

Patients' Views on Periodontal Disease; Attitudes to Oral Health and Expectancy of Periodontal Treatment: A Qualitative Interview Study

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Purpose: The aim of the study was to explore and gain an understanding of patients' views on their periodontal conditions, their perceived impact of periodontitis on daily life, as well as their attitudes to oral health and expectations of treatment.

Materials and Methods: The study subjects were patients with chronic periodontitis, who had been referred to a specialist clinic. The constant comparative method for grounded theory was used to collect and analyse the data. Audiotaped, open-ended interviews were conducted after periodontal examination, but before treatment. The interviews were transcribed verbatim and consecutively analysed in hierarchical coding processes and continued until saturation was reached ($n = 17$). In the analysis, a conceptual model that outlined the steps involved in the diagnosis of periodontitis was generated. The core concept of the model, keeping up appearance and self-esteem, was related to the following four additional categories and their dimensions; doing what you have to do – trying to live up to the norm, suddenly having a shameful and disabling disease, feeling deserted and in the hands of an authority, and investing all in a treatment with an unpredictable outcome.

Results: The results illustrated that subjects diagnosed with chronic periodontitis felt ashamed and were willing to invest all they had in terms of time, effort and financial resources to become healthy and to maintain their self-esteem. However, they perceived a low degree of control over treatment decisions and treatment outcome.

Conclusions: The results demonstrate the vulnerability of patients diagnosed with chronic periodontitis and emphasise the importance of communication in dentistry.

Key words: chronic periodontitis, grounded theory, interviews, oral health

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The progression of periodontal disease results in the loss of the tooth-supporting tissues and eventually tooth loss, with consequences for the patient

in terms of deteriorating chewing function and poor aesthetics. These events may, in turn, adversely affect the patient's general well-being and daily life functioning. Thus, in relation to the concept of oral health, not only biological factors, but also behavioural and subjective dimensions, are of importance (Locker, 1988). However, the predominant focus in research has so far been on clinical findings, with the definition of oral health as the absence of clinical signs and symptoms of oral disease (Locker, 1988). How different biopsychosocial factors interact in the process of periodontal disease is poorly studied.

Although there are effective programmes for the prevention, treatment and control of periodontal diseases (Axelsson et al, 2002), such programmes are demanding, not only in terms of time and money, but

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also with regards to efforts to establish and maintain a high standard of oral hygiene. Furthermore, treatment directed at the control of the disease may be perceived as uncomfortable and painful for some patients (de Jongh and Stouthard, 1993; Karadottir et al, 2002; Chung et al, 2003; van Steenberghe et al, 2004). Sensitive root surfaces and aesthetic problems owing to gingival recession are also negative effects experienced following treatment (Tammamo et al, 2000). Hence, there are several aspects of periodontal care that may cause stress for the suffering individual.

Trulsson et al (2002) investigated the processes patients with deteriorating dental status had experienced before treatment with implant-supported fixed prostheses. These patients expressed that they had made considerable economical and mental efforts to improve their dental status over the years, and feelings of shame and guilt, because of their poor oral health status, were common. It was also evident that deteriorated oral health had adverse effects on self-esteem and self-image, with consequences on daily life (Trulsson et al, 2002). Thus, self-perceived oral health is an important part of general health and well-being as also demonstrated among, for example, dental fear patients (Abrahamsson et al, 2002). In addition, data presented by Needleman et al (2004) and more recently by Ng and Leung (2006) have demonstrated a significant association between oral health related quality of life variables and periodontal conditions. However, to the authors' knowledge, no study has specifically focused on psychosocial interactions related to periodontal health or disease. The understanding of such psychosocial processes may provide valuable information in relation to prevention, as well as in the treatment and control of periodontal disease.

The aim of this study was, therefore, to adopt a qualitative research approach to explore patients' subjective views on their periodontal conditions, the perceived impact of periodontitis on daily life, as well as attitudes to oral health and expectancy of treatment.

