

An interview study of persons who attribute health problems to dental filling materials – part two in a triangulation study on 65 and 75 years old Swedes

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Abstract

© Dental materials are perceived as a health problem by some people, although scientists do not agree about possible causes of such problems. The aim of this paper was to gain a deeper knowledge and understanding of experiences from living with health problems attributed to dental materials. Addressed topics were the type of problem, both as to general and oral health, perceived causes of the problems, their experienced effect on life, and reception by health professionals.

Persons, who in a previous large questionnaire study had answered that they had experienced troubles from dental materials and also agreed to answer follow-up questions, were contacted with a request to take part in an interview study. Eleven individual interviews were held. The interviews were transcribed verbatim and the material was analysed according to the Qualitative Content Analysis method. Meaning units were extracted and condensed into a number of codes, which were combined into subcategories, categories, and themes.

Four themes were identified: 1) Long-term oral, mental, and somatic difficulties of varying character, caused by dental amalgam. 2) Problems treated mainly by replacement of dental material in fillings. 3) Powerful effects on life, mostly negative. 4) The reception by health professionals was generally good, but with elements of encounters where they felt treated with nonchalance and lack of respect.

In conclusion, people who attributed their health difficulties to dental materials had a complex range of problems and the perception was that amalgam/mercury was the cause of the troubles. The reception from health professionals was perceived as generally good, although with occasional negative experiences.

Key words

Dental amalgam, interviews, qualitative content analysis, oral health

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Hälsoproblem relaterade till dentala material – en intervjustudie

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Sammanfattning

⊙ Att dentala material upplevs som ett hälsoproblem av vissa personer är ett välkänt faktum. Vetenskapen har däremot inte varit, och är fortfarande, inte överens om vad som orsakar dessa personers problem. Amalgam/kvicksilver är det material som vanligast lyfts fram som orsak till upplevda besvär. Antalet personer i Sverige som upplever dessa besvär uppskattas till mellan 70 000 – 300 000. Personer med besvär från dentala material upplever sig ofta dåligt bemötta, både från sjukvårds- och tandvårdspersonal.

Syftet med denna studie var att söka en djupare förståelse för upplevelser av att leva med hälsoproblem relaterade till dentala material. Typ av problem, allmänna-/orala hälsoproblem, orsaker till upplevda problem, effekter på livet och bemötandet från vårdpersonal har studerats.

Personer som i en tidigare genomförd enkätundersökning hade svarat att de upplevt problem från dentala material och samtidigt accepterat att svara på följdfrågor, kontaktades brevlades med en förfrågan om deltagande i en intervjustudie. Elva enskilda intervjuer genomfördes, transkriberades och analyserades enligt metoden kvalitativ innehållsanalys. Ur textmaterialet har meningsbärande enheter lyfts ur som sedan kondenserats till ett antal koder som förts samman till sub-kategorier, kategorier och teman.

Fyra teman identifierades: 1) Långvariga orala, mentala och somatiska besvär av varierande karaktär, orsakade av dentalt amalgam. 2) Besvär åtgärdade med i huvudsak byte av dentalt material i fyllningar, resulterande i ingen till påtaglig förbättring. 3) Stark påverkan på livet, till allra största delen negativ men även ett drag av stärkande påverkan. 4) Som helhet ett övervägande gott bemötande från sjukvårds- och tandvårdspersonal men de allra flesta hade varit med om enstaka möten som upplevts som nonchalanta och respektlösa.

Sammanfattningsvis hade de personer som relaterade hälsobesvär till dentala material en komplex besvärsbild. Samtliga intervjuade ansåg att det var amalgam/kvicksilver som var orsaken till upplevda besvär. Bemötandet från sjukvården och tandvården ansågs i det stora hela ha varit bra men där enskilda möten stod för negativa upplevelser.

Introduction

It is a well-known fact that dental materials are perceived as a health problem by some people. Scientists, on the other hand, have not been, and still are not, in agreement about what causes these people's problems (4, 13, 17, 25). Amalgam is usually the material that is considered to cause the problems, but metals such as gold and titanium have also been singled out, amalgam is mostly a mixture of silver, copper, tin, and mercury. For many years it was believed that amalgam did not affect the rest of the body.

In Sweden in the 1970s, a debate began about the suitability of using amalgam as a filling material. People felt that they had become ill as a result of amalgam, with a condition that was called "oral galvanism". In the 1980s, the Swedish National Board of Health and Welfare recommended that amalgam should not be used on pregnant women, and since 2009 it is prohibited to use amalgam as filling material.

It has been pointed out that people with health problems attributed to dental replacement materials often feel that they do not receive a good reception from staff in medical and dental care (19). The Swedish National Board of Health and Welfare has heeded these complaints, and published general recommendations in 1998 about how to handle this group of people (20).

In two Swedish counties, Örebro and Östergötland, all persons born in 1932 and 1942 were surveyed in a questionnaire study in 2007 (7, 11, 21, 23, 24). The study population has, *inter alia*, been investigated for the occurrence of health problems attributed to dental materials (23). The results showed that about 10 % reported some form of trouble from dental filling materials and roughly 5 % had asked dental staff about the side effects of dental replacement materials. This is one way to look at a problem, to see to what extent the problem occurs, how common it is in a specific group or a population, and to study relations to given factors, e.g. socioeconomic. To broaden the knowledge and understanding of the problems requires other additive study methods. One way of doing that is to use qualitative research methods, like interview studies.

The aim of this study was to gain a deeper knowledge and understanding for experiences of living with health problems attributed to dental materials. The study considers the type of problem, general and oral health problems, causes of the problems,

their effect on life and the reception by health professionals.

Material and method

Study group and procedure

In the above described questionnaire study the total number of respondents was 9813. More information about the questionnaire study has been presented in earlier works (7, 21, 22, 23).

Two of the items in the questionnaire were used for selecting informants. The questions were: "Do you think that you have trouble from material in dental fillings?" and "Have you asked anyone in dental care during the past year about the side effects of dental replacement materials?" To the first question 863 persons (10%) replied that they felt, to some degree, that they had trouble from material in dental fillings and the second question elicited the answer yes from 439 persons (5%).

In the questionnaire, there was also the question "Do you allow us to return with follow-up questions?" Almost 79% (7360 persons) replied "yes" to that request. Those who consented to this and also answered "yes" to either of the two above-mentioned questions were asked if they were willing to take part in an interview study. Information was provided about the purpose of the study and contact details. The request was accompanied by a response envelope and a form, which could be signed and returned to give informed consent, if they were interested in taking part. Each person was then contacted by the investigator by telephone to arrange a time and place to hold the interview. A consecutive procedure was used. A few requests were sent at a time, and interviews and analyses proceeded in parallel. The process for the collection of interview data from the first to the last interview took a total of approximately six months. An interview diary was kept throughout the course of the work.

Interviews

Eleven individual interviews were held. As part of the method, in order to get as much information as possible, variation in the study group was endeavoured between gender, counties, and the two age groups. Six interviews were conducted in the county of Östergötland and 5 in Örebro. Seven women and four men took part; only one person was born in 1932, the rest in 1942.

It was not decided in advance how many interviews would be held; instead we carried on until a sense of information saturation was reached, no

more new information was added. All interviews were conducted by the same investigator (KS), a dental hygienist and doctor of odontology who had no previous relationship to any of the informants. On all occasions it was the first meeting between the interviewer and the informant. The interviews were mostly (7 instances) held in a private room at the public library in the respective place, while 2 interviews were held in the local parish hall and 2 in the informants' homes. The interviews took from 30 minutes to just over an hour and were held in a conversational style in which open questions were posed based on the aim of the study. An interview guide with notes of basic domains was used as support. The basic domains were: problems experienced, the causes, effect on daily life, effect on life as a whole, and reception by health professionals.

Questions were asked based on these domains, with follow-up questions and more penetrating questions. On several occasions during the conversations, the interviewer briefly summed up what had been said so that the informant had a chance to confirm or correct.

In order to supplement information arising from the individual interviews and to consider whether

more individual interviews should be held, a digitally recorded focus-group interview was held with people who represented a patient organization "Dental Care Injury Association" (Tandvårdsskadeförbundet). After the focus-group interview was conducted, it was considered that no further individual interviews should be held, since no new information really emerged. It was deemed that information saturation about the questions had been reached.

Data analysis

Content Analysis has developed from having been solely a quantitative method so that it also can be used as a qualitative research method (10). Analysis of a text or an observation is always dependent on a subjective understanding and interpretation. Reality can be interpreted in different ways. To achieve credibility in an analysis, it is important to give a detailed account of how the data were collected and how the analysis was performed. The process of analysis can take slightly different forms but follows mostly the same pattern (6, 8, 10).

The interviews were recorded on a digital recorder and transcribed verbatim by an experienced medical secretary. Three of the individual inter-

© **Table 1.** Examples of meaning units, condensed units, codes, subcategories, categories and themes

Meaning unit	Condensed meaning unit	Code	Subcategories	Categories	Theme
and I felt so bad, it was almost as if I didn't want to live any longer	Almost did not want to live	Depression	Depression	Mental problems	Long-term problems of varying character
And terrible pressure in my head, couldn't remember, couldn't read anything, everything got blurred	Could not remember, could not read, everything got blurred	Memory problems	Memory/concentration problems		
began to feel sore in all my joints, in small ones, not the knee but in small joints	Sore joints	Joint pain	Joint/muscle problems	Somatic problems	
I had migraine, but I kept going	I had migraine	Migraine	Headaches	Oral problems	
feel sores and have so many, many blisters in my mouth	Blisters in the mouth	Blisters	Problems with oral soft tissues		
reacted badly to cold and heat and it was really really difficult	Problems with heat and cold	Shooting pains	Tooth problems		

views were not transcribed but analysed solely via the recordings. These three informants turned out to experience not so clear trouble from dental replacement materials, why only parts of the interview contributed to the analysis.

The analyses were performed as the interviews proceeded, and the interview questions were continually developed on the basis of previously obtained results. The analyses were done by both authors (KS and BS), who continuously checked their findings against each other. All the interviews have been listened through over and over again, and the transcribed text has been read repeatedly. Meaning units from each interview have been picked out and condensed to clarify the content. Codes were created on the basis of the condensed meaning units and were then grouped in subcategories and categories, finally yielding themes (see Table 1).

Ethical aspects

Ethical requirements were satisfied by obtaining informed consent and guaranteeing confidentiality. Informants can only be identified in recorded material, written transcripts and in presentations through a code key that is stored in Örebro County council data server, accessible only by the researcher. Contact was made in advance with representatives of psychiatry in case any psychological assistance would be needed in connection with the interviews. Ethical approval for the study was obtained from the Regional Ethical Review Board in Lund (Reg. no. 2009/343).

Results

Meaning units were extracted from the text and condensed into a number of codes combined into subcategories, categories, and themes (see Table 2).

Theme – Long-term problems of varying character caused by dental amalgam

All the informants had long-term problems behind them. For some, it felt like a lifelong suffering. The type of trouble varied greatly, and all the informants thought that the cause of the problems was the mercury in dental amalgam.

Oral problems

As a whole, oral problems were not the major difficulty. Only a few informants said that they have or had any great problems from the mouth. One person had a problem with contact allergy (oral lichen), but otherwise, it was dry mouth and blisters

that some mentioned, and problems with the teeth, as a general expression.

- *“you feel sore and have so many, many blisters in the mouth, I had, you know.”*
- *“have had, got problems with my teeth or with the fillings, you could say.”*

Somatic problems

Somatic problems were a much greater source of difficulty, as regards both the type and the scope of the problems. More diffuse problems were described, such as a general sense of illness, pains in the body, joint/muscle problems, and dizziness/balance problems, as well as more distinct problems, such as headaches, skin complaints, and eye problems. Tiredness was a common difficulty in this group. The informants said that they were badly affected by these problems.

- *“that it might have some connection with my teeth that I was often so terribly tired, had pains in my body and felt dizzy and nauseous, had problems roughly like what you think of if you get the flu.”*

Mental problems

Mental health and mental functions were affected in most of the informants. Depression and difficulties in remembering and concentrating were mentioned by some people. Some said that sleeping difficulties were a major problem.

- *“one aspect of it all is that you have a tendency to get terribly depressed.”*
- *“and if I’m tired I don’t remember anything, I couldn’t remember that Stockholm is our capital, you know.”*

Causes of the problems – Dental materials

All the informants thought that their problems were caused by the mercury in dental amalgam, sometimes in combination with other metals.

- *“that there could be a link with the mercury in the amalgam, and so I began to look into this and then I started talking to doctors and dentists and so on, that I was a textbook case of amalgam, eh, mercury poisoning.”*
- *“first of all they were able to measure the mercury vapour that was still there. I had so much vapour that it was roughly half of what is permitted for working in a workshop.”*

Duration – Long-term problems

In most cases the problems had persisted for a long time. A couple of informants described it as lifelong.

© Table 2. Results. Subcategories, categories and themes based on the different domains.

Domains	Subcategories	Categories	Themes
Problems	Various oral problems	Oral problems	Long-term problems of varying character caused by dental amalgam
	Problems with oral soft tissues		
	Tooth problems		
	Headaches	Somatic problems	
	Joint/muscle problems		
	Pains in the body		
	General sense of illness		
	Problems in ear/nose/throat		
	Tiredness		
	Gastrointestinal problems		
	Dizziness/balance problems		
	Skin problems		
	Eye problems		
	Hypersensitivity		
	Depression	Mental problems	
	Memory/concentration problems		
Sleeping problems			
Anger/disappointment			
Anxiety			
Cause	Amalgam/Mercury	Dental materials	
Duration	Lifelong problems	Long-term problems	
	Lasting problems		
Measures	Change fillings	Odontological treatment	Problems treated mainly with change of dental material in fillings resulting in anything from no improvement to noticeable improvement
	Psychiatric treatment	Medical treatment	
	Polyp operation		
	Other treatment	Alternative medical treatment	
Result of measures	No improvement	Varying results of measures taken	
	Some improvement		
	Noticeable improvement		
Effect on life	Working life affected	Life restricted	Powerful effect on life, mostly negative but also some strengthening effects
	Social life affected		
	Own strength increased	Life strengthened	
	Greater humility		
	No great effect	Not affected	
Reception	Nice reception	Pleased with reception	Good reception from health professionals on the whole. Isolated encounters were often the cause of the negative experiences
	Receiving confirmation and being listened to		
	Good information		
	Not seen or listened to	Displeased with reception	
	Distrusted, misunderstood		
	Unpleasant reception		

One informant claimed to have been affected even in the womb by his mother's amalgam fillings.

- *"so these problems had actually been with me since birth because my mother had huge problems with her teeth and had many amalgam fillings."*

Theme – Problems treated mainly by change of dental material in fillings, resulting in anything from no improvement to noticeable improvement

Odontological treatment

All the informants had had their amalgam removed, apart from the three who at the time of the interviews stated no problems that they attributed to dental materials. Some had had the fillings changed at public expense, while others had paid for it themselves. Several described how they became sicker during the amalgam removal, and some told what they had done to reduce the problems during the process.

- *"I said I want you to take out all the amalgam but I already had problems with the ones that I have, I have read about that, understood that you could get really sick."*
- *"I had all the amalgam removed and my dentist said, you have to get rid of it, you won't get better before that, he said."*

Medical treatment

One informant said that a serious polyp growth was a type of problem caused by amalgam. Another informant had severe depressions that were treated with drugs, psychological therapy and ECT (electroconvulsive therapy).

- *"then I asked the doctor for ECT because I thought perhaps it could help against this too, and the fact that I was depressed and that. So I went, I had four, four ECT treatments."*

Alternative medical treatment

Many of the informants had chosen to have alternative forms of treatment, both to ascertain the cause of the problems they experienced and to find solutions to them.

- *"I have met a doctor in Stockholm who has helped me through this using millimetre wave therapy and breathing assistance which I believe in, millimetre wave therapy, and it's frequency medicine, you know, that you can go in and reprogram millimetre waves in the body."*
- *"a scan that is very special and you can't have it here in Sweden, it's called cavitation, no, cavital scan, and it lets you see the infections in the dentin."*

Results of treatments –

The most frequent treatment was amalgam removal. The results turned out to vary from no improvement to noticeable improvement

- *"I can still feel a little now but I've become much better, but it probably took, once all the amalgam was away, it took about two years."*
- *"and the migraine got slightly better but I had it every day all the same, I suppose I thought I would get much better."*

Theme – Powerful effect on life, mostly negative but also some strengthening effects

Life restricted

Both working life and social life had been affected to some extent for all the informants. For some, the problems had led to long-term sick listing and early retirement. Somatic problems such as joint/muscle pain had restricted their ability to engage in leisure activities, because the body could not cope with physical exertion. The problems had also led some people to socialize less with others.

- *"I felt so bad that I didn't have the strength for any social life."*

Life strengthened

Even if the effect on life was mostly restricting, there were also some features that served to strengthen people.

- *"I'm happy for every day I can be here, and it doesn't matter, I have lived a wonderful life."*

Not affected

All the informants felt that the problems had affected their life negatively in some way. Some of them said that there were aspects of life that had not been affected, at least not as much.

- *"I didn't feel like giving in to this, so I had this great thirst for life, plus that I had, I was out, even if I didn't have the energy to be out walking, not everybody has had the strength to do that."*

Theme – Good reception from health professionals on the whole. Isolated encounters are often the cause of the negative experiences

Pleased with reception

The majority of the informants were generally satisfied with the manner in which they had been treated by the staff in both medical and dental care. Some even said that the reception had been very good or fantastically good. The main features of a good encounter were "being listened to", "taken seriously",

“receiving affirmation” and “being shown consideration”.

- “I got affirmation, she told me a lot about the disease, she told me exactly how to act and, and what, what was important to do.”

Displeased with reception

Experiences of poor reception almost always consisted of encounters with one specific person. Common features of this kind of bad encounter were “merely being sent on to somewhere else all the time”, “lack of interest in the problems”, “being ignored” and “a sense of being distrusted”.

- “I’ll send this over to a specialist, when they say this is not my department.”
- “met a doctor who didn’t listen to me one second but just asked about the divorce and wanted to prescribe nerve tablets and the like for me.”

Discussion

The main findings were that the problems varied in character, usually were protracted and mostly having a serious effect on life. The cause of the troubles, as stated by the informants, was dental materials, by mercury poisoning from amalgam. Most informants had undergone amalgam removal, with varying results. Many had also tried different kinds of alternative medicine.

As regards the reception they received from health professionals, the general impression was mainly positive, a sense of having been treated with respect, being listened to and helped. Several, however, had experienced isolated encounters with a therapist – either a doctor or a dentist – as a source of dissatisfaction.

Method discussion

In work with interview studies, important concepts are validity and reliability. To achieve this requires great care in the data collection, preferably transcribed interviews to facilitate the analysis, and that more than one person should perform the analysis (6, 8, 10). Additionally, in qualitative studies it is important to gain access to informants who can give as much information as possible. Despite the selection from persons previous having had claimed to have problems with dental fillings materials, it turned out that three informants after all, did not have that obvious problems, revealing a problem in informant selection from questionnaires. Further, when selecting informants, it is customary to aim for as large variation as possible regarding e.g. age and gender. A

disadvantage in this study is that all the informants who were potential participants came from two older age groups, born in 1942 or 1932. Results could possibly have been different if the informants had represented a greater range of ages.

The number of persons to interview is an important question. Few interviewees entail the risk of losing information, while a large number of interviews can cause difficulties in the analysis. In this study, it was felt that saturation was achieved after 11 individual interviews and a focus-group interview. The interviewer is also important in interview studies, for example if he or she already has some relationship to the interviewee or not, or if he or she is a professional in the sphere or not. In this case, the interviewer (KS) had no previous relationship with the informants, but did belong to the profession. It is possible that a person outside the odontological world would have elicited different answers but on the other hand, the interviewer had knowledge of the context and settings.

