Acta Odontologica Scandinavica, 2009; 67: 212–221

informa
healthcare

ORIGINAL ARTICLE

The meaning of oral health-related quality of life for elderly persons with dementia

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Abstract

Objective. Studies of oral health developments increasingly include self-reported assessments of how oral health affects quality of life (QoL), referred to as "oral health-related QoL". People with dementia are often excluded in studies of oral health-related QoL and thus our aim in this study was to explore this area in elderly persons with dementia. ***Material and methods.*** Eighteen elderly individuals (aged between 78 and 94 years) with dementia of varying degrees of severity were interviewed with the aid of an interview guide; pictures and objects were used as stimulus material (triggers). The material was analyzed using grounded theory as point of departure, and a professional assessment of the oral health of the participants was used as reference. ***Results.*** Four categories were identified: the ability to chew and eat, independence, oral problems, and the teeth are important. These factors are largely consistent with those that have emerged in earlier studies of the elderly, but in some cases less pronounced in persons with dementia. ***Conclusion.*** The use of triggers is a positive way to communicate oral health-related QoL among persons suffering from dementia, although the material used in this study needs further evaluation and development.

Key Words: *Communication, dementia, oral health, quality of life*

Introduction

Oral health is considered an important component of general health and quality of life [1], and people with good oral health have been found to age with enhanced quality of life and fewer illnesses compared to others in poor oral health [2,3]. This article focuses on quality of life (QoL) as an effect of oral health in old persons with dementia.

QoL is a relative concept. It means different things to different people in different contexts. QoL is affected to varying degree by physical, mental, and social abilities [4] and may vary with respect to factors such as age, gender, and cultural conditions [5]. Therefore, QoL is not a directly measurable variable, but a construct of several interdependent factors based on individual perceptions.

Researchers have made major efforts to define and operationalize the concept of QoL in the field of oral health-related QoL [6]. In such contexts, measuring the consequences of poor oral health is a priority; for example, problems concerning nutrition and social interaction, emotional and psychological function, and the mouth itself. It is thus deterioration of QoL that is measured rather than QoL as a positive value [7].

Inglehart & Bagramian [8] have proposed a working definition of oral health-related QoL on the premise that oral health-related QoL is a perception based on the functions of the mouth, pain and discomfort, and psychological and social factors.

Oral health-related QoL is a perception that has to be communicated by individuals themselves. Measurements are therefore carried out mainly through written or oral communication with the subjects under study. Currently available instruments are mainly questionnaires developed internationally, primarily for use in research contexts [6]. Several

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(Received 30 September 2008; accepted 27 February 2009)

ISSN 0001-6357 print/ISSN 1502-3850 online
DOI: 10.1080/00016350902855296

of the most commonly used instruments are designed for an older target group [7], but practically all were designed in ways that exclude older patients with varying degrees of dementia and communication difficulties.

Consequently, none of the currently available instruments is intended to measure oral health-related QoL in persons with dementia. It is thus impossible to plan systematically and follow-up dental care with respect to oral health-related QoL for this group, even though older patients with dementia are a target group covered by the reformed dental care benefit system for the elderly and people with disabilities in Sweden [9].

Over the past year, Locker [10] and Allen [6] have criticized what they regard as careless use of the concept of "QoL" in the field of odontology. They criticize the assumption that the measured variables relate to QoL and that it is made without the relationship being studied explicitly. These same studies concluded that qualitative studies were needed to define the meaning of the concept in elderly persons with dementia.

Recent studies indicate that there are various avenues of communication available for reaching people suffering from dementia, although the method of communication has to be adapted to the unique situation of each individual [11]. Few persons with dementia are able to respond to a traditional questionnaire.

Based on recent research and experience communicating with elderly people with dementia [12,13], and on research into the development of instruments for measuring general QoL in persons with dementia [14], it should be possible to develop communication methods for measuring perceptions of oral health. Experience of working with persons with dementia or autism indicates that communication using drawings, photographs, and objects can be successful [15,16].

Against this background, this article aims to define the meaning of oral health-related QoL and is the first step in a larger project, the overall purpose of which is to find a method by which to measure QoL as an effect of oral health in persons with dementia.

Material and methods

We adopted a grounded theory methodology, which is considered appropriate for use in less frequently studied fields. This methodology, with roots in sociology, recommends using interviews to define and explore processes. Data collection and analysis comprise a simultaneous process in this methodology, and the first interview guides the researcher's selection of the next interviewee [17]. Dewing [18], however, claims that studies involving persons with dementia often call for a specific approach to protect all parties in the study. In this present study, the method for selecting interviewees had to be adapted.

Data were gathered through individual interviews using an interview guide. In addition, a dental examination was carried out to acquire objective information regarding the oral health of interviewees.

Participants

Interviewees were selected based on the principles of convenience sampling, which is the use of the most conveniently available subjects [19]. To be suitable for participation in the present study, a subject had to have been diagnosed with dementia and to have lived in group housing for persons with dementia. In order to compile as heterogeneous a group as possible, interviewees were selected based on different stages of dementia, from mild to severe. The selected group is described in Table I.

Support

The study was supported by the division manager of each group housing unit. All respondents – both interviewees and family members – provided oral consent to participation in both an interview and an oral health examination.

The Regional Ethics Review Committee in Linköping (reg. no. 186-06) reviewed the study from an ethics standpoint.

Interviews

An interview guide was formulated based on the themes of perceived level of oral health (or lack of it), the significance of teeth based on function, and social and psychological aspects of oral health. Each interview was conducted in a calm, private, environment

Table I. Number of interviewed (*n*), age, diagnosis and FAST-scale*** level.

No. of interviewed	18	
Age	78–94 years	
Gender	Female (*n* 15); male (*n* 3)	
Diagnose	Alzheimer's disease	(*n* 11)
	Vascular dementia	(*n* 4)
	Mixed dementia*	(*n* 2)
	Dementia NOS**	(*n* 1)
FAST-scale*** level	Level 4	(*n* 3)
	Level 5	(*n* 1)
	Level 6	(*n* 8; 6a = *n* 3, 6b = *n* 1, 6d = *n* 4)
	Level 7	(*n* 7; 7a = 3, 7b = 3)

*Mixed dementia = Alzheimer's disease and vascular dementia.
**NOS = Not otherwise specified.
***FAST = Functional Assessment Staging Test [20]. FAST-scale estimate levels of functional capacity from 1 to 7, where a higher number represents a lower functional capacity.

familiar to the interviewee. It was important to establish good contact and to meet the interviewees in ways conducive to them. The questions were short, concrete, and uncomplicated, making it easier for respondents to answer. It was also important to wait for the answers to emerge. On several occasions it was necessary to return to the subject by repeating what the interviewee had said. These considerations are important when interviewing persons with dementia and learning difficulties [18,21].

Throughout the interviews, "triggers," that is, photographs or objects associated with the subject, were used to clarify the questions, as well as on occasions to keep the discussion on track [16].

The photographs used most frequently were those showing a mouth with a complete set of teeth, various foods, and teeth in poor condition. The objects used were a complete removable denture and a toothbrush.

The interviews lasted between 11 and 26 minutes – the time determined by the interviewee's verbal acumen and ability to concentrate on the subject.

According to Manusov [22], it is important to observe non-verbal expressions during interviews, since it is difficult to capture everything verbally. During the interviews, we therefore observed body language and expression of emotions conveyed in the situation. Body language was observed with a focus on facial expression, shaking of the head, eye contact (gaze), what the interviewee did, and other information about how the interaction proceeded. Observations were recorded during or in direct connection with data collection.

A nurse (I.E.) with specialist training and experience in dealing with persons with dementia conducted the interviews, at the conclusion of which all interviewees showed their appreciation by thanking the interviewer for a pleasant time either verbally or by hugging or patting on the cheek.

The recorded interviews were transcribed verbatim by a person experienced in this field and the text was adapted to the conventions of the written word to facilitate reading. In the quotations cited in the Results section, interpolated or implied statements are given in square brackets. The interviewer listened to all recordings after they were transcribed and printed, and added information where possible by filling in words that had been omitted from the printouts because of difficulties understanding what the interviewee had said.

Analysis of interviews

All data from the interviews were coded and classified using grounded theory [17] as a point of departure. According to Strauss & Corbin [17], analysis is a four-step process:

1. *Naive reading* – acquire an initial understanding of the data content.
2. *Open coding* – data are read line by line and informative data (indicators) are identified and assigned conceptual code names. The conceptual codes are categorized based on similar content, and the different groups are assigned a more abstract category.
3. *Axial coding* – the categories are compared with the purpose of investigating how they relate to each other. Connections in the categories are sought and subcategories are identified and developed based on these connections.
4. *Selective coding* – the central information in the data is identified and a core category emerges that can be said explains everything found in the material.