METHOD

Grounded theory

The constant comparative method for grounded theory, described by Glaser and Strauss (1967) and further developed by Strauss and Corbin (1990; 1998) and by Charmaz (1995; 2000), was used in collecting and analysing the data. This qualitative method

aims at generating concepts, models or theories grounded in empirical data. The basic principles of grounded theory include constant comparisons, theoretical sampling, theoretical sensitivity and saturation. Constant comparisons include one piece of data being compared with other pieces of data. Concepts must earn their way into data and, therefore, different parts of the data are continuously compared in terms of differences and similarities. A specific category is compared with other categories, as well as with data from different subjects, and data are compared with an emerging category. The developing category acts as a guide to further questioning, that is, theoretical sampling, until saturation is reached. Saturation, although somewhat 'elastic', is reached when new data fit into the categories already devised (Charmaz, 2000). Theoretical sensitivity refers to the researcher's reflexive way of developing research questions and analysis.

Study group and procedure

Participants were selected on a consecutive basis among patients referred (referrals from both private dental clinics and community clinics) to the clinic of periodontics at the Institute of Odontology in Göteborg, Sweden. To form a heterogeneous group, and to cover the variation in experiences, informants were strategically selected to represent men and women of different ages and with different social backgrounds. Patients with psychiatric diagnoses or patients with evident difficulties with the Swedish language were excluded. At the first consultation, a clinician gave verbal and written information concerning the aims and procedure of the study. If a person was interested in participating, he or she was later called by one of the interviewers (KHA and UH) to schedule an appointment for the interview before the start of treatment. The interviewer was not known to the participant in advance and did not take part in the treatment of the patients. The Ethics Committee of Göteborg University evaluated the study protocol and all participants gave their written consent.

The study sample consisted of 17 individuals (seven men and ten women), between 41 and 68 years of age (mean 56.8 years). The individuals had different educational backgrounds and occupational status. Seven of the individuals reported general health problems (e.g. diabetes and high blood pressure), of which five were on some type of medication. Three of the individuals were current smokers and three former smokers.

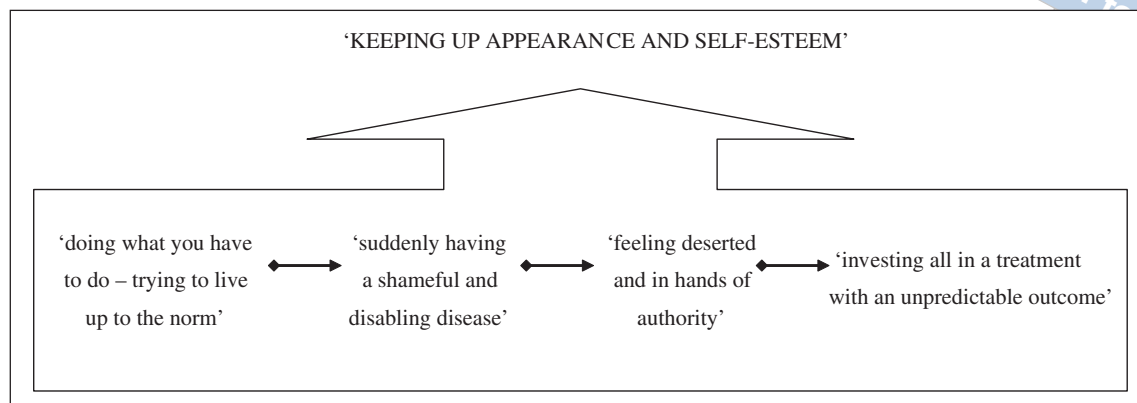


Fig 1 A conceptual model clarifying the process of being diagnosed with chronic periodontitis and depicting the core concept; keeping up appearance and self-esteem.

Open interviews

Open interviews, lasting for 30 to 60 min (mean 46 min), were conducted individually in a conversational style by UH (a sociologist) and KHA (a dental hygienist with a MSc in psychology) in a quiet room away from the clinic. The interviews were audiotaped. An interview guide was used and the thoughts and feelings of the participants were considered on themes such as (i) how they had got periodontal disease, (ii) what were their experiences from previous dental care, (iii) how were life consequences related to oral problems, (iv) what were the feelings during the clinical examination and about their diagnosis of periodontitis and (v) what were their expectations of the treatment. On the basis of participants' responses to these themes, the interviewer asked relevant follow-up and probing questions. During the interview, the participants had the opportunity to raise their own questions. Data collection and analysis were conducted simultaneously and continued until new interviews did not provide additional information, that is, until saturation was reached (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Charmaz, 2000; Dellve et al, 2002).