Results discussion

Many informants had a combination of several problems, which agrees with earlier reports (2, 3, 12). Several studies have investigated the association between the occurrence of amalgam and various states of illness, without being able to draw any unambiguous conclusions (5, 25, 26). Some studies have found that the problems cannot be attributed to amalgam but are in fact the result of somatization, a process by which mental disturbances or strains find expression in physical symptoms (2, 3, 9). All the informants who experienced problems in this study stated amalgam/mercury as the cause. No one wondered about other causes or factors influencing their problems. Amalgam removal is of course a common measure for people who believe that amalgam is the cause of their problems. The outcome of replacing all amalgam fillings thus varied in this study group, from no change to a good improvement. Other studies likewise show varying results: in their study Lindh *et al.* (14) found that 70% of the patients experienced a significant improvement, while Nerdrum *et al.* (16) conclude that their results do not support the hypothesis that amalgam removal brings an improvement back to a normal state of health.

Whatever the cause of the problems, these are highly tangible ailments that cause great suffering. A natural reaction is to look for the cause of the problems, and it is not unusual for people to use other sources of information than traditional medicine or

odontology; examples of this are mediums and natural healers of various kinds. One problem with this is that such methods have not undergone any testing or supervision. People who seek other than traditional sources of information can, at worst, end up in the hands of someone who makes their condition worse. This is yet another reason why both medical and odontological staff must take good care of people with this type of problem. A poor reception can leave deep marks on a person, and the memory can often persist for a long time. It has been shown that a good reception alone can have a positive effect on health. People who feel that they have been given a good reception feel less ill and get well quicker (18).

For several of the informants, the problems had led to long-term sick listing and their social life had been affected. It is interesting that some of the informants told of how they had battled against their difficulties and had not let them take over. The factors making some people able to live their lives and manage their jobs and their private life despite serious problems leads one's thoughts to *Antonovsky's* studies of factors of significance for health, what can make people healthy, salutogenesis (1). His answer was that it is a person's sense of coherence that is the explanation. In the interviews, however, this aspect was not specifically considered, but a salutogenic perspective ought to be included in continued research

This study has been conducted as part of a larger project, the first part of which consisted of a quantitative study with data material from a questionnaire study. It was found there that people who experienced problems from dental material also felt that they had poorer general health and oral health than the group who had no problems from dental materials. The group with problems had also had their fillings changed more often than the group with no problems, and they felt that the behaviour of dental staff towards them was worse and they were generally less satisfied with their dental care (23). The present study (which included people from the first study) followed up those findings by investigating the types of difficulties experienced. The results of the first study were confirmed here in that all the informants felt a negative effect on their health. The increased frequency of amalgam removal was also confirmed. On the other hand, this interview study yielded partly different results about the quality of the encounter with health professionals. A more positive picture emerged in the interviews than in the questionnaire study. A possible explanation is that

in a questionnaire item, there is often just one possible response alternative. It is not possible to give nuances or elaborate on an answer as one can during an interview. Perhaps an isolated bad encounter can overshadow a larger number of good encounters, and the isolated case is what the informant refers to when no other alternative is given.

To sum up, this interview study confirms previous findings showing that people who attribute their health problems to dental materials have a complex picture of symptoms – somatic, mental and oral – with the first two types dominating. All the informants believed that it was amalgam/mercury that was the cause of the problems they experienced, and they had all had their amalgam fillings replaced, with varying results. They felt that the reception they received from dental and medical staff was generally good, but most of them had experienced isolated encounters when they were not treated with respect and consideration.

Continued research is needed, both to ascertain any shared properties among people who attribute their health problems to dental materials, and what makes certain people with these problems cope with their lives better than others, despite similar problems. A salutogenic perspective could then be important.

Although problems with amalgam as filling material will disappear in Sweden over time, since it is now prohibited to use amalgam, there will probably still be people who attribute health problems to dental materials. The Dental Care Injury Association is talking about both present and future problems with gold, titanium and dental composites. The best thing that society can do must be to engage more in preventive work, chiefly among children and adolescents, to prevent, as far as possible, damage to teeth that requires filling material.

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