

## Caries as experienced by adult caries active patients: a qualitative study

Huei-Min Chiang<sup>a</sup>, Sofia Tranaeus<sup>b,c</sup> and Karin Sunnegårdh-Grönberg<sup>d</sup>

<sup>a</sup>Public Dental Service, Folk tandvården Vännäs, Vännäs, Sweden; <sup>b</sup>Health Technology Assessment-Odontology (HTA-O), Faculty of Odontology, Malmö University, Malmö, Sweden; <sup>c</sup>Division of Cariology and Endodontology Department of Dental Medicine, Karolinska institutet, Huddinge, Sweden; <sup>d</sup>Department of Odontology, Umeå University, Umeå, Sweden

### ABSTRACT

**Objective:** In the western world, increased oral health has resulted in a skewed occurrence of caries disease where relatively few individuals now account for most caries disease. This study examines how adults with recurrent caries activity experience caries disease and treatment.

**Materials and methods:** The study is based on qualitative data from individual interviews, which were subjected to qualitative content analysis. The interviews were semi-structured and thematic and an interview guide was used that consisted of two main areas with open ended questions. Meaning units were condensed and labelled with a code which preserved the core content of the reduced text. Codes were assigned to different subcategories according to their similarities or differences. Subcategories formed categories which describe the manifest content of the text.

**Results:** The domain “experience with caries” consisted of four subcategories that formed the main category Caries – an unwelcomed acquaintance. The domain “experience with caries treatment” consisted of three subcategories that formed the category Caries treatment – pain for gain.

**Conclusion:** Comprehensive non-operative treatment and close follow-ups should precede restorations; this would probably gain insight in how to avoid new cavities to a greater extent. If to be supportive, information and advice about self-care given to individuals with recurrent cavities should be delivered with respect to the patient’s feelings about their experience of dental caries.

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### Introduction

Large scale and well defined caries preventive strategies can achieve a general decline in caries prevalence [1,2]. However, increased oral health in the western world has resulted in a skewed occurrence of caries disease [3] where a minority of individuals now accounts for most caries disease [4]. This skewedness makes it difficult to employ caries prevention strategies. Although caries is a preventable disease, inequality of oral health caused by shortcomings in various caries preventive strategies has become a reality. Paradoxically, today more teeth are at risk of developing a cavity than ever before even though improved oral health in general has increased the number of standing teeth [4]. In Swedish dental public service, caries prevention and non-operative treatment strategies are targeted to patients at risk, i.e. patients – groups and/or individuals – with elevated caries risk. These strategies include intensified counselling about oral hygiene and diet, additional use of fluoride, and regular visits to the dental clinic. Nevertheless, recent a study has showed that individuals classified with high caries risk continuously develop caries over a seven-year period, that require restorative treatment, and only a small fraction of these individuals are re-classified as low caries risk [5]. This same study showed that preventive measures and non-operative

treatment were associated with improvements in caries risk assessment and maintenance measures, but the extent of delivered treatment to high caries risk individuals was unacceptably low [5]. Another recent study investigating information and experiences related to caries and its treatment found that many caries active patients reported negative experiences [6]. Preventing caries disease in individuals who develop cavities under circumstances where most people can preserve health has obviously become a challenge for patients as well as dental health care professionals. If the profession’s intention is to provide truly successful caries preventive strategies leading to equal and improved oral health, even for the most afflicted individuals, the profession needs a deeper understanding of the patients’ perspectives regarding caries disease and its prevention. This study explores and describes the experience with caries and with caries treatment as perceived by adults with recurrent caries activity over several years.

### Materials and methods

This study is based on qualitative data from individual interviews, which were subjected to qualitative content analysis [7]. Individual interviews give a deeper

**CONTACT** Karin Sunnegårdh-Grönberg  [karin.sunnegardh@odont.umu.se](mailto:karin.sunnegardh@odont.umu.se)  Department of odontology, University of Umeå, 901 87 Umeå, Sweden

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understanding of the adult patients' perspective [8] of caries and caries treatment.

### **Context of the study**

In Sweden has caries declined and oral health improved substantially the past decades. The caries preventive strategies used have been successful in the vast majority of the population but a minority still have troublesome problems with recurrent caries symptoms, i.e. cavity formation. Oral health-care for adults is provided either by the Swedish Public Dental Health Service or by the private sector. Adult dental care is financed partly by patient charges and partly by the Swedish Social Insurance Agency at several levels. A high-cost threshold is applied and costs above 3000 SEK (~325 €) are subsidized with 50% at a yearly basis.

### **Participants**

The participants were recruited from two Public Dental Health Service clinics in Västerbotten County, Sweden. Both clinics are located in the same building as the School of Dentistry. The participants visited regularly these clinics for their dental treatment. The operating dentists at the Public Dental Health Service clinics invited the participants as the study progressed and gave verbal and written information about the study. The inclusion criteria, set as individuals older than 20 years of age with an ongoing caries activity and a caries experience of at least five caries lesion which had been subjected to operative treatment within the last three years. Exclusion criteria was difficulties speaking the Swedish language. The invited participants were then contacted by phone and an agreement on time for the interview was made. The participants, five men and nine women, were between 20 and 77 years of age. The socio-economic background varied among them and they were students, employees, sick-listed people and pensioners. One was of foreign origin. They were informed that their participation was voluntary and that they at any time could end their participation without having to provide a reason. All gave written consent and none chose to discontinue participation. The study was performed according to the ethical guidelines described in the Helsinki Declaration (World Medical Association, 2008) and approved by the regional ethical review board in Umeå, Sweden (Dnr: 2011-105-31).

### **Data collection**

The interviews were conducted by a person not involved in the dental treatment of the participants but with odontological qualifications (dental hygienist). This was performed to assure the understanding of the oral health perspective in order to be able to ask relevant follow-up questions and avoid preconceptions based on knowledge about participant's former dental treatment and compliance. The participants were free to choose the sight for the interview and all interviews took place outside the dental clinics between September 2011 and December 2013. Each interview lasted

approximately between one and one and a half hour and was tape-recorded and transcribed verbatim, including notions of non-verbal expressions such as laughter and pauses. The interviews were semi-structured and thematic and an interview guide was used consisting of two main areas with open ended questions. The areas were about experiences of health, oral health and dental caries and experiences of caries treatment and self-care. The participants were encouraged to talk about their experiences in a narrative way and follow-up questions were asked when needed to obtain a deeper understanding, for example 'What does caries mean to you?' and with follow up-questions like 'How did you feel ...?'. The sampling was purposive up to data saturation, i.e. when no new information according to the study aim is found. This was assessed to occur after 14 interviews when the content and arguments in the written interviews were perceived as recurring by the authors and no further participants were recruited thereafter. The recruitment of the 14 participants was done consecutively.

### **Analysis**

The qualitative content analysis was made according to Graneheim and Lundman [7] and is a suitable method to reveal variation in content [9]. All interviews were listened to and read through several times in order to get a sense of the whole by all of the authors. Then the text was discussed together and two domains were identified; 'experience with caries' and 'experience with caries treatment'. A domain is a rough structure of a content area identified and dealing with a specific topic. Text which did not address the aim of the study and therefore not could be sorted into one of the two identified domains was excluded. The excluded text was roughly estimated to be about 30% of the total text. The analysis was then performed in several steps mainly by one of the authors (HMC). Firstly, meaning units that is words, sentences or paragraphs which are similar and related to each other through their content and context were identified. The meaning units were then condensed and labelled with a code which preserved the core content of the reduced text. Secondly, the codes were sorted into different subcategories divided by their similarities or differences. The codes within a subcategory were different from all other codes and one code could not be included in more than one subcategory. In this way four subcategories were identified for the domain 'experience with caries' and three subcategories for the domain 'experience with caries treatment'. Finally, one category for each domain could be formulated. The categories describe the manifest content in the text. During the analysis process the interpretation of data was repeatedly discussed between all the authors and consensus was reached when needed. The authors preunderstanding of the topic must be considered since all authors are dentists some working in the clinic, with research or with education of dentists.

## Results

The qualitative content analysis revealed one core category for each of the domains 'experience with caries' and 'experience with caries treatment'. The domain 'experience with caries' consists of four subcategories:

- my teeth are no problem as long as they function
- how caries is viewed changes with more experience
- caries is my own fault
- caries is out of my control.

These subcategories form the category: Caries – an unwelcomed acquaintance.

The domain 'experience with caries treatment' consists of three subcategories:

- treatment has changed over time,
- sense of vulnerability during caries treatment
- shared responsibility is a virtue.

These subcategories generate the category: Caries treatment – pain for gain.

### *Caries: an unwelcomed acquaintance*

Caries and cavities are not perceived as a problem as long as teeth are functional and do not cause pain, but since it is recognized that an active caries disease leads to new cavities, it is desirable to become caries free. With increasing experience of cavities and acquired knowledge of caries prevention, the perception of the caries disease changes. Experience of such consequences as root fillings and tooth extractions has a profound impact on understanding the impact of personal oral hygiene. A clear link is understood between the level of oral hygiene and an eventual progression of cavities, and the participants blame themselves when developing new cavities. The extent of cavity formation is seen as a result of accurate tooth brushing and diet but is also described as something which is out of one's own control. Most participants expect new cavities at the next dental visit but have not abandoned hope for becoming caries free someday. Dental visits are described as an underlying threat since it seems impossible for the individual to know anything about potential cavities in advance. The participants deeply wish to be spared from the worry of new cavities and to finally have healthy teeth.

Like, it's just a cavity, that's all. It's nothing that makes me think—I don't think of it as an illness I have; it's a cavity and I get it filled. But they do come back, so it's like... It would be different if I'd had a cavity once and then got it fixed and that was the end of it, but I've had a lot of cavities, and they keep coming back. (participant 14)

Yes, so I did learn something from... In reality, it was knowledge that I would have preferred not to have, or an experience that I could have lived without. (p. 1)

### *My teeth are no problem as long as they function*

Caries is simply described as injury to the tooth which lasts a lifetime and evidently sooner or later will cause trouble of

some kind. But as long as teeth can be restored and used for mastication and not generate pain, formation of new cavities is not seen as a symptom of a disease in itself. Caries is only described as a problem when fillings are lost, when it is painful to eat or drink and when food is impacted between teeth due to inferior quality filling. Toothache is a reminder to seek dental care, but mostly in everyday life, caries disease does not seem to be too big of a problem to worry about.

I don't feel like [cavities] are a bother, unless something breaks, but in normal cases... I don't go around thinking about the fact that I have cavities in my teeth every day, that much I can say. I think about it very, very rarely. When I visit the dentist – that's when I think about it (p. 4)

### *How caries is viewed changes with more experience*

New caries lesions are described as inevitable and caries as a state of normality. Caries is recognized as something natural, and there is not so much to do about the fact that you get new cavities. Caries is always there, but it is obvious that not everyone gets caries lesions. The participants learn about the caries disease and personal oral hygiene through their recurrent cavity formation. This experience changes the perception about the disease and what it truly implies and results in a better understanding of the disease. Increased caries experience and consequences like root fillings and tooth loss result in a longing for healthy teeth and personal oral hygiene becomes more prioritized in general. The many efforts to improve oral hygiene are stressed. Eventually, it is realized that the caries disease is bigger than just a cavity and caries is described more as a chronic condition that must be accepted and lived with.

I've experienced the whole spectrum where... where the tooth couldn't be saved, but simply had to be removed. And I've had... I don't even know how many root canals I've had, but it's a few anyway... and it's, it's the result of bad brushing. I have to admit it... Anyway, I think I'm considerably better about brushing my teeth these days than what I was... when I first came to the Dentistry School. Because, at that time, I think I could go for days without brushing my teeth. I guess I'm still not perfect at it, though. (p. 2)

### *Caries is my own fault*

Avoiding cavities is seen as the individual's personal responsibility. Participants say they must clean their teeth to avoid caries, and the success of proper personal oral hygiene is a personal responsibility. Most of the participants express a link between their many attempts to live up to the oral hygiene instructions from dental profession while also experiencing recurrence of cavities. New cavities confirm failure in personal oral hygiene and lead to feelings of guilt and shame. They really want to succeed with personal oral hygiene but new cavities leave no one else to blame but themselves. Continued occurrence of caries is described as a personal defeat and a hopeless situation.

Even if you know that it's, like, caries that causes cavities, you still don't really view the cavities as a product of caries. Instead, you

view them more as a product of not brushing your teeth properly/.../It's possible to counteract it if I just take care of myself. I don't take good enough care of myself, and so I get cavities. (p. 12)

### ***Caries is out of my control***

The participants are eager to understand why new cavities form in their teeth specifically. They have different theories about why they cannot control caries and efforts are made to identify correlations between the individual's caries situation and personal oral hygiene, life style and general health. They make connections between personal experience with medication, night work, saliva and dry mouth as decisive factors in addition to recognizing the impact of personal oral hygiene and diet. Many participants have noticed that others do not need to brush their teeth to the same extent and also eat frequently more sweets but still do not develop cavities. These kind of observations lead to the acknowledgment that the true cause of the caries disease is unclear and raises the question about the influence of genetics. Participants say that it is impossible to know if they have any new cavities ongoing or not and only examinations conducted by dental professionals can reveal the actual state of their teeth. Fillings are not assumed to last for a lifetime and lost fillings are frequently described. Filling cavities is seen as expensive and the expense for mouth rinse and dental floss is seen as an extra cost. This difficulty in estimating the future costs of dental care makes budgeting for the individual uncertain. The difficulty of controlling caries and of fully comprehending the causes of the caries disease together with higher expenses for dental care than for others impacts the individual negatively and caries is described as something uncertain and out of one's control.

I've had such serious problems that I've really tried to lift my game; I brush my teeth for ten minutes every night and I use dental floss and everything, so... My goal is, like, to avoid, try to avoid it, and things have gone well recently, since I switched to daytime work. (p. 7)

You never know how long fillings will last, so it's a given that you'll have to have them replaced./.../But I think I need to be prepared for the fact that they won't last for the rest of my life, you know. So, I know that, some day, there will be a bill that I'll have to pay, and I'll pay it, of course. I mean, I don't want to be walking around without teeth, that's for sure. (p. 4)

In one way perhaps you wise up and realize that your teeth are very important. But, in another way, perhaps you also get a little apathetic, because it happens so darn often. Almost every time you come in, there are more cavities and so, in the end, it's almost like you get to thinking, like, that it makes no difference because I get nothing but cavities anyway, or something along those lines. Because, over time, you – the fact that it happens over and over again almost makes you stop caring. (p. 6)

### ***Caries treatment: pain for gain***

Participants describe that caries treatment has changed during the last decades from being radical and rough without

anaesthetics to today's focus on painless treatment and warm reception. Dental sessions are situations described with feelings of being exposed and vulnerable, having to totally rely on the dentist's competence and judgment and being in a position of submission. A prerequisite for successful caries treatment is seen as the patient and therapist taking mutual responsibility, but the exact boundary of responsibility varies. The level of personal oral hygiene needed to control caries is experienced to be hard and demanding to achieve. All the participants describe their sense of unease when coming face to face with the facts of their teeth at dental visits since it reveals the truth of their personal oral hygiene. Some of the participants note that dental professionals try hard to relief stress when presenting negative facts and this is greatly appreciated. Participants in general express the need for positive feed-back about oral hygiene and that the regular visits to the dental clinic are of great value since they are a repetitive reminder about personal oral hygiene and good habits.

It's like/.../a life-long battle/.../no matter what you do, no matter how far along you come with other things, it will still always be/.../that you have to brush your teeth to avoid getting cavities./.../don't need to worry about your oral health, but the threat that it can, like, come back again will always be there. (p. 12)

### ***Caries treatment has changed over time***

The elderly participants describe the change in caries treatment over time and that it has become less radical and rough and with a more gently approach. It is noted that dentists from different generations are trained differently and do not practice the same kind of treatments. It is also expressed that society takes a greater responsibility for the individual's dental health than before and some participants believe that if they had grown up today their teeth would be less affected by caries and would be healthier. The participants often describe a hope that future dental care will be more holistic and dental care will embrace more preventive care and less focus on simply routine restorations. The participant's experiences make them convinced that restoring tooth cavities is not enough to stop caries.

That, nowadays, there's probably more of a caring aspect included in their training – empathy, caring. Things were probably more mechanical in the past./.../We would have had many better mouths back then if it had been like it is today. (p. 1)

So much suffering, so much pain, so much fright, and so much shame that wouldn't have existed and which, I believe, creates an obstacle. (p. 1)

### ***Sense of vulnerability during caries treatment***

Participants experience caries as something they cannot control without help from their dentist. Needing to ask for help causes a sense of vulnerability, exposure and dependence while actively taking part in their own treatment helps

reduce these negative feelings. Reclining in the dentist chair during treatment reinforces these negative feelings and can discourage the patient's ability to communicate with the dentist, particularly if suffering from dental anxiety. Several participants describe a struggle to trust the competence of the dentist during treatment. Increased participation in general treatment and in specific treatment measures eases feelings of being at a disadvantage and enhance a sense of control. One participant, who previously worked at a dental clinic, noted that visiting the clinic as a patient feels unfamiliar and uncomfortable. The participants are anxious not to be seen as annoying or troublesome and therefore avoid challenging decisions or asking questions at all. The view of how much stress the dentist is experiencing also determines whether informants ask questions or not.

I haven't felt that there has been time; that I've been able to discuss a matter or a procedure. Instead, I've been presented with a fait accompli and, at times, I've had the feeling that they were doing it to make money. (p. 1)

### **Shared responsibility is a virtue**

As described by the participants, a prerequisite for successful caries treatment is seen as a mutual responsibility between patient and dental caregiver but the exact boundary of responsibility is unclear. Information and knowledge about the caries disease and its prevention is wanted, and the dental profession is seen as having responsibility for this. Some participants even express it as an obligation of the dental profession not only to supply the right information but also to do so in a successful way so that the patient truly becomes caries free. Most of the participants acknowledge difficulties in managing personal oral hygiene and failure in terms of recurrent cavities, and they would like to free themselves from a sense of guilt and shame. Several participants also stated that once contact with the clinic has been established, responsibility for the caries treatment is assumed fully by the clinic. Most participants greatly value regularly check-ups. These check-ups are described as reassuring and the participants expect the clinic to call them to appoint on a timely and prearranged basis.

Well, every individual is 100 percent responsible for their own health, in reality, except for in cases where you seek help, that is ... then you transfer the responsibility. (p. 9)

## **Discussion**

This study explores how adult caries patients experience repeated caries treatment. This study produced three main findings about the struggle with caries disease with respect to customizing efficient caries prevention strategies:

1. In the beginning, patients do not view caries as disease, but solely as cavities. If cavities are not restored, they may limit the function of teeth. Patients gain more insight about caries the more times they are treated for caries, and these experiences provide them with more knowledge about caries prevention.

Eventually, patients recognize that caries is more than just cavities – it is a disease.

2. Longing for healthy teeth is profound and to succeed with caries prevention is truly desired. Since cavities still appear, failure is obvious. Feelings of shame and guilt become overwhelming, and the struggle with caries disease becomes a hopeless situation.
3. Patients want dental professionals to help them with caries prevention and treatment of cavities. In addition, patients desire regular contact with the clinic. However, the question of who is responsible for doing what in managing caries disease is often unclear.

The way caries active patients perceive and experience caries disease and its prevention and treatment may differ depending on the severity of the disease and extent of its consequences. Although the results from this qualitative study cannot be generalized to all patients with caries, the qualitative research approach gives a deeper understanding about subject areas inadequately understood [8,10] such as how and why people who are affected with caries disease struggle and how they gain insight with repeated experience with caries disease. This study sample represents a population more or less resistant to caries prevention and treatment performed in Public Dental Health Service today. Another strength of this study is that the participants had at least five operatively treated caries lesions within the last three years. Although this study is not a quantitative study [11], this study sample (active caries patients) makes it possible to examine the conditions that interfere with caries prevention and treatment and how to develop caries preventive strategies on the individual level. In a study of teenagers' attitudes about oral health, Hattne et al. [12] found that the teenagers believed that they could improve their oral health, but they also found that the teenagers believed that all oral health problems could be fixed by a dentist. In addition, Hattne et al. [12] showed that adequate information about caries risk was perceived as important. These findings are somewhat in line with the present study as they reflect the individual's thoughts about how to become healthy (i.e. being caries inactive), who is responsible for oral care, and what knowledge and support is needed for achieving good oral health. In the present study, the participants were older and had to take economic responsibility for their dental care. Repeated cavities, root canal fillings, tooth extractions, and economic costs contributed to insight into the fact that dentists can restore teeth but that there will be no 'quick fix' for caries disease, an insight that adolescents had not formed [12]. Other studies found that adult patients with active caries who are aware of their caries situation [6,13] try to change their eating habits, use more fluoride, and receive more information about the caries disease and instruction on oral hygiene from the dental professionals compared to patients with inactive caries [5]. These findings are in line with the present study. Although the research methodologies differ, they describe the efforts caries patients take when offered caries preventive strategies that do not control their caries disease. It is noteworthy that the participants in the present study are eager to understand why they developed new cavities. They

observe, draw conclusions, and construct theories about how caries arise, which include explanations such as genetics, dry mouth, medication, saliva, night work, diet, and oral hygiene. In fact, the individuals' empirical knowledge of their own caries situation is not only met with respect by the professionals per se but also is recognized by them. The preventive strategies should start with and build on the patients' personal knowledge. This approach would most likely empower patients' decision-making [14], enhance compliance, and affect caries activity. Clearly, these caries patients need new strategies for treating and preventing caries disease. A more detailed awareness about caries risk is needed [15] together with a non-invasive strategy based on close follow-ups that monitor change of caries activity with respect to the actual caries preventive actions used [16]. This approach must be done without appealing to guilt and shame. In caries active adults, these non-invasive strategies, however, may be expensive in the short term compared with operatively restoring caries lesions. Therefore, the social insurance system may need to offer more economic aid for caries prevention, especially for these high-risk groups. To this end, in 2011 the National Board of Health and Welfare launched the National Guidelines for Adult Dental Care [17] to promote effective treatment options and dental care on equal terms. The guidelines have most likely had little impact on the treatment of recurrent caries in adult patients since they do not address caries risk profiling or caries treatment on the individual level [18]. Perhaps this patient group does not truly receive dental care on equal terms, as caries disease evidently is not prevented – i.e. new cavities continue to occur. The participants desired regular check-ups, and this placed some of the responsibility for caries treatment on the clinics. A previous study conducted in Public Dental Health Clinics, which provides caries risk profiling in adult patients and individualized preventive dental care, showed that individual risk-based recall to dental examinations differed significantly for high caries risk compared with low caries risk patients (a mean time of 13.4 and 17.5 months, respectively) [5]. In another study, also conducted within Public Dental Health Clinics but where individual risk-based recall to dental examinations was not used in a systematic manner, it was shown that individual risk-based recall to dental examinations of caries active and caries inactive adult patients also differed significantly (a mean time of 1.6 and 2.1 years, respectively) [19]. Unfortunately, none of these studies could show any reduction of new cavities despite shorter recall intervals offered to adult patients with active caries. This finding emphasizes that caries prevention needs to improve for adults with recurrent caries activity [20]. Therefore, successful caries prevention requires a better understanding about the barriers and promoters associated with caries prevention. Exploring the dental profession's experiences using caries preventive strategies in caries active adults is one of several research questions that needs further investigation. Another interesting research area is about caries diagnosis in general dentistry. Successful caries management requires correct caries diagnosis. Irrespective

of treatment, success depends on implementing measures and treatments that correspond to the individual's specific needs and caries diagnosis.

In conclusion, this qualitative study provides insight into how dealing with recurrent cavities and caries prevention is experienced by caries active adults. Information and advice given should be delivered with respect and with consideration of the patient's personal experience with caries. In addition, it is crucial that every restoration due to active caries include comprehensive non-operative treatment and close follow-ups that monitor the patient's understanding of the impact of self-care on caries.

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## Disclosure statement

No potential conflict of interest was reported by the authors.

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