Analysis of data

The interviews were transcribed verbatim and consecutively analysed in hierarchical coding processes, through open, axial and selective coding (Strauss and Corbin, 1998). Open coding of the interview transcripts ensured that the substance of the data was caught and segmented into substantive codes and labelled concretely. The process of open coding generated clusters of substantive codes with a similar content, which, in turn, were summarised into categories. These categories were given more abstract labels

than the substantive codes belonging to them. In the axial coding process, each category was further elaborated, and dimensions were identified. Furthermore, the relationships between categories were sought and verified in the data. In the selective coding process, categories and their dimensions were saturated by additional information, assessed by new interviews or added by re-coding the earlier assessed data (i.e. theoretical sampling). In the last step of the hierarchical analysis process, a core concept was identified. This core concept represented the interpretation of the core expression or meaning in the data and was related to all the other relevant categories grounded in the data. The core concept and its related categories describe a psychosocial process related to being diagnosed with chronic periodontitis. During the entire process of analysis, ideas, preliminary assumptions and theoretical reflections were written down in memos to keep track of the analysis (Glaser and Strauss, 1967). According to Charmaz (2000), the unit of analysis in a grounded theory study concerns the events and actions in the data rather than the different individuals per se, therefore, the number of participants is of less importance than the content and quality of the data.

RESULTS

In the analysis of the data, a conceptual model that outlined the steps in the diagnosis of chronic periodontitis was generated. The core concept of the model, that is keeping up appearance and self-esteem, was related to four additional categories: doing what you have to do – trying to live up to the norm; suddenly having a shameful and disabling disease; feeling deserted and in the hands of an authority; and investing all in a treatment with an unpredictable outcome (Fig 1). Each category was

Table 1 Description of categories depicting the core concept – keeping up appearance and self-esteem, that is, higher order categories and underlying categories/dimensions

Doing what you have to do – trying to live up to the norm

The norm is to have nice teeth and a healthy mouth

Regular dental care and trust in dental professionals

Irregular dental care and avoidance behaviour

Symptoms, but often with a somewhat diffuse character

Strategies to suppress oral symptoms

Suddenly having a shameful and disabling disease

The insight of having chronic periodontitis

The perceived reason for the periodontal disease

Life consequences of the periodontal disease/poor oral health status

Feeling deserted and in the hands of an authority

Feelings of being deserted and without control

Disappointments directed to dental professionals

Investing all in a treatment with an unpredictable outcome

My teeth are a part of me and my personality

Thoughts and feelings about periodontal treatment

Priorities

Frustration and feelings of unjust

composed of a number of underlying categories or dimensions (Table 1). Thus, the core concept describes the central meaning of being diagnosed with chronic periodontitis, and the conceptual model shows how the participants, diagnosed with a disabling oral disease that they felt ashamed of, were striving to live up to their normative values of nice teeth and a healthy mouth. They were willing to invest all they had in terms of time, effort and finances in the treatment to become free from their periodontal disease for the benefit of their appearance and self-esteem. However, they perceived a low degree of control over treatment decisions and treatment outcome. Each category included in the conceptual model is described in the following sections, together with selected quotations from the interviews to illustrate the content of the categories.

Doing what you have to do – trying to live up to the norm

The participants described how they were striving to live up to the norm to have nice looking teeth and a healthy mouth. Most of the participants presented a history of regular visits to the clinician, and in some cases also to a dental hygienist, and expressed that they had great confidence that dental professionals

provide good care in the best interest of their patients. Some participants had been told that they had deep pockets around their teeth, but had not understood the consequences. Some said that they had been referred to a dental hygienist, but without understanding why. A few patients felt that their oral problems became worse after the visit to the dental hygienist and, therefore, that their treatment had been interrupted. Most of the participants described that they felt secure because they had regular and stable contact with a dental clinic. Even when they had symptoms (e.g. bleeding gums, pain and tooth mobility) and felt suspicious that something was wrong, they mostly relied on the fact that their clinician had told them everