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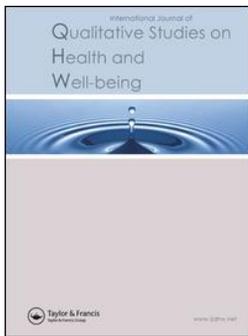
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ORIGINAL ARTICLE

## 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 & Dahlöf, 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

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 their 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 aisle 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-Jørgensen, 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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