Most of the analysis was carried out by the interviewer (I.E.) under the guidance of one of the co-authors (E.C.). A few interviews were analyzed jointly by the interviewer (I.E.) and the dentist (A.H.), who carried out the clinical examination. All authors were involved in the analysis and writing process.

Reliability

To ensure reliability, Lincoln & Guba [23] suggest working based on the four criteria of credibility, dependability, confirmability, and transferability. To fulfill these criteria in this study, the material was analyzed by several people, and the examination process was carefully coded and categorized (Table II). Illustrative quotations are presented in the results section below, and findings could be said to apply to a group of people similar to the study participants, but no attempt is made to generalize the results based on such a small sample.

Oral health examination

Two to three weeks after interviews, each participant had an oral health examination which provided a picture of his or her oral and dental status. The examination was carried out by a dentist (A.H.) together with an assistant whose task was to record chart notes and handle instruments. The examinations were carried out in each participant's apartment using available seating or with the participant lying in bed. The dentist and the assistant wore typical dental office apparel and introduced themselves and clearly explained the purpose of the visit. The intra-oral examination was carried out using a flashlight as the light source, a mirror, an explorer, a graduated periodontal probe, and a wooden spatula. One participant was severely ill and could not be examined.

Table II. Overview of the analyze process included three steps carried out, where categories,subcategories and core category identified

Open coding			
Four categories were identified			
↓			
Ability to chew and eat ↔	*Independence* ↔	*Oral problems* ↔	*Teeth are important*
↓			
Axial coding			
The dimensions of categories were developed and subcategories were identified			
↓			
Ability to chew and eat ↔	*Independence* ↔	*Oral problems* ↔	*Teeth are important*
- Significance of teeth for eating	- taking care of oral hygiene		- unaware of dental status
- changes linked to age			- acceptance of edentulism
			- Apperance of teeth less important
↓			
Selective codning			
The central phenomenon and core category were identified.			
Retained function and independence			

The oral examination included identifying the presence of pain or problems concerning the face and/or mouth as well as the ability to open the mouth and chew. In addition, an intra-oral examination was performed to record edentulous jaws, the presence of removable partial and complete dentures, number of teeth, dental caries, periodontitis, and mucosal changes. The subject's oral hygiene was noted.

Results

An overview of the three-step analysis process is presented in Table II. Four categories were identified: *ability to chew and eat, independence, oral problems,* and *teeth are important*. The analysis let us identify a core category describing the meaning of oral health-related QoL for the person with dementia: *Retained function and independence*.

Ability to chew and eat

The interviews clearly indicated that it was important to be able to chew and eat. Some interviewees mentioned the *importance of teeth for eating*. One recurrent theme in the interviews, however, was that it was mainly the ability to chew and eat that was crucial, whether with or without teeth, or with a removable denture:

> . . . I don't have a tooth in my mouth. . . . So far I have managed to eat and . . . that's the main thing.

Significance of teeth for eating. – Those who have permanent teeth felt that, to be able to eat, it was important to have their own permanent teeth. When asked why teeth were so important, one person answered, ". . . it's when you want to have food".

Interviewees with removable dentures felt that eating and chewing with dentures was just fine, and that eating would not be possible without them. However, one concluded that it would be possible to eat even without dentures, since the jaws would probably gradually harden.

> ". . . [I]t would have happened little by little, so the gums . . . they would have resisted so they would probably become rather hard so it would probably have gone well."

Those who had no teeth at all (neither their own permanent teeth nor removable dentures) share this opinion based on experience. They described how, after they had been without their teeth for a period of time, the jaw changed; it became hard, which made it possible for them to chew food even without teeth. Having no teeth did not appear to be a problem, since this did not prevent them from eating and chewing: "My mouth is so hard . . . so I can still chew".

Those who have natural teeth talked about changing the food they ate, since some foods have a tendency to get stuck in places or in gaps where teeth are missing. They mentioned the fact that it took time to chew, and that eating could be quite difficult. Some of them, including those who had dentures, perceived their teeth as brittle, i.e. there was a risk that "they will break" if certain foods are eaten. Participants who had no teeth at all and did not wear dentures, or who wore dentures only in the upper or lower jaw, spoke most about choosing certain foods. They adapted their diet or food choices:

> I have to chew it up without teeth and have . . . you soak it and so on . . ..You eat this type of food to avoid chewing.

Changes linked to age. – The interviewees did not usually describe the need to change how they ate as a major problem; they noted this as a consequence of the changes in dental status that they believed accompany aging. Some food did not taste the way it used to because of changes in the sense of taste (changes considered to be due to age), so people refrain from eating certain foods; fruit was

mentioned as an example. They felt that this was to be expected. The main thing was that they could choose what they wanted to eat and that they could eat the food.

> Age is even an issue then. And you don't think like that about your teeth. You eat the type of food that makes you feel good.

Unreliable teeth were associated by many with growing old. They become weaker and suddenly you can have pain and the teeth can break. The mouth/jaw also changes over the years. The interviewees saw these changes as part of aging and something to be expected. One expressed it as follows: "They [the teeth] become a little ... a little more sensitive when you get older."

The answers suggest that, with age, teeth are important mainly for eating. The importance of having nice teeth for the sake of appearance decreases; that is, as long as relatives and children still come to visit.

> I'm pretty old ... they [the children] come and visit me so often ... it doesn't prevent anything at all, I can chew so well ... I don't think about it [appearance].

Independence

Almost everyone mentioned that it was important to *take care of oral hygiene* personally, even though some added that you had to accept help when you could no longer manage independently. Most of the interviewees found it difficult to imagine getting help. A few felt they had not been good enough at taking care of their teeth and that they had been careless and therefore now had dentures; nevertheless, they did not want others' help with oral hygiene. Getting help with oral hygiene was described as horrible and the interviewees all found it difficult to accept "that someone else goes around and pokes in your mouth". However, one person said that it would be acceptable for the care personnel to brush her dentures when they were out of her mouth. "No ... When you have others who are there [in the mouth] and scratch ... I manage that just fine."

Taking care of oral hygiene. – It is important to be careful with one's teeth, both with respect to what is eaten and actually keeping them clean. Most felt that it was important to take care of their teeth by brushing daily, several stating that they brushed perhaps two or three times a day. Some felt it was important to brush their teeth and to use a toothbrush, but could not explain why this was important: "It's supposed to be good [to brush], ... I don't know why it (toothbrush) is useful ...."

A few felt that tooth care and being careful with the teeth were things that were learned in childhood, and that as long as there were teeth left it was important to brush them. When teeth were lost, oral hygiene was less important, since there was nothing to brush or take care of: "I don't have any teeth now ... of course it [brushing] is important for keeping your teeth."

Brushing the teeth is important mainly for a personal sense of well-being. One of the reasons the interviewees felt that brushing teeth was important was "... being clean", the desire that the mouth should feel clean and fresh. It was also important to brush one's teeth because, as one person said, "... you probably think that they can break otherwise".

Brushing the teeth and keeping them clean was also important on occasions when in company with others, according to some respondents. If the teeth were not brushed and clean, an odor could develop; also, bits of food could get stuck, which was described as extremely unpleasant. To the direct question why it was important to brush the teeth, the answer was: "So that you don't smell and things like that ... you want to remove bits of food if there are any."

Oral problems

Those who said their mouths felt good often added that they felt good because they did not have any problems or any pain, which was expressed as "... not complaining as long as teeth don't hurt". There were also those who said that their mouth did not feel good at all and mentioned this as an obstacle to feeling good in general. One person said that how your mouth felt probably "... can have a very large effect on a person's general sense of well-being".

Those who said their mouth did not feel good often spoke spontaneously about discomfort in the mouth. As mentioned above, discomfort was the perception that the teeth could fall out at any moment, food getting stuck in gaps where teeth were missing, and crumbs tending to get in under ill-fitting dentures. Another problem one person described was that brushing hurt so much that s/he did not brush. Dry mouth was mentioned spontaneously by one individual and described as a curse that caused the dentures to chafe to the point they could not be worn:

> ... your mouth gets so dry so that it's impossible to wearthem [the dentures], they are so hard ... no, I can't have themin my mouth.

A few individuals who found it difficult to express themselves verbally pointed to their mouths and shook their heads as though to emphasize that they wanted to express discomfort – their body language demonstrating how they put their teeth in and that it

felt unpleasant. At the same time, they expressed some doubt that the problems in their mouth could be corrected.

> The interviewee points enthusiastically to her lower jaw on the inside of the teeth and says: "... something that came in here. ..." At the same time she pulls with her fingers as though to pull something loose and throw it on the floor with her hand, and says, "Yes. Yes ... take it with your fingers." She touches her teeth and shows that they are loose and says, "... so much that falls out here ... and hangs in there. ... It falls out here."

Teeth are important

The interviewees felt that it was of value to take care of their teeth by going to the dentist as long as they had teeth. If the dentist could not carry out regular checkups, dental caries would develop, which in turn would cause toothache and mouth pain. However, some doubt was expressed as to whether dental care was provided to the elderly and whether the resources, interest, and opportunities were there for anything to be done about bad teeth caused by growing old. This doubt was expressed as follows: "... find it hard to believe that they [dentists] care about someone who is 84 years old." Although these opinions were expressed, there is unawareness of personal dental status. The interviewees also stated that edentulism needed to be accepted at higher ages and that the teeth became less important in the case of older persons with dementia.

Unaware of dental status. – Awareness of personal dental status varies. Asking those who lacked teeth, or who had dentures, how they lost their teeth resulted in vague answers. The interviewees often answered that they did not know. In answering whether they had their own permanent teeth, a few were certain at first, but then were doubtful and asked a question in return: "Or what does it look like in my mouth?"

Acceptance of edentulism. – Removable dentures is something that the interviewees who had their own permanent teeth wanted to avoid as long as possible. One person expressed distaste at the thought of needing dentures as: "Oh, no. As long as it's possible I'm going to try to manage some other way." Nevertheless, the interviewees concluded that if their permanent teeth did not work for some reason, they would just have to accept dentures. They would have to get used to dentures, ultimately, probably when there was no other alternative: "You learn little by little", according to one person.

Appearance of teeth less important. – Much has been said about different views and perceptions of the appearance and importance of the teeth. Even if appearance of the teeth was described as of decreased importance, the interviewees suggested that there was a limit to the changes that could be considered acceptable. Several said that the mere sight of poor teeth aroused disgust. One person did not even want to look at a picture of people with bad teeth. This interviewee said: "It's horrible ... seeing a person without any teeth ... I don't like that."

Among some, the appearance of their teeth was considered less important because they were not invited to social events as often as in the past. Only people who were familiar to them came to visit, in which case the appearance of the teeth was irrelevant. The only time it could be important was if a complete stranger came to visit.

> I don't go to parties often ... [but] then you have to brushyour teeth.

The condition and appearance of the teeth could also be perceived as less important because the person was now alone. Everyone of significance in the interviewee's environment was gone, so there was no longer any reason to think about the appearance and condition of their teeth.

> And I'm by myself, I don't have anyone so ... I don'tcare about it [appearance]. All my relatives and all my ... are gone.

Results of oral health examination

The oral health examination included 17 of the 18 interviewees; one person was too ill to participate. There were five with natural teeth in both jaws, two with natural teeth in the lower jaw, and one with natural teeth in the upper jaw. Nine persons were edentulous in both jaws. The results of the examination are given briefly in Table III.

Participants with teeth had obvious damage from dental caries, and moderate amounts of gingivitis and periodontitis were found.

There appeared to be a correlation between the clinical examination and the interviewee's comments about chewing ability and oral problems. However,

Table III. Result of the oral examination.

No. of persons	Oral status
5	Dentate both jaws
3	Dentate one jaw (1 in the upper jaw 2 in the lower jaw)
9	Edentulous both jaws (6 wearing removable dentures in both jaws, 2 wearing dentures in the upper jaw and 1 wearing no denture at all)

some interviewees described subjective experience of conditions such as dry mouth that could not be observed in the clinical examination. Occasionally, the information provided by the person in interview about the number of teeth deviated from the clinical examination. In the clinical examination, interviewees who said that good oral hygiene was important were found to have good oral hygiene themselves. One exception with respect to consistency between the clinical examination and the interview was someone who claimed to be unable to brush any more due to pain, but who still proved to have very good oral hygiene.

Prominent findings, retained function and independence

A predominant finding in the material was the desire to *retain function* and to be *independent* with respect to oral hygiene (Figure 1).

Retained function refers to the ability to chew and eat, which requires the absence of problems in the mouth. However, even if certain problems are present, function can be retained by choosing certain types of food and avoiding others. For some participants, the teeth were important for chewing/eating and appearance and for avoiding oral problems. They therefore had to be looked after by toothbrushing and by visiting the dentist regularly. However, other participants said they could chew and eat even without teeth by adapting their choice of food, in which case function was retained. Moreover, most interviewees had a strong desire to be allowed to take care of their teeth personally – a manifestation of the desire for independence.

Discussion

In this study, people with dementia were asked about factors relating to the mouth that were important for that person's sense of well-being and how they affected well-being. Many of the elderly comprising the target group of the reformed dental care benefit system [9] are persons with dementia. There is thus a need for knowledge of the factors that are significant for oral health-related QoL for these persons, in part to enable the development of instruments for evaluating the dental care benefit system.

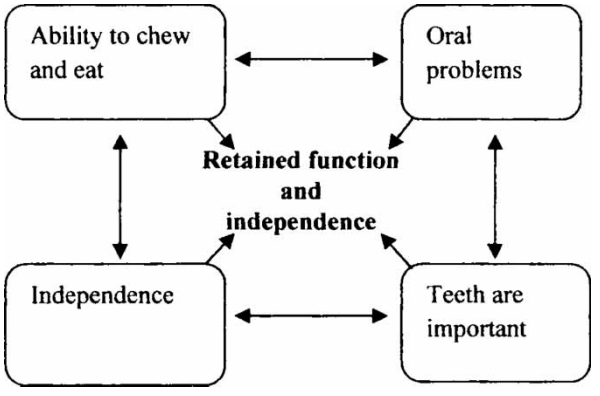

Figure 1. The meaning of oral health-related quality of life in elderly persons with dementia.

The interviewees were persons with a diagnosis of dementia in various stages and who lived in group housing for persons with dementia. They were aged between 78 and 94, and can be said to constitute a representative group since this is the age group in which most people are diagnosed with dementia [24]. The group consisted primarily of women, which was not surprising since women form the majority in group housing for dementia [24].

No one in a really early phase of dementia was included among the interviewees because persons with mild dementia seldom live in institutional housing [24]. It was important to capture the degree of severity of dementia among the interviewees in order to be able to reach those who had communication difficulties. The triggers (stimulus material) used in the study were intended for persons with speech disorders, but we found that the triggers were, as Murphy et al. [16] suggest, also helpful in keeping the focus on the subject during all of the interviews.

Oral status of the interviewees varied, which can be said to be representative of this age group [25]. Some participants had natural teeth while others were edentulous in one or both jaws and wore removable dentures. It was probably of significance for the clinical examination that the dentist introduced him/herself and approached the person openly and respectfully. The professional clinical attire may also have made it easier for participants to understand and accept the situation and to allow themselves to be examined.

The ability of the interviewees to understand and express themselves linguistically was limited in some cases; several also had difficulty staying on task and focusing on the questions. Despite these problems, persons with dementia can contribute valuable information in an interview [11,26], though the conduct of the interviewer is important. Based on their experience studying people with communication difficulties, Allan & Killick [12] and Booth & Booth [21] emphasize the importance of focusing on the subject, i.e. referring to what the person says, waiting for answers, and guiding the conversation to new subjects. By associating with what the interviewee has said and keeping the focus using "triggers", the interviewer can guide the interview forward, though this somewhat active approach may have contributed to the omission of important information. The interviewee may have been interrupted when trying to complete a thought that would have led to a response to the question. In a few cases, however, the interviewer remained silent for long

periods to provide an opportunity for reflection and to wait for answers from the interviewee. In such cases the interviewee provided extremely fragmented incoherent information that was difficult or impossible to interpret.

Because of the inability to concentrate and the fatigue of persons with dementia [11,27], there was also a risk that the interviewees would lose concentration and want to interrupt the interview before the questions were answered. It was therefore important not to spend too much time in each area, though this might have entailed the loss of some information.

Because of the compromised ability of the interviewees to express themselves linguistically, it was also important to observe body language to try to understand what they wanted to say. Body language reinforces what is said [22]. Notes were taken with respect to body language and mimicry in an effort to capture non-verbal language. Some information about mimicry and body language might have been missed, which perhaps could have been avoided if the interviews had been videotaped. However, in light of the participants' impaired brain capacity, with reduced ability to sort stimuli and concentrate on what was important in the moment [27], videotaping might have been distracting and have influenced the ability of the interviewee to stay on task.

Questions that placed demands on memory (e.g. "Was it difficult when you lost your teeth?") were intentionally omitted from the interview because it is inappropriate to ask questions involving the memory of a person who can no longer remember [11]. Nevertheless, some questions relating to memory were asked and it was clear that most responded based on how things were or felt from a "here and now" perspective. This could be one reason why certain factors included in the instrument for measuring oral health-related QoL [8] among healthy older individuals are not fully consistent with the findings of this study of persons with dementia.

There is also reason to believe that how a person defines QoL in general can vary over time, and opinions can change when a condition such as dementia develops [14,28]. Compared to the earlier working model [8], there is a difference in the ranking of the factors described as indicating oral health-related QoL by persons with dementia. There would also appear to be differences between the specific factors mentioned by the interviewees and those included in the earlier working model [8].

The interviewees spoke about function with respect to ability to eat. Functions required in order to eat (i.e. chewing, biting, and swallowing) in the Inglehart & Bagramian [8] working model of oral health-related QoL were not mentioned spontaneously. When directly asked about the ability to chew, the need to adapt food choices and meal times was mentioned, though these were of negligible importance.

Inglehart & Bagramian [8] include pain and discomfort in their working model, and the interviewees in the present study likewise mentioned various forms of discomfort. Even with respect to pain and discomfort, the interviewees talked about the subject and its significance based on their current feelings at the time of interview, as is often the case [29]. If none of the interviewees had happened to perceive discomfort at the time of the interviews, it is doubtful that discomfort could be included as a factor of significance for the meaning of oral health-related QoL.

The interviewees said that the significance of psychological and social factors, such as appearance of the teeth and mouth, was different because their social life was less important. The need to perceive oneself as someone, as having an identity, as visible, and as part of a context can be found in the person with dementia throughout the disease process [30]. However, factors other than good appearance, such as the ability to chew and eat, and visits from children are more important.

Another explanation given for the decreased importance of the appearance of the teeth was that not much more could be expected because of advanced age. Attitudes such as this might possibly influence opinions about what is meant by oral health-related QoL. There are attitudes about, and expectations of, physical, mental and social decline in the aging process that are not relevant [31].

Factors not mentioned at all, or at least not given any particular attention, by the interviewees who live in group housing for individuals with dementia were communication/speaking and swallowing.

The question is why retaining the ability to chew and eat was mentioned as the most important. Someone said that food presented the pleasure "of being able to eat what you want and like". One reason could be that they see meals as social occasions. With progressive dementia, interaction with other people can decline, in part because of the difficulties conversing that accompany the disease [32]. The lack of interaction with other people is perceived extremely negatively by persons with dementia and is in no way unique to this diagnosis group. The need for social interaction is a basic human need [33]. Meals and eating can be positive experiences since they provide times of social interaction for the person with dementia.

In the category of independence, all of the interviewees said they could take care of their oral hygiene independently even though some received help on occasion. It was important for everyone to be able to brush their teeth and otherwise take care of their oral hygiene independently. The finding that they brushed their teeth themselves was surprising, leading to the question whether they really did brush on their own. This might involve a phenomenon described by Miesen [29]; namely the person with

dementia using an occurrence from the past to express a feeling in the present. Although such descriptions may have nothing to do with whether the interviewees actually brushed their own teeth or received help, they may still say something about what the interviewees preferred in terms of QoL. Recognizing the desire for independence can be highly significant when caring for a person with dementia.

The importance of perceiving oneself as autonomous does not decrease with dementia [34]. For most people, the mouth is an extremely intimate area [35], and therefore it is perhaps even more important that people be able to take care of their own oral hygiene independently. Remaining independent while demented requires human support, but not obviously so. The support must be provided in a way that the person still experiences independence as much as possible. The ability to manage actions increases self-esteem in persons with dementia, as they feel in control of their situation [30,34]. If persons with dementia are to perceive oral health-related QoL, a high priority has to be placed on efforts enabling them to carry out their own oral hygiene independently well into the course of the disease.

Conclusions

In summary, the starting point of this study was the fact that none of the currently available instruments measure oral health-related QoL in persons with dementia. It was thus impossible to plan systematically and follow-up dental care in respect of oral health-related QoL. Awareness of the factors that are significant for oral health-related QoL in persons with dementia can be used in developing new measures.

Our experience of using triggers was positive. Triggers focused the interviewee's attention on the subject and facilitated communication. They are thus useful communication tools when measuring oral health-related QoL in persons with dementia. However, there is still a need to evaluate and further develop the materials used in this study.

Acknowledgments

The study was supported by the Medical Research Council of Southeast Sweden.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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