundman (2004). The transcribed interviews were read several times and further analyzed to identify statements that represented each participant's perception of xerostomia. Expressions related to causes, consequences, empathy for patients with xerostomia and views on its management became apparent upon preliminary analysis. Statements relating to the same central meaning were grouped into meaning-units which upon further examination were condensed and re-evaluated and labelled with a code. Upon comparing the various codes, based on similarities and dissimilarities, they were sorted into three categories and seven subcategories which constituted the manifest content of the interview text. For example, a statement like *really, there isn't much one has to offer* led to the subcategory *Low priority condition* of category *Insufficient support*. All three authors corroborated throughout the analytical process in accordance with the process of negotiated consensus described by Göransson, *et al.* (1998). The categories were discussed and reconsidered several times and upon final consensus, the underlying meaning, which expresses the latent content of the categories, was formulated into a theme.

Paper II

The analytical procedure was guided by the grounded theory approach (Glaser, 1992). This method allowed SF to generate a theoretical understanding of the meaning of xerostomia. Sampling, data collection, and data analysis were all parts of a sequential, simultaneous process and the authors applied their professional and methodological experiences when moving between inductive and deductive reasoning during the analysis. In the first stage, so called open coding, the transcribed interviews were scrutinized

line by line to conceptualize data, then broken down into parts and closely examined. The identified concepts (meaning) were then labelled using words expressed by the participants (in vivo codes) e.g. *I slur when I speak, I cannot articulate my words.* By conceptualizing the codes, initial large amounts of data were then reduced into smaller units.

During the selective coding process, the codes were compared with each other, with newly generated concepts and with written memos. After continuous discussions among the authors well familiar with the grounded theory, a core category, *an aggravating misery* emerged. Following a constant comparison for similarities and differences, the conceptually similar codes representing meaning, patterns and processes were grouped into subcategories. The interrelationships between them were specified e.g. *I have no saliva so I slur when trying to spea*k, *I feel sad and dejected and I prefer to withdraw.* The categories were saturated with additional information upon subsequent interviews or by re-coding previously assessed data (Glaser, 1978; 1992). Finally, the categories were continuously compared and refined until they did relate to each other, to the core category and could explain the participants´ remedial strategies to resolve the main concern of xerostomia.

FINDINGS

Paper I

The theme: *Xerostomia is a well-known problem, yet there is inadequate management of patients with xerostomia,* expresses the latent content of the text. Health care professionals were aware of xerostomia as an escalating problem that causes permanent distressing complaints and deteriorating oral health. Yet, the findings show indifferent empathy, clinical ignorance and lack of a holistic view. Three categories and seven subcategories constituted the manifest content (Table 1).

Table 1. Theme, categories and subcategories describing views of xerostomia among health care professionals (N 16).

Theme	**XEROSTOMIA IS A WELL-KNOWN PROBLEM, YET THERE IS INADEQUATE MANAGEMENT OF PATIENTS WITH XEROSTOMIA**		
Category	**Awareness of xerostomia**	**Indifferent attitude**	**Insufficient support**
Sub-Category	Contributory factors Oral consequences Psycho-social consequences	Trivial problem Lack of professional commitment	Low priority condition Inadequate preparedness

Paper II

A model (Figure 2) was generated to elucidate the main concern of xerostomia among afflicted participants and how they handle various aspects of their condition. The core category was labelled: *An aggravating misery* meaning that xerostomia has a devastating and debilitating impact on multiple domains of well-being. Xerostomia was perceived as a burden and as a condition the afflicted participants were constantly reminded of. The model involves three different categories/remedial strategies namely *professional consultation*, *search for affirmation* and *social withdrawal* which express the participants resolve to ease their suffering from xerostomia.

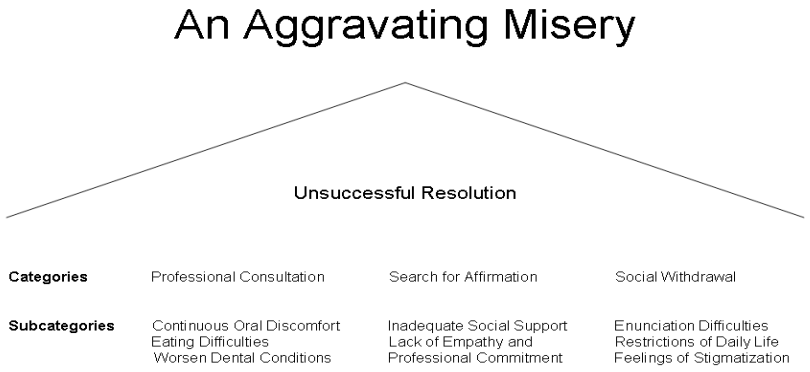

Figure 2. The main concern of xerostomia and remedial strategies.

DISCUSSION

Methodological considerations

Paper I

Qualitative content analysis was selected as the method to explore and describe various views of xerostomia among health care professionals. Since there are no established criteria for sample size in qualitative research, the number of informants was determined in accordance with the need for informational variety. The dominance of female subjects closely reflects the combined gender distribution within the health care services addressed. The data collected through interviews were considered adequate, as no new information was disclosed after the 15th session. The information was considered trustworthy and plausible since the interviewed participants were thoroughly informed and genuinely interested in the purpose of the study. Procedural accuracy was also optimized by having all interviews and transcriptions conducted by one and the same person (SF). However, one cannot fully eliminate the risk of preconceptions considering the interviewer's knowledge and experiences of xerostomia. Furthermore, misunderstandings may occur during any interview situation or misinterpretation of written recordings. All authors were therefore actively engaged in every step of the analytical process until final agreement concerning categorizations was reached. This process of negotiated consensus (Göransson, *et al.,* 1998) was implemented to strengthen the trustworthiness of the analysis. Conscientiousness was also documented by presenting citations corresponding to the emerged categories and the empirical data.

Paper II

A grounded theory study should be judged by fit, work, relevance and modifiability (Glaser, 1992). The findings of this study imply a holistic understanding of the meaning of xerostomia based on individual and shared personal experiences among fifteen afflicted adults. Extensive, open-ended interviews disclosed comprehensive descriptions, later transcribed, scrutinized, broken down, and coded. Memo-writing and theoretical sampling saturated the emerging categories with information. During the analytical process, the authors reflected upon and discussed the tentative categories rather than forcing them into preconceived classifications. Citations corresponding to each conceptual subcategory exemplify that they were grounded in the data. Because each qualitative study has its own premises and participants, the findings are generally not transferable. A grounded theory has to be modified whenever conditions are changing. Consequently, the findings, of the present study are not transferable to populations at large but highly plausible as to afflicted adults suffering from xerostomia.

Discussion of the findings

Paper I

Health care professionals recognized that duration and severity of xerostomia have accumulative, adverse effects on oral health and oral functions, which in turn may influence quality of life, especially social interactions with friends and family members. In addition, they were cognizant of the fact that xerostomia is a common condition, particularly among seniors, which is in agreement with Orrelana, *et al.* (2006) who reported that at least twenty-five percent of elderly complain of daily recurring mouth dryness. Ikebe, *et al.* (2007) found xerostomia to be a serious quality of life issue among independently living, relatively healthy elderly. Perceptions of dry mouth were significantly associated with inadequate taste, tense feelings, difficulties relaxing and less life satisfaction (Ikebe, *et al.,* 2007). Thomson, *et al.* (2006a) observed the condition to be surprisingly common among younger adults and associated with an abundance of untreated dental decay. Present findings show that dental personnel usually considered xerostomia as a contributing factor when rampant caries was evident. Above

and beyond patient information and preventive efforts, it was a general understanding that xerostomia raised the costs of dental care and limited the choice of dental restorations.

Health care professionals largely acknowledged xerostomia as a side effect of certain medications, which is in agreement with recent studies (Shinkai, *et al.,* 2006; Thomson, *et al.,* 2006c). Less common was the awareness of xerostomia occurring as a consequence of systemic diseases (von Bultzinglöwen, *et al.*, 2007), while it was generally recognized as the result of undue stress among younger cohorts. Patients´ complaints were perceived as diffuse and subjective and expressed in various ways depending upon patients´ age and psychological condition. Mental conditions such as stress and depression have earlier been reported to cause xerostomia (Anttila, *et al.,* 1998; Bergdahl & Bergdahl, 2000). Lynge Pedersen, *et al.* (2005) observed that patients had reported symptoms of oral dryness ten years prior to the diagnosis of primary Sjögren´s syndrome. Hyposalivation is also among the early symptoms of diabetes Type 1, which further emphasises the importance of additional anamnestic information and follow-up tests among younger individuals complaining of dry mouth (Moore, *et al.,* 2001). Busato, *et al.* (2009) found numerous adolescents with diabetes Type 1 (52,9%) experiencing oral dryness. Their symptoms did not seem related to hyposalivation but were highly correlated with a need to drink which influenced their quality of life (Busato, *et al.,* 2009). Health care personnel should therefore be more attentive to complaints of dry mouth, obtain an adequate medical history, and explore each incident of unknown cause (Fox, *et al.,* 2000; Pembernton & Thornhill, 2001; Schoofs, 2001).

The findings reveal that patients in general rarely were questioned about oral dryness during routine medical and dental examinations, unless xerostomia was the prime reason for consultation. It was often assumed that the problem was attended by someone else within the health care system. This ignorance seemed related to the acumen that oral dryness was of minor importance which is corroborated by Friedman and Isfeld (2008) who labelled xerostomia as one of the least diagnosed and inadequately managed

oral health conditions. Present findings highlight the importance of collaboration between the medical and dental profession to improve both oral and systemic health. Ogden *et al.* (2002) found doctors´ ambivalence to have a negative impact upon patients' confidence while the referral to a specialist had a positive influence. In this context, Fox, *et al.* (2000) emphasized that questions concerning xerostomia should be conducted as a part of the standard health questionnaire and that evaluation should be conducted proactively at each office visit. Andersson (2004) subsequently suggested the introduction of an oral assessment guide to determine existing oral health problems and to outline palliative strategies for patients admitted to hospitals. Further, community health services should in general pay more attention to the recognition and treatment of dry mouth problems (Willumsen, *et al.,* 2009).

Health care professionals were aware of their fragmentary and inadequate professional support. Enhanced comprehension and interdisciplinary collaboration were therefore considered prerequisites to improve compassion for and support of patients with xerostomia. This corresponds with Paulsson (2000) who found that enhanced knowledge among nursing personnel generated increased motivation and attitude to oral health. Communication and proficient teamwork between the dental and the health care team in general were considered important to achieve and preserve good oral health (Paulsson, 2000; Andersson, 2004). Education and training of health care professionals should therefore emphasize the significance of communication skills and how improved exchange among peers as well as between practitioners and patients will serve the diagnostic quest, lead to better treatment options and level of care (Madrid, *et al.,* 2006; Migliorati & Madrid, 2010).

Paper II

The findings reveal that xerostomia not only influences the conditions of the oral cavity but the individual as a whole. The afflicted participants perceived xerostomia as a burden and as an aggravating misery. This chronic oral condition influenced the participants' broader well-being by impacting everyday life both physically and psychosocially. These observations agree with

previous studies mentioned in the introduction (Wärnberg-Gerdin, *et al.,* 2005; Matear, *et al.,* 2006; Tomson, *et al.,* 2006a; Ikebe, *et al.,* 2007; Dirix, *et al.,* 2008). Present findings emphasize the importance of assessing the subjective symptoms of xerostomia (Fox, *et al.,* 1987; Hawkins, *et al.,* 2005) in addition to traditional biological and clinical variables (Navazesh & Kumar, 2008).

Previous observations by Wolff and Kleinberg (1998) have shown that there is a variation in the thickness of the fluid layer of the oral mucosa and that the hard palate and the lips have the thinnest coverage. Recently, Eliason, *et al.* (2009) suggested that labial gland saliva may influence subjective feelings of dry mouth both in individuals with normal and subnormal whole saliva flow. This may explain the participants' frequent complaints of a gritty, sandpaper-like sensation with dry, crusty lips and a dry inflexible tongue sticking to their palate. Reoccurring dental decay, painful ulcerations and fungal infections resulted in frequent professional consultations and escalating health care expenses. This is in agreement with Fox, *et al.,* (2008) who emphasised the importance of early recognition of xerostomia-like symptoms to minimize oral morbidities and dental costs. Consequently, related oral complaints and deteriorating dental conditions constitute a significant burden of illness (Locker, 2003; Parker, *et al.,* 2007).

The compounded psychosocial impact of xerostomia constrained afflicted participants from important essentials in life. They often resembled xerostomia with grievance. Participants with xerostomia of long duration communicated worries about mouth dryness and subsequent oral health consequences as well as the possibility of a serious, underlying disease. Dysphagia and altered taste perception were frequently expressed, especially by persons subjected to radiation therapy, corroborating (Mese & Matsuo, 2007). An earlier retrospective study, (Wijers, *et al.* 2002) confirmed that xerostomia is a major late sequela of radiation therapy among long-term survivors. Besides oral impairment, Jham, *et al.,* (2008), Dirix, *et al.,* (2008) found that xerostomia compounded the emotional impact among survivors of head and neck cancer, causing worry, tension, and feelings of depression.

Strange eating habits, halitosis and unattractive facial appearance led to feelings of stigmatization. This concurs with earlier studies, showing that dental appearance affects judgment of facial attractiveness (Trulsson, *et al.,* 2002). The participants noticed how their behaviours were constantly scrutinized which made them uncomfortable while socializing. Their oral dryness and poor articulation were also found to impede communication with others. They were embarrassed having to clarify their messages repeatedly which refrained them from conversations. This relates to self-esteem and the ability to mingle with others without being ashamed of bad looking teeth and/or foul odour (Hallberg & Haag, 2007; Hattne, *et al.,* 2007).

The participants felt abandoned by health care professionals, who showed little empathy for their condition. They characterized the personnel as non-compliant and inattentive and questioned their professional competence to address xerostomia. The participants´ symptoms were often neglected and hardly ever communicated. These observations corroborate findings by Meirovitz, *et al.*, (2006) that professional observers underestimated the severity of xerostomia compared to conditions expressed by the patients. The questionnaire proposed by Fox, *et al.* (2000) concerning xerostomia is therefore especially important as Hawkins and Locker (2005) found that dentists assume that patients will provide this information without being asked. Barry, *et al.* (2006) have proposed that health providers may lack confidence to deal with patients´ complex agendas and seeing them as overly time consuming. In the present study, it was obvious that patients with xerostomia were reluctant to communicate their problems since dental and medical offices were perceived as stressful, impersonal and dominated by routine procedures.

Although it might be difficult to assess the severity of someone's subjective symptoms, critical curiosity is an essential quality for health care professionals to inquire rather than just dismissing existing problems. Sondell, (2001) has coined the phrase *if the dentists talked less and if they listened a little more to the patients - it would be beneficial for the overall treatment result*.

Alma and Smaling (2006) have subsequently proposed that *the caregiver needs to be trained in the dialogical-hermeneutical type of empathic understanding that requires mental, social and especially imaginative, competences*. In addition, caregivers need communication skills to handle different types of consultations to reach a patient-centered medical approach which has a humanistic, bio-psychosocial perspective (Bensing, 2000).

CONCLUSIONS AND IMPLICATIONS

Xerostomia is not a trivial condition for those afflicted. It has a devastating and a debilitating impact on multiple domains of well-being.

Xerostomia is a common yet, an underestimated and in many ways ignored problem.

There is an obvious need to enhance the professional competence of managing xerostomia.

A holistic view, additional education and better interdisciplinary collaborations are essential strategies to improve compassion for and support of individuals afflicted by xerostomia.

Further studies concerning the complexities of xerostomia seem essential.

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I

NURSE KNOWLEDGE AND ATTITUDES

Journal of Clinical Nursing

Views of xerostomia among health care professionals: a qualitative study

Solgun Folke, Bengt Fridlund and Gun Paulsson

Aim. To explore and describe views of xerostomia among health care professionals.

Background. Xerostomia (dry mouth) is caused by changes in quality and quantity of saliva due to poor health, certain drugs and radiation therapy. It is a common symptom, particularly among older people and has devastating consequences with regard to oral health and general well-being.

Methods. Data were obtained and categorised by interviewing 16 health care professionals. Qualitative content analysis was chosen as the method of analysis.

Design. Qualitative.

Results. The latent content was formulated into a theme: xerostomia is a well-known problem, yet there is inadequate management of patients with xerostomia. The findings identified three categories expressing the manifest content: awareness of xerostomia, indifferent attitude and insufficient support.

Conclusions. Although xerostomia was recognised as commonly occurring, it was considered to be an underestimated and an ignored problem. Proper attention to conditions of xerostomia and subsequent patient management were viewed as fragmentary and inadequate. Additional qualitative studies among patients with xerostomia would be desirable to gain further understanding of the problems with xerostomia, its professional recognition and management.

Relevance to clinical practice. A holistic view, positive professional attitudes and enhanced knowledge of xerostomia seem essential to augment collaboration among health care professionals and to improve compassion for and support of patients with xerostomia.

Key words: content analysis, health care professionals, nurses, nursing, well-being, xerostomia

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Introduction

Xerostomia, the subjective feeling of dry mouth, is a symptom most frequently associated with alterations in salivary quality and quantity due to poor health, certain drugs and radiation therapy (Cooke *et al.* 1996). Hyposalivation is considered to be the most common contributing factor. However, the sensation and complaint of dry mouth has been expressed by individuals with normal salivary flow rates (Fox *et al.* 1987, Longman *et al.* 2000). Furthermore, it is known that several systemic disorders such as rheumatoid arthritis, HIV, Sjögren's syndrome and diabetes mellitus cause xerostomia (Schiodt 1992, Russel & Reisine 1998, Fox *et al.* 2000, Sandberg *et al.* 2000, Moore *et al.* 2001). Xerostomia is also found to be related to depression, stress and anxiety (Bergdahl & Bergdahl 2000). The condition of xerostomia is a serious, often permanent and almost ubiquitous sequalae among patients subjected to radiation therapy in association with head and neck malignancies (Bågesund *et al.* 2000, Wijers *et al.* 2002). A considerable number of studies report a subjective sensation of dry mouth as a side effect of various medications. A definite association between

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xerostomia and the total number of drugs taken has also been reported (Nederfors *et al.* 1997, Field *et al.* 2001). The prevalence of xerostomia varies widely (14–46%) depending on the population studied and whether and how questions are asked about the sensation of dry mouth (Locker 1995, Nederfors *et al.* 1997, Pajukoski *et al.* 2001).

From an holistic view, oral health is described as 'a standard of health of oral and related tissues which enables an individual to speak and socialise without active disease, discomfort or embarrassment which contributes to general well-being' (Kay & Locker 1997, p. 8). Thus, oral health is best understood through clinical observations and self-reported indicators, symptoms and perceptions (Gift *et al.* 1997). Saliva plays an important role in the maintenance of oral health and tissue integrity and serves important functions during mastication (Sreebny 2000). In contrast, xerostomia has devastating consequences with regard to oral heath. It also has profound debilitating effects upon quality of life by influencing basic functions such as sleep, speech, eating and swallowing (Locker 1993, McGrath *et al.* 2000). These conditions have been ignored and underestimated by health care professionals (Sreebny 2000). Consequently, symptoms of xerostomia must be taken seriously and managed appropriately to enhance patients' well-being (Cooke *et al.* 1996). It would therefore seem relevant to explore and describe views of xerostomia among health care professionals.

Methods

Design and methodological approach

A qualitative design was chosen to explore and describe health care professionals' views of xerostomia. Data, based on qualitative interviews and subsequently transcribed text, were examined using qualitative content analysis. Content analysis has been used differently in quantitative versus qualitative studies. In qualitative studies, it is a process of systematically analysing and coding messages in any type of conversation (Kondracki *et al.* 2002). The analysis, in this study, did focus on both manifest and latent content of the transcribed interview text (Graneheim & Lundman 2004). The manifest content was identified by the visible, obvious components while the latent content did involve an interpretation of the underlying meaning of the text.

Participants

A selection of 16 participants was made to acquire a broad representation of health care professionals with various exposures to patients with xerostomia. The participants were strategically selected in reference to gender, age, occupation, years of professional experience and finally urban and rural engagement. The cohort consisted of 13 women and 3 men. Their age ranged from 42–63 years with a mean age of 52 years. One man and three women were physicians. Three were general practitioners and one specialised in psychiatry. Two men and two women were dentists, four women were dental hygienists and four women served as district nurses. The interviewed subjects had been professionally active between 3–35 years and were still associated with either public or private health care including medical home care.

Interview

This study introduced an interview sequence addressing various aspects of xerostomia. Each individual interview was conducted following informal conversation about his or her previous education and professional experiences. The subsequent interview commenced with introductory questions to facilitate a more profound conversation about the participant's personal views of xerostomia. The following questions were asked: What is xerostomia? What is the impact of xerostomia? Please relate to a situation that has affected you greatly. How do you view your own management and support of patients with xerostomia? The participants were encouraged, during the interview, to elaborate and to provide more detailed statements relating to their experiences by responding to follow-up questions such as: How do you mean? What else can you tell me? How would you like to describe that? Can you explain further?

Data collection

The interviews were conducted during January and February 2003 by SF who is familiar with qualitative methods and has professional experiences as a dental hygienist. Necessary permissions were given by the Ethics Committee of Lund University, Lund, Sweden. Prior to data collection, two test interviews were conducted (by SF) to assess each question. Necessary adjustments, such as changing the framing of the question, followed when required to eliminate further misconceptions or irrelevancies. The participants selected were approached by telephone or e-mail, informed about the aim of the study and that obtained information would be considered strictly confidential. Signed, informed consent was procured from each participant prior to interviews. These were conducted at the participants' work place and lasted 20–30 minutes. Each conversation was tape-recorded and subsequently transcribed verbatim (by SF). The comprehensive data collection comprised 139 pages.

Data analysis

The data analysis was carried out using qualitative content analysis in accordance with Graneheim and Lundman (2004). The transcribed interviews were read several times to comprehend what was expressed by each participant and to obtain a sense of the whole. Four major perceptions became apparent upon preliminary analysis of all transcribed interviews, namely: expressions related to causes, consequences, empathy for patients with xerostomia and views on management. Furthermore, the interviews were analysed to identify statements that represented each participant's perception of xerostomia. A total of 393 specific statements were documented upon the scrutiny of 16 interviews. By comparing different statements within their context and with each other, the statements that related to the same central meaning were grouped into meaning units. Upon further examination, the numbers of meaning units were condensed into groups representing the same core content. Subsequently, the condensed meaning units were abstracted, that is, re-evaluated in consideration to the whole context, described and interpreted on a higher logical level and labelled with a code. Upon comparing the various codes, based on similarities and dissimilarities, they were sorted into three categories and seven subcategories which constitute the manifest content of the interview text. For example, a statement like 'They can't function in daily life without continuously moistening their mucous membranes' led to the subcategory 'Psycho-social consequences' which became part of the category 'Awareness of xerostomia' while the statement 'Really, there isn't much one has to offer' led to the subcategory 'Low priority condition' as part of the category 'Insufficient support'. All three authors corroborated throughout the analytical process in accordance with the process of negotiated consensus described by Göransson *et al.* (1998). The categories were discussed and reflected upon several times and after final consensus, the underlying meaning, which expresses the latent content of the categories, was formulated into a theme.

Results

A theme, 'Xerostomia is a well-known problem, yet there is inadequate management of patients with xerostomia', expressing the latent content of the text, was formulated upon analysis of data. Health care professionals were aware of xerostomia as an escalating problem that causes permanent distressing complaint and deteriorating oral health. Yet, the findings showed indifferent empathy and clinical ignorance due to a professional specialist perspective and lack of a holistic view. Three categories and seven subcategories constituted the manifest content (Table 1).

Awareness of xerostomia

Health care professionals expressed diverse knowledge of xerostomia. It was generally perceived as a common problem among an increasing number of unhealthy older individuals consuming large amounts of different drugs. Xerostomia was also recognised as the result of undue stress due to high demands and expectations among younger cohorts. Health care professionals also perceived the impact of xerostomia on patients' well-being.

Contributory factors

Medications as well as radiation to the head and neck region were seen as the main causes of xerostomia. Physical and mental conditions separate or in combination with drug intake were also considered as contributory to xerostomia, while lifestyle factors and ageing were viewed as potential but less severe predisposing factors:

> Yes, it is a major problem for many individuals on medication because xerostomia is a side effect of so many drugs, Sjögren's syndrome and radiation therapy. Many individuals experience xerostomia due to anxiety, anguish and stress, alcohol abuse and heavy smoking. Especially those under stress, suffer from dry mouth. (interview 2)

Oral consequences

Xerostomia of long duration was considered to have oral consequences by harming teeth and soft tissues of the oral cavity as well as contributing to oral malfunctions such as inabilities to eat, speak, chew and swallow. Despite patient information and preventive efforts, it was a general understanding that xerostomia raised the costs of dental care and limited the choice of dental restorations:

Table 1 Theme, categories and subcategories describing views of xerostomia among health care professionals (n = 16)

Theme	Xerostomia is a well-known problem, yet there is inadequate management of patients with xerostomia		
Category	Awareness of xerostomia	Indifferent attitude	Insufficient support
Subcategory	Contributory factors	Trivial problem	Low priority condition
	Oral consequences	Lack of professional commitment	Inadequate preparedness
	Psycho-social consequences		

Yes, it is caries upon caries lesions. It completely jeopardises extensive prosthetic reconstructions. You try to repair these lesions by extending dental fillings. This becomes an increasingly complex problem because seniors are expected to retain their teeth longer. It just does not seem feasible to replace every tooth beyond repair with implants. Likewise, it is difficult to implement and maintain good oral hygiene among patients with xerostomia. Compromised oral hygiene will, in return, contribute to periodontal problems and bad breath. Also, mucous membranes become dry which causes a burning sensation and predisposes for Candida infections. It is almost impossible for these patients to wear dentures. It is really a big problem. (interview 5)

Psycho-social consequences

Health care professionals were aware of constant discomfort among xerostomia patients and how the condition influenced their mood swings. Insomnia, eating and swallowing difficulties due to xerostomia, was also perceived to negatively influence patients' quality of life. Furthermore, xerostomia was seen to restrict social aspects of life such as communication and interactions at work, with friends and family members. Health care professionals experienced that patients with xerostomia were ashamed of their appearance due to decayed teeth and adhering food on their teeth while eating. Additionally, fear of bad breath (halitosis) and difficulties when speaking were considered to cause low self-esteem and social isolation, especially among older people:

I think it of it as a painful source of irritation. I imagine it is like a tiny, nagging irritation that follows you all day long and makes it difficult to fall asleep at night. At times you wake up in panic and you have to take a sip of water. It is like a sore, which never heals. (interview 15)

Patients experience bad breath and do not want to be among others for dinner. They are afraid of clicking their tongue while drinking and they have problems expressing themselves. Such matters influence social interactions which are important aspects of well-being especially among older people. (interview 3)

Indifferent attitude

The health care professionals experienced a high prevalence of xerostomia among older people and an increasing number of afflicted young individuals. However, the problem received little attention. Patients' symptoms were often neglected due to a combination of inadequate diagnosis and insufficient empathy. Inadequate comprehension of the impact of xerostomia and uncertainty among professionals, how to address the problem, were considered to be key reasons for not discussing the health sequalae of xerostomia with patients or colleagues.

Trivial problem

Xerostomia was recognised as a not measurable, subjective symptom expressed in various ways depending on patients' age and psychological condition. Attitude statements by interviewed subjects revealed xerostomia to be a diffuse, trivial problem that afflicted individuals have to endure and cope with:

It is difficult to determine who really suffers from the symptom, because in my opinion it is a subjective feeling among xerostomia patients. I have some grumpy patients who complain of symptoms of dry mouth even when I explain that they have saliva production. Under such conditions the patient's perception is the determinant factor and it is impossible for a health care provider to objectively measure such a feeling. I believe it is a matter of the patient's state of mind. (interview 6)

Lack of professional commitment

Patients in general were rarely questioned about oral dryness during routine medical and dental examinations unless xerostomia was the prime reason for a consultation. Likewise, examination and documentation of xerostomia were rarely performed. Oral dryness was generally considered to be of minor importance. It was often assumed that the problem was attended by someone else within the health care system:

I think patients feel neglected in many instances of health care because no one pays attention to the symptoms of dry mouth. But as a doctor, it is not a concern of mine. I have no solutions and that is why I do not bother to ask or talk about it. Maybe the dentists or the dental hygienists will address the matter, but I do not know. (interview 16)

Insufficient support

Even if patients communicated their symptoms, health care professionals were aware of their fragmentary and inadequate professional support. Their ability to deliver palliative assistance by implementing effective saliva substitutes was seen as a prerequisite for support.

Low priority condition

Deficient empathy, inadequate knowledge, lack of time and low priority for xerostomia management were viewed as reasons for insufficient support. Likewise, the trend towards greater subspecialisation within the health care system was considered contributory to the poor management of patients with xerostomia:

My knowledge of xerostomia is very limited, as you may have noticed. But my feeling is that we cannot place more effort on it than

try to prevent dental decay. On the other hand, this is where we should be able to assist the patients because it is about the oral cavity after all. If it was not, then they would talk to the district nurse, should they not? (interview 11)

Inadequate preparedness

Improved education, sufficient knowledge and professional communication from a holistic perspective were perceived to enhance empathy for and management of patients with xerostomia:

Well, dry mouth is not an isolated problem. Thus, there is need for a holistic approach. Everyone has to pay attention to this problem. There is a need for collaboration and agreement. Xerostomia was never addressed during my medical education. As a practitioner, I have never had any discussion with any of my colleagues or with anyone from dentistry about the consequences of xerostomia. This is a much neglected problem and there is a need for increased information and enhanced education among health care personnel. (interview 13)

Discussion

Collection of information in qualitative studies is founded on concepts of applicability, trustworthiness, reasonableness and conscientiousness. Applicability is reached by identifying the phenomenon studied through relevant selection of informants and data collection method (Fridlund & Hildingh 2000). In this study, qualitative content analysis was selected as the method of analysis considering the aim of exploring and describing various views of xerostomia from interviews with health care professionals. The thematic interview sequence was based on previously published information and the interviewer's experiences as a dental hygienist. The chosen introductory questions, directed at all participants, were tested and modified in two trial interviews (not included in the study) to arrive at questions which exclusively focused on the essential aspects of xerostomia. There are no established criteria for sample size in qualitative research. Rather, the sample size is determined on the need for informational variety. Thus, the selection of 16 participants was meant to acquire a broad variety of descriptions among health care professionals as they experience patients with xerostomia in their daily practice. The dominance of female subjects closely reflects the combined gender distribution within the health care services addressed. The amounts of data obtained in reference to interviews conducted were considered adequate as no new information, considering the aim of exploring various views of xerostomia, was added after the 15th interview. The interviewed participants were thoroughly informed about the purpose of the study and their expressions were therefore considered trustworthy and reasonable. Trustworthiness regarding data collection and interpretation was optimised by having all interviews and transcriptions conducted by one and the same individual (SF). However, one cannot fully eliminate the risk of preconceptions considering the interviewer's knowledge and experience of xerostomia. Furthermore, misunderstandings during any interview situation or misinterpretation of written recordings may occur. All authors were therefore actively engaged in the analytical process to optimise reasonableness. The authors collaborated in every step of the analysis until final agreement concerning categorisations was reached. This process of negotiated consensus (Göransson *et al.* 1998) was implemented to strengthen the trustworthiness of the analysis. Thorough and iterative comparison of individual statements, similarities and dissimilarities within the entire transcribed material was conducted to achieve consensus of conscientiousness among authors. Conscientiousness was also documented by presenting citations corresponding to the emerged categories and the empirical data.

Each health care professional of this study perceived drug therapy as the primary cause of xerostomia. This confirms previous studies by Nederfors *et al.* (1997) and Field *et al.* (2001). Furthermore, the awareness of increasing prevalence of xerostomia among younger individuals subjected to antidepressants had generated serious concerns of lingering effects on oral health. Although xerostomia may be reversible upon termination of certain medications, one should not ignore underlying conditions such as depression, stress, anguish and anxiety which by themselves generate a subjective sensation of dry mouth due to decreased salivary secretion at rest (Bergdahl & Bergdahl 2000). It was also recognised among the health care professionals that xerostomia occurs as a consequence of systemic diseases such as Sjögren's syndrome and diabetes. Health care personnel should therefore pay more attention to complaints of dry mouth and explore each incident of unknown cause (Fox *et al.* 2000, Schoofs 2001). Hyposalivation is also among the early symptoms of diabetes type 1 which emphasises the importance of additional anamnestic information and follow-up tests even among younger individuals complaining of dry mouth (Moore *et al.* 2001). Some of the interviewed health care professionals correlated xerostomia with ageing. This, however, contradict current scientific evidence which indicates unaltered salivary function throughout life among healthy individuals (Fox 1997). The interviewed subjects generally considered duration and severity of xerostomia to have correlative and accumulative effects on oral health.

Resulting dental decay destroys teeth and undermines restorations despite patient information and preventive efforts by health care personnel. Periodontal diseases were seen to increase as well, as xerostomia complicates implementation of adequate oral hygiene. Likewise, xerostomia was perceived to present serious problems among geriatric patients suffering from and receiving longstanding medication for physical and mental illnesses. Interviewed health care professionals were also aware that these patients often suffer from dry mucous membranes, Candida infections, ill-fitting dentures, pain and inability to eat, speak, chew and swallow. These conditions may result in malnutrition and accidental suffocation. Increasing intraoral concentrations of periodontally related gram negative microorganisms may also enhance the risk for pneumonia (Ship *et al.* 2002). The interviewed subjects expressed awareness of the ill-effects of xerostomia on daily life. They recognised that afflicted patients feel and sleep much better if xerostomia could be eliminated. The condition was considered painful, uncomfortable and nagging because patients were reminded of something abnormal. This confirms the observations of McGrath *et al.* (2000) that oral health has a strong influence on quality of life. They demonstrated that associated negative factors such as pain, oral dryness and compromised ability to speak and eat have immediate detrimental effects and contribute to lesser self-confidence among patients. Each health care professional in this study realised that xerostomia induces difficulties in swallowing and calls for different feeding and eating habits. This was perceived to have a serious impact on social behaviour particularly among older individuals as gathering at the dining table often constitute a highlight of their day. Locker (1993) found that the most common problems among older people were being prevented eating foods they prefer and are comfortable with. Xerostomia was also viewed to reduce the enjoyment of food and sharing meals with others. This is supported by Russel and Reisine (1998) who reported that younger individuals with xerostomia and eating difficulties withdrew from external workplaces when they had to share their meals with fellow workers. The interviewed subjects also conveyed the observations that dry mouth make the tongue adhere to the palate and the lips to the teeth which brought about an appreciation of xerostomia being a social handicap at gatherings. Other studies have likewise indicated that limited understanding of xerostomia among family members, fellow workers and health care providers cause afflicted individuals to withdraw from social life in favour of isolation (Schoofs 2001, Rydholm & Strang 2002, Wijers *et al.* 2002).

Health care professionals of this study perceived xerostomia as prevalent. Yet, the problem was rarely discussed among patients and caregivers. Although the prevalence of xerostomia and salivary gland dysfunction is difficult to determine due to several methodologies and diagnostic criteria, Fox *et al.* (2000) have estimated an age and disease related prevalence of 72% among older people. The interviewed health care professionals generally experienced patients' complaints of dry mouth as diffuse and bearable which often led to clinical ignorance. Inadequacies among providers may, therefore, determine whether xerostomia is discovered, managed or not. Consequently, it is essential to obtain subjective patient information about dry lips and mouth, difficulty swallowing and speaking. Patients should be encouraged to describe their symptoms and when and where they occur. Likewise, it is important to perform measurement of salivary function and refer to appropriate expertise for follow-up, final diagnosis and treatment (Fox 1997). One reason why xerostomia is neglected, as described in this study, is because xerostomia is rarely the primary reason for seeking medical or dental attention. Another cause was unawareness how to manage xerostomia in combination with the anticipation that other disciplines will address the problem. Inadequate basic education, lack of continuing education and insufficient clinical experience are contributory factors which have brought about the attitude that certain aspects of oral health are less important than it ought to be among health care providers (Paulsson 2000, Wårdh *et al.* 2000).

Interviewed health care professionals expressed their dissatisfaction of being unable to assist patients with xerostomia due to low priority and inadequate time devoted to such patients. It was also perceived that patients suffering from xerostomia rarely disclose their problems. Consequently, health care professionals assumed that these patients have no problems or obtained assistance elsewhere. Whether that is the case or not was rarely confirmed. Pemberton and Thornhill (2001) recommend physicians to obtain an adequate medical history upon suspicion of xerostomia to disclose all possible etiological factors. At the time of prescribing a drug which influences salivary production, it is imperative that medical providers inform about potential side effects and recommend sugar-free, saliva stimulating products and fluoride applications (Pemberton & Thornhill 2001). Interviewed subjects, engaged in home health care, were able to identify patients suffering from xerostomia and implement appropriate means in collaboration with co-workers and family members. A holistic view and adequate information is therefore essential to obtain optimal support among nurses while caring for these patients (Paulsson 2000, Wårdh *et al.* 2000). Dental personnel, on the other hand, usually addressed xerostomia patients when restorative care was inevitable due to rampant caries. These observations are

in support of the conclusion of McArthur *et al.* (1997) that dental and other health care professionals need to be better informed about xerostomia and the Sjögren's syndrome and its sequela. Likewise Daniels (2000) has emphasised the importance of a detailed medical and dental history, palpation of salivary glands, intraoral examination, salivary flow measurements and screening for oral candidosis by dental providers whenever xerostomia is in question. Empathy, ability to listen to the patient and early diagnosis of xerostomia may help mitigate symptoms and reduce anxiety (Daniels 2000). The interviewed subjects agreed that inadequate empathy, knowledge and professional collaboration as well as segmentation of care were the prime reasons for insufficient management of patients with xerostomia. Education based on holistic paradigms was therefore suggested to make oral health a fully integrated part of general health.

Conclusions

The underlying meaning of the findings revealed awareness, yet inadequate management of patients with xerostomia. The interviewed health care professionals described xerostomia as a consequence of drug therapy with subsequent negative impact on oral health and well-being. Xerostomia was recognised as common, particularly among older people, yet it was considered to be an underestimated and in many ways an ignored problem. A holistic view and enhanced knowledge by means of additional education were considered prerequisites among health care providers to promote interdisciplinary collaboration and to improve compassion for and support of patients with xerostomia. Additional qualitative studies among patients with xerostomia would gain further understanding of the problems with xerostomia, its professional recognition and management.

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Contributions

Study design: SF, GP; data collection and analysis: SF, GP and manuscript preparation: SF, GP, BF.

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II

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ORIGINAL ARTICLE

The subjective meaning of xerostomia—an aggravating misery

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Abstract
Xerostomia, the subjective sensation of dry mouth, is associated with qualitative and quantitative changes of saliva. Poor health, certain medications and radiation therapy constitute major risk factors. To gain further understanding of this condition the present study explored the main concern of xerostomia expressed by afflicted adults. Qualitative interviews were conducted with 15 participants and analysed according to the grounded theory method. *An aggravating misery* was identified as the core category, meaning that the main concern of xerostomia is its devastating and debilitating impact on multiple domains of well-being. *Professional consultation*, *search for affirmation* and *social withdrawal* were strategies of management. The findings reveal that xerostomia is not a trivial condition for those suffering. Oral impairment as well as physical and psychosocial consequences of xerostomia has a negative impact on quality of life. There is an obvious need to enhance professional competence to improve the compassion for and the support of individuals afflicted by xerostomia.

Key words: *Grounded theory, oral health related quality of life, well-being, xerostomia.*

Introduction

Xerostomia denotes the subjective sensation of dry mouth (Fox, van der Ven, Sonies, Weiffenbach & Baum, 1985). This particular condition is associated with qualitative and quantitative changes of the saliva generally referred to as salivary hypofunction, or the objective finding of reduced salivary flow rate. However, xerostomia may occur despite normal salivary gland activity (Fox, Busch & Baum, 1987; Hay et al., 1998). Certain prescribed medications constitute major risk factors (Thomson, Chalmers, Spencer, Slade & Carter, 2006). The association between transient xerostomia and the total intake of various drugs has also been reported (Nederfors, Isaksson, Mörnstad & Dahlöf, 1997; Field & Fear et al., 2001). Permanent xerostomia may also occur following radiation therapy of head and neck malignancies (Bruce, 2004). The ramifications of resulting salivary alterations are serious and may contribute to other ill-health conditions (Wijers et al., 2002). Xerostomia is also associated with systemic disorders, such as rheumatoid arthritis and Sjögren's syndrome (Russel & Reisine, 1998; Fox, Stern & Michelson, 2000). Further, diabetics frequently express symptoms of dry mouth (Sandberg, Sundberg, Fjellstrom & Wikblad, 2000; Moore, Guggenheimer, Etzel, Weyant & Orchard, 2001) as well as individuals suffering from depression, stress and anxiety (Anttila, Knuuttila & Sakki, 1998; Bergdahl & Bergdahl, 2000).

Unfortunately, there is a stereotypical conception that xerostomia only occurs in elderly individuals while, in reality, it may occur at any age (Bergdahl, 2000; Bågesund, Winiarski & Dahllöf, 2000; Thomson, Poulton, Broadbent & Al-Kubaisy, 2006). In addition, the reported prevalence of xerostomia varies greatly (10–47 %), depending on the population studied and whether or how questions address the sensation of dry mouth (Nederfors et al., 1997; Ikebe, Nokubi, Sajima, Kobayashi, Hata & Ono et al., 2001; Pajukoski, Meurman, Halonen & Sulkava, 2001). During the past decade, dry mouth has received increased attention as it affects important aspects of oral tissues and basic oral functions. Patients generally report a sore, painful mouth, recurring dental caries and often express difficulties

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eating, articulating words and wearing a prosthesis (Cassolato & Turnbull, 2003; Locker, 2003; Ikebe, Morii, Kashiwagi, Nokubi & Ettinger, 2005).

Quality of life is influenced by the extent we feel capable of participating in activities that meet our needs and expectations. It is usually assessed by studying how factors such as function, pain, psychological, and social aspects affect the well-being of an individual. When these considerations are related to orofacial concerns, the concept is labelled oral health related quality of life (Inglehart & Bagramian, 2002). Oral diseases and associated disorders may affect physical and psychosocial function which in turn can lead to negative health perceptions, dissatisfaction with oral health and diminished well-being and quality of life (Locker, 2003). Recently, the relationship between xerostomia and well-being has systematically been investigated using different health related quality of life scales (Wärnberg Gerdin, Einarson, Jonsson, Aronsson & Johansson, 2005; Matear, Locker, Stephens & Lawrence, 2006). Their studies clearly indicate a correlation between quality of life and oral health among individuals with xerostomia. Yet, the question remains whether oral health related quality of life can be assessed and measured by means of questionnaires and structured interviews (MacEntee & Prosth, 2007). Since xerostomia affects general well-being, it supports the assertion that dry mouth is an important condition that merits concerted research to understand how to support afflicted individuals better. Thus, to gain a more profound appreciation of the impact of xerostomia it is relevant to apply a qualitative research method based on unstructured interviews. Such a technique allows the researcher to elicit, interpret and describe a wide range of detailed and sometimes unknown information and to approach the participants' subjective experiences. Therefore, the aim of the present study was to explore the main concern of xerostomia and attempted remedies.

Method

Grounded theory

To address the purpose of this study the inductive, comparative research method of "classical" grounded theory was chosen (Glaser & Strauss, 1967). Grounded theory is suitable for gaining a deeper understanding of a phenomenon or to gain more knowledge of an area already explored. The method was originally developed by two sociologists Glaser and Strauss (1967) and later modified by Strauss and Corbin (1998) and Charmaz (2006). Grounded theory aims at revealing the participants´ perspectives of the main concern under study and at conceptualizing patterns of human behaviour. The aim is also to generate substantive or formal theories, models or concepts from empirical data rather than to test existing hypotheses or theories (Glaser & Strauss, 1967). A substantive theory is applicable to a delimited and specific area, i.e. living with, or caring for patients with xerostomia whereas a formal theory is more general and with a broader application area (Glaser & Strauss, 1967; Glaser, 1978; Hallberg, 2006). Systematic abstraction, constant comparison, and conceptualization of empirical data constitute the theory-generating process of a grounded theory study (Glaser & Strauss, 1967; Glaser, 1978; Hallberg, 2006). Collection and analysis of data are simultaneous and continuous processes. Initial open sampling aims at maximizing variations of descriptions. Subsequent theoretical sampling is guided by concepts generated upon analysis of data from previous interviews and written notes. Data collection continues until theoretical saturation is achieved, meaning that additional data do not contribute any new information. Grounded theory is built on symbolic interactionism and a meaning is constructed, developed and modified through social processes and social interactions between people. Thus, the intent of a grounded theory study is to envision a "reality", based on interactions between the researcher and the information provided by the informants (Glaser & Strauss, 1967; Glaser, 1978). As such, the grounded theory may be a valuable complement in clinical practice to promote both a better understanding of and a greater empathy for individuals suffering from xerostomia.

Participants and data collection

The study group consisted of 15 participants with subjective complaints of dry mouth, five men (20–74 years of age) and ten women (19–81 years of age) living in the south-west part of Sweden. These individuals were recruited in accordance with the principles for grounded theory (Glaser & Strauss, 1967), forming a heterogeneous group from contrasting milieu and background. They had previously expressed a variety of experiences of xerostomia when visiting their dental hygienist. The participants were strategically identified based on the following variables: Complaints and duration of xerostomia, gender, age and family status. Upon consent, potential participants with subjective xerostomia problems were recruited from patient pools of four dental hygienists. Eleven subjects were chosen representing a broad range of discomforts and associated experiences while suffering from xerostomia. In addition, and with the assistance of a local patient organization (Laryngforeningen), two men and two women were included having developed dry mouth follow-

ing radiation treatment of head and neck cancer. Five persons were single, eight married, one divorced and one was widowed. The youngest were two students, two worked full-time, three part-time, three were on sick leave and five were retired. All chosen individuals were initially contacted over the telephone by the principal investigator (PI). The aim of the study and associated procedures were described. Information was provided about the confidentiality of personal interviews as well as the prerequisite of a signed informed consent. The study design was approved by the Research Ethics Committee at Halmstad University (90–2007–646).

Qualitative, conversational style interviews were conducted by the PI at the home of the informants or in a neutral setting at Halmstad University. The PI was not previously known to the participants. The face to face dialogue varied from 45 to 60 min, was tape-recorded and later transcribed verbatim by the interviewer. The initial open sampling process was aimed at maximizing variations of the data in order to get ideas about what to ask next. It started by interviewing two persons who had suffered from xerostomia for a long time and who felt comfortable articulating their various experiences. The collection of data and the analysis were simultaneous processes and the subsequent theoretical sampling was guided by concepts and categories emerging from new interviews and concomitant processing of data. The PI also recorded thoughts, possible interpretations and additional questions which seemed valuable to analytical integration and further data collection. Theoretical sampling continued until saturation was reached, meaning that additional data did not bring new information to the developed categories.

The present study used a few broad introductory questions such as: "Please tell me what it means to suffer from xerostomia!" "What impact does xerostomia have on your well-being and everyday life?" During subsequent informal conversations, the participants themselves brought up other aspects of xerostomia. Throughout the dialogue the participants were encouraged to elaborate or become more specific as to follow-up questions such as: "In what way?", "How does that feel?" "Can you describe such a situation?" "What do you do in a situation like that?"

Data analysis

The analytical procedure was guided by the grounded theory approach (e.g. Glaser, 1992). This method allowed the PI, who has a professional background as a dental hygienist, to generate a theoretical understanding of the meaning of xerostomia by giving voice to the participants themselves during the interviews. Sampling, data collection, and data analysis were all parts of a simultaneous process and the authors applied their professional and methodological experiences when moving between inductive and deductive reasoning during the analysis.

The first stage was open coding. The transcribed interviews and the written notes were scrutinized line by line to conceptualize data. The data were then broken down into parts and closely examined to identify thoughts, perceptions, experiences and reflexions expressed by the participants. The identified concepts (meaning) were then labelled using words expressed by the participants (in vivo codes), e.g. *I slur when I speak. My tongue is glued to my palate and I mumble. My lips are dry and rigid and I cannot articulate my words.* By conceptualizing the codes, initial large amounts of data were then reduced into smaller, more manageable units. Collected and generated data were continuously reviewed to determine nuances and their relevance, the main concerns of xerostomia and means of alleviation.

During the selective coding process the codes were compared with each other and with newly generated concepts as well as with the written memos. After continuous discussions among the authors well familiar with the grounded theory, a core category, *an aggravating misery* emerged. After a constant comparison for similarities and differences, the conceptually similar codes representing meaning, patterns and processes were grouped into categories and given more abstract labels than the codes assigned. Additional development of each category was done by specifying subcategories and interrelationships between them. The conceptual categories were saturated with additional information upon subsequent interviews or by re-coding previously assessed data (Glaser, 1978; 1992). Finally, the categories were continuously compared and refined until they did relate to each other and to the core category and could explain the participants' remedial strategies to resolve the main concerns of xerostomia.

Findings

In the analysis a model was generated illuminating the main concern of xerostomia among afflicted participants and how they handle this. The core category was labelled *an aggravating misery* meaning that xerostomia has a devastating and debilitating impact on multiple domains of well-being. The model (Figure 1) involves three different categories/remedial strategies**;** *professional consultation*, *search for affirmation* and *social withdrawal* explaining what the participants do in order to resolve their problems with xerostomia.

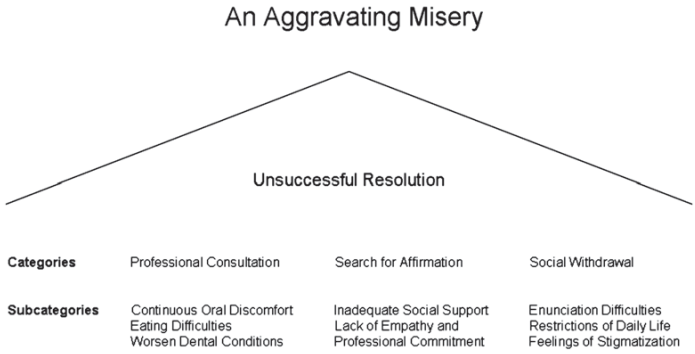

Figure 1. The main concern of xerostomia and remedial strategies.

Xerostomia was perceived as a burden, an aggravating misery, and a condition the participants were constantly reminded of. Several aspects of life had changed with enhancing xerostomia symptoms. All study participants had experienced a variety of oral problems due to xerostomia. They could not recall having saliva lubricating their oral mucous membrane to allow uninhibited movements of tongue and lips. Some were mostly affected by dryness and the pain while others encountered increased oral functional problems. The participants expressed regrets of being unable to enjoy various dishes and meals and they were disappointed that food did not taste the way it used to. Further, the participants expressed a feeling of resignation due to lack of confirmation and support. Peers and friends were tired of listening to their complaints. They felt abandoned by health care professionals who did not seem to take their problems seriously or provide any professional guidance. Concomitantly, it was felt that health care institutions had become too specialized to pay attention to the individual as a whole. Speaking difficulties, bad breath (halitosis) and strange eating habits made the participants feel ashamed and stigmatized while socializing. Some had to discontinue work and leisure activities while others missed closeness with family and friends. In short, escalating isolation and loneliness:

> It is nerve wrecking and it has a profound effect on my quality of life. The discomfort is psychologically very stressful. Nobody seems to understand and it is getting worse every year. … my outlook on life has certainly changed. Sometimes I feel totally melancholic and I have absolutely no hope that things will improve. It is hard to find a job and I no longer have the urge to see my friends and relatives. My dog has become my new companion in life but, I cannot even whistle to get his attention.

Professional consultation

Oral conditions such as pain and discomfort, further described in the subcategories *continuous oral discomfort*, *eating difficulties* and *worsen dental conditions*, resulted in frequent professional consultations to the dentist. Ulcers and fungal infections had often brought about long-term antimycotic therapy. The participants consulted also dental hygienists and nurses for advice and remedies. Thus, the expense for dental care had escalated substantially upon suffering from xerostomia. Participants with xerostomia of long duration expressed worries about serious, underlying diseases and turned to their physicians for explanations. Younger participants tried more proactive solutions, but gradually became aware of the consequences of xerostomia during everyday life.

Continuous oral discomfort

The participants complained of a gritty, sandpaper-like sensation in their mouths. Their sparse saliva was described as very viscous and one person characterized it as "burned asphalt". Dry, crusty and rigid lips adhered to each other and to moistureless tooth surfaces. This resulted in lisping, slur and inability to articulate words. Dehydrated mucous membranes caused their tongue to stick to the palate, and it became hard to open the mouth unless water was introduced. The participants described their tongue as inflexible and one size too big for

their oral cavity. It could appear as intensely red, shiny with white patches and deep, painful fissures: "I stumble on words; my mouth, my palate and tongue continuously feel rough and uncomfortable. The foul odour and the smarting pain of my tongue are so intense."

Eating difficulties

Lesser epithelial coverage of the oral mucosa, the back of the tongue and the corners of the mouth constrained the participants from eating hot or spicy food. Problems with swallowing were frequent. Especially the feeling of "swallowing into the wrong throat" was expressed by persons subjected to radiation therapy. Participants with xerostomia of long duration were unable to chew and swallow meat unless it was mixed in a blender. The alteration of smell was likewise a serious problem and led to uncertainties and discomfort:

> I try to swallow but food just moves around and stays in my mouth. Sometimes it gets stuck in my throat. Sometimes it tends to enter my respiratory passage. I have to mince my food and soak it in water before I dare to swallow. I have avoided meat and bread ever since I suffered xerostomia 20 years ago. That kind of food is not worth trying.

Worsen dental conditions

The participants were greatly worried about their teeth. They had observed deterioration and considered xerostomia as the main cause. Annual dental visits revealed new cavities, especially decayed root surfaces of the front teeth. In addition, many previous restorations had to be replaced due to secondary decay. Lack of saliva made it impossible to wear an occlusal splint at night to ease bruxism which often resulted in fractured and severely abraded front teeth:

> For three consecutive years I had no new dental cavities. Upon experiencing oral dryness I now have dental decay each time I visit my dentist. In addition, I have been grinding my teeth for some time particularly my front teeth and I tried to use a protective splint at night, but having no lubricating saliva it was impossible to wear.

Search for affirmation

The afflicted participants searched for affirmation. However, they were often met with inadequate understanding and sympathy, which is further described in the subcategories *inadequate social support* and *lack of empathy and professional commitment*. When consulting health care professionals their symptoms were often neglected and considered to be of minor importance.

Inadequate social support

The participants were disappointed because the general public was mostly unaware of xerostomia. As a consequence, their various behaviours were constantly scrutinized. Close friends often questioned why they were bringing water bottles and mouth sprays along on all occasions. Family members could make remarks about participants' bad breath but showed little appreciation of the underlying cause which amplified the perception that the problems of a dry mouth were not understood nor taken seriously by others. They were truly aggravated when their close partner in life displayed such indifference. One woman indicated that she no longer made the effort to explain her situation to her husband. She justified her rationale by recognizing that xerostomia was a concealed handicap that few conceived of:

> The problem of having a dry mouth is rarely a topic for discussion. It does not show. I cannot identify anyone, not even among my closest friends, who truly understand the consequences of such a condition. I get sick and tired of explaining, because they never stop making comments. No, I just keep quiet, because I have given up a long time ago. Sometimes my son asks me to go to the bathroom and brush my teeth because of my foul odour. I am grateful for his candour but it makes me sad.

Lack of empathy and professional commitment

Participants who underwent radiation therapy for head and neck cancer were dissatisfied with the information provided by their physicians as to the potential side effects such as xerostomia. They were told of the possibilities of developing xerostomia, but also that it was transient and would be resolved within six months upon completion of treatment. Much later, when the afflicted persons repeatedly tried to explain their continued and sometimes aggravated xerostomia, they perceived little or no empathy from health care professionals. Two participants had unsuccessfully consulted their physicians to discuss how their current medication may influence the severity of their xerostomia. Upon receiving no medical guidance these individuals altered, on their own, the dosage of diuretics to ease their oral

dryness. Their awareness that health professionals considered them whining and annoying was amplified by the fact that their concerns were considered trivial and that dry mouth is something one has to endure and get used to.

An elderly lady with xerostomia of long duration had never had any health professional explain the symptoms or underlying causes despite frequent visits to health care clinics. She felt that no one believed in her or paid attention to her complaints. The elderly participants had experienced a long chain of health professionals but no one had focused on their xerostomia and medically addressed the problem. It was annoying to repeat that particular health history at each medical or dental visit as if their condition of xerostomia was never entered into the medical or dental record:

> They cannot understand the discomfort and I get bloody mad when health care personnel not even take my complaints seriously. They dismiss my concerns by saying that they have seen worse problems. Xerostomia is simply something afflicted individuals have to tolerate, period. One physician said once—dry mouth is something most retired individuals at your age experience. Health care professionals only care about there own discipline and their area of expertise. How I feel beyond their scope seems to be of little concern.

Two young participants found little knowledge and empathy for their condition during their dental visits. When they expressed worries about mouth dryness and associated oral health consequences, they were met with distrust due to their young age. They characterized the personnel as non-compliant and inattentive. In addition, they were critical of salivary secretions test because the results did not seem to meet the criteria of xerostomia and did not reflect the severe oral dryness they had to face on a daily basis. Dental offices were also conceived as stressful, impersonal and dominated by routine procedures. While the elderly participants expressed confidence in delivered restorative dentistry, they questioned the professional competence to address xerostomia in general practice. The dental personnel paid little or no attention to their complaints and seemed to have very limited knowledge of prescription-free palliative drugs. As a consequence, the afflicted individuals came up with remedies of their own, such as rinsing with cooking oil or sucking on ice cubes. Younger participants pursued the literature, the Internet, contacted patient organizations, and consulted pharmacies to gather further knowledge about prescription-free preparations. They were also keener on testing these products:

> They seem so stressed. It is remarkable that I am unable to have an informative conversation with my dentist. He has restored so many of my teeth, and yet, he does not question why I have so many new cavities each time. I have repeatedly complained about my dry mouth and he ought to recognize that I have practically no saliva. I just do not think the dental providers understand or want to engage in this problem. Most likely they may not have any advice to share. They remain courteous but stunningly uninformed about xerostomia.

Social withdrawal

Participants who had been known for their extrovert behaviour, recreational pursuits and active participation in various associational events preferred to stay at home to avoid comments or pity. They often felt unsure of themselves and gradually avoided to meet with others, particularly strangers. Three subcategories, *enunciation difficulties*, *restrictions in daily life* and *feelings of stigmatization*, describe causes of the social withdrawal.

Enunciation difficulties

Participants working in professional settings found xerostomia to impede their communication with customers and colleagues. They were embarrassed having to clarify their messages repeatedly. One woman related to her difficulties of answering the telephone because her tongue was often "glued" to her palate. She felt she was frequently misunderstood and refrained from further telephone conversations. This awkwardness kept her from initiating conversations and to decline invitations to join her fellow workers for social gatherings. The students felt particularly handicapped when speaking before a group. They felt uneasy and embarrassed having to interrupt oral presentations to lubricate their mouth. They preferred to study by themselves and turn in written responses to their exercises. Others expressed their discontent of not having daily communication with relatives and family members due to their dry mouth and inadequate articulation:

> I work as a receptionist and I always need to have a glass of water handy. My words get stuck, customers get frustrated and they repeat their questions over and over. My fellow workers are also tired of listening to my lisping. But my husband's attitude is the worst thing of all because he continuously tells me that my speech is too slurred and that he is getting tired of listening. We hardly ever communicate anymore.

> At school when I have to present my homework or a project before the class I feel very nervous and my mouth dries up in no time. I stand silent before my classmates who keep staring at me. I feel so stupid.

Restrictions of daily life

The participants would frequently wake up at night feeling unable to open their mouth. They were experiencing thick, sticky mucous, which was difficult to dislodge or discharge and had to consume water throughout the night. These nocturnal patterns were disturbing to the surroundings as well and couples preferred separate bedrooms. Sleep deprivations made the afflicted individuals drowsy during daytime, which also curtailed their activities and social interactions. Even daily chores such as shopping were sometimes considered too demanding. One man had to leave his fitness programme and abandon soccer because of xerostomia. It became too cumbersome to drink water at the sidelines all the time. He felt that he was no longer a member of the team, and he kept missing the interactions with his former team mates. Participants who previously enjoyed chorus singing had dropped out due to xerostomia and they complained about losing their togetherness with other chorus members. Socializing with friends was highly treasured among younger participants, and they went out of their way to manage their oral dryness. When attending movies, they always brought water and lozenges along. They also preferred to be seated next to the isle to easily reach the foyer in case of a coughing spell:

> "It is hopeless; I try to mime to make it look like I am singing and the other day, I had to take a sip of water a shop attendant approached me and asked if I was consuming alcohol. I refuse to return to that store again."

A male participant who previously enjoyed gourmet food and informal dinner events at home was deeply regretful of having to discontinue these pleasant and joyful occasions because of his altered sense of taste and smell and his difficulties with swallowing. These lifestyle changes made him lose interest for cooking:

> I use to enjoy being in the kitchen preparing food from all kinds of recipes. Now, I am deeply saddened and I profoundly regret my inability to enjoy these pleasures and enjoyments. In the past, my friends used to come here and enjoy good times. It is not like that anymore. It influences my spirit. I get irritated, depressed and grumpy. I have been suggested to join friends for various trips, but I find it disconcerting knowing that I have to stick to my menu of liquid and mushy food. In addition, I have lost interest in returning to my work place.

Feelings of stigmatization

To share meals with others was most trying for the participants. They stated that they would not go out for dinner because they were ashamed of their eating habits. They would make embarrassing noises while eating, chop their food into minute pieces and use their fingers to dislodge sticky food from their dry tooth surfaces. It brought about an unpleasant state of mind. Each meal became time consuming. Food was often left behind on the plate to allow other dishes to be served timely to joining guests. Such considerations and circumstances made participants avoid luncheons with friends and fellow workers to avoid comments about their table manners. This prudence contributed to even greater isolation of the afflicted participants at the workplace. Lack of saliva jeopardized the fixation of removable dentures which, in turn contributed to eating difficulties and lesser confidence in various social settings. The participants were also concerned about bad breath. When using oral lozenges as temporary remedies to disguise foul breath, colleagues at work frequently made sly remarks about these oral habits. Further, to have abraded front teeth was seen to be both destructive and aesthetically uncomfortable. As a consequence, the participants tried to keep a certain physical distance to others or cover their mouth when talking or laughing:

> I feel very uncomfortable, even among family and friends. It is no fun poking around with my knife and fork. Others make comments about my table manners. It is embarrassing to say the least. I feel insecure being watched all the time. In addition, my teeth look terrible and I am very embarrassed over my appearance.

Discussion

A grounded theory study should be judged by fit, work, relevance and modifiability (Glaser, 1992). The findings of this study imply a holistic understanding of the meaning of xerostomia based on individual and shared personal experiences among 15 afflicted adults. Extensive, open-ended interviews disclosed comprehensive descriptions and deepened understanding. Data were scrutinized, broken down and coded into meaningful concepts. Memo writing and theoretical sampling saturated the emerging

categories with information. During the analytical process, the authors reflected upon and discussed the tentative categories rather than forcing them into preconceived classifications. Citations corresponding to each conceptual subcategory further exemplify that they were grounded in the data.

Since each qualitative study has its own premises and participants, the findings are generally not transferable. A grounded theory has to be modified whenever conditions are changing. Consequently, the findings, of the present study are not transferable to the population at large but highly plausible as to other afflicted adults with xerostomia in the same conditions. The observations would also serve as a valuable reference for health care professionals to promote both a better understanding of and a greater empathy for individuals afflicted by xerostomia.

The findings reveal the complexities of xerostomia which broadens the focus from the oral cavity to the individual as a whole. The core category, *an aggravating misery,* indicates that xerostomia has a devastating and debilitating impact on multiple domains of well-being. Although based on data from a relatively small sample, which is a necessary condition for qualitative analysis, the findings underscore that xerostomia is not a trivial condition for those afflicted. Oral impairment as well as physical and psychosocial consequences of xerostomia has negative impacts on the participants' quality of life. The afflicted participants resembled xerostomia with grievance because they had to abstain from important essentials in life. Sreebny (2000, p.141) describes it in one brief sentence: "a word without saliva is a word without pleasure … like living with a drought." The observations further corroborate recent studies indicative of the pervasive influence of xerostomia on oral health-related quality of life among old and medically compromised individuals (Matear et al., 2006; Wärnberg Gerdin et al., 2005) as well as among 32-year old relatively healthy adults (Thomson & Poulton et al., 2006).

Continuous oral discomfort, concur with the clinical panorama described by Locker (1993) who found oral dryness to be the most common of 22 oral symptoms and complaints in an elderly adult population. Insufficient amount of saliva during the mastication and the swallowing compromise proper nutrition and increase the risk of aspiration of food particles. This confirms studies showing associations between nutritional deficiencies and the avoidance of "difficult-to-chew" foods among seniors with xerostomia (Rhodus, 1990; Budtz-Jörgensen, Chung & Rapin, 2001). The present study does not disclose the underlying cause of oral dryness among the participants. However, many older persons may be at risk for multiple oral complications due to medications (Shinkai, Hatch, Schmidt & Sartori, 2006). This may explain frequent complaints of oral pain and burning sensations among the older participants of this study.

Generally, there is a poor correlation between salivary flow rate and xerostomia (Hay et al., 1998). An objectively determined dry mouth was associated with oral pain (Bergdahl, 2000; Wärnberg Gerdin et al., 2005) while, subjectively perceived oral dryness might be of psychological origin (Anttila et al., 1998). The participants of this study were critical towards salivary secretions tests performed by dental personnel because the tests did not reflect the 24-hour-a-day cycle of problems. Similar concerns were expressed by Fox et al. (1998) who reported that one of the most common xerostomic complaints, dryness at night or on awakening, were not associated with measurable decreased salivary function. Apparently, the subjective sensation of xerostomia is what matters most to an individual.

The category *search for affirmation* describes the participants' expressions of resignation and dissatisfaction. This can be compared with powerlessness, vulnerability when distrust, stigmatization and apathy suppress an individual's own resources to resolve problems (Strandmark, 2004). The lack of human support and empathy compounded the participants' feelings of alienation while some compensatory consolation was perceived from having a pet. This concurs with the views of Strandmark (2004) who pointed out that domestic animals can facilitate companionship and self-esteem.

The term social support refers to different kinds of support that people exchange; aid, affection and affirmation. Family members and close friends usually belong to the inner circle of an individual's social network while acquaintances and health care professionals are parts of second or third circles (Sarment & Antonucci, 2002). Whenever a health care professional assists an individual to cope with speaking or eating difficulties, that person often becomes a core member of the social network. Hence, anyone becomes important who extends symptom relief for oral dryness. The participants of this study had experienced little ability among health care professionals to address their needs for symptom relief and dental decay prevention. This observation coincides with the perception how health care professionals' view xerostomia. They acknowledge the frequent occurrence of xerostomia, yet concede to the reality that the conditions are ignored and inadequately managed (Folke, Fridlund & Paulsson, 2009). Accordingly, the participants of this study felt abandoned by their health care professionals who paid little or no attention to their worries about oral health

ramifications and well-being in general. As a matter of fact, Kay, Ward and Locker (2003) found it common among patients of general dentistry to worry about their oral health and their personal appearance as well as avoidance of socializing due to deteriorated oral conditions.

Previous, studies have also shown that alterations of salivary flow and composition as well as rampant dental caries may serve as potential indicators of various undiagnosed systemic diseases (Field & Longman et al., 2001) and especially for autoimmune salivary gland dysfunction of primary Sjögren's syndrome (Lynge Pedersen, Bardow & Nauntofte, 2005). Therefore, it is essential for all health care professionals to contemplate the problems associated with xerostomia. Their clinical evaluation should include an overall impression of the patient with special attention to the patient's physical and emotional makeup. Patients should be questioned in greater detail about the nature, frequency and duration of dry mouth and health care professionals should gently explore and pay attention to direct or inconspicuous symptomatic complaints. Fox et al. (2000) emphasize that questions concerning xerostomia should be included as part of the standard health questionnaire and that valuation should be conducted proactively at each patient visit.

In addition, the participants of this study experienced exhaustion and despair due to psychosocial consequences of oral dryness. Fear of misunderstandings and feelings of embarrassment contributed to their cognizance of social decline. According to Jokovic and Locker (1997), expressions of satisfaction and dissatisfaction are complex entities and incorporate perceptions, values and expectations. MacEntee and Prosth (2007) suggested that humans over time develop a capacity to adapt to and cope with oral ill health and impairments and thereby modify their expectations and activities. For elderly participants of this study, daily life became more restricted. They stayed primarily at home to manage their xerostomia symptoms in a secluded environment. Younger participants tried more proactive solutions but had to struggle to maintain their ordinary everyday activities.

Both male and female participants experienced an unattractive facial appearance due to cracked lips, decayed and/or abraded teeth. This feature contributed to an unpleasant state of mind while socializing. This is in line with earlier studies, showing that dental appearance affects judgment of facial attractiveness regardless of gender (Trulsson, Strandmark, Mohlin & Berggren, 2002). Consequently, the ability to mingle with others without being embarrassed over bad looking teeth or foul odour is important for optimizing self-esteem (Hallberg & Haag, 2007; Hattne, Folke & Twetman, 2007). Nalcaci and Baran (2007) concluded that one factor most strongly associated with self-reported halitosis and perceived taste disturbance was subjective oral dryness. From a psychosocial aspect, the aesthetic concerns, halitosis, slurred speech and associated anxiety had a profound impact on self-confidence among the participants of this study. They withdrew from social events feeling embarrassed and shameful in public. Further, they felt their awkward eating habits placing additional restrictions on their social life. In this context, one should not ignore the compounded psychosocial impact of xerostomia among individuals with head and neck malignities as shown by (Rydholm & Strang, 2002; Andreassen, Randers, Ternulf Nyhlin & Mattiasson 2007).

Conclusion and implications

The core category *an aggravating misery* indicates that xerostomia has a devastating and debilitating impact on multiple domains of well-being. Participants were seeking professional consultation, searching for affirmation and withdraw from socializing attending to solve their xerostomia problems. The number of afflicted individuals increases with advancing age due to chronic diseases and adverse medications. Thus, further studies concerning the complexities of xerostomia seem essential. In addition, there is an obvious need to enhance the professional competence of managing xerostomia. A holistic view, additional education and better interdisciplinary collaboration are essential to improve compassion for and support of individuals afflicted by xerostomia.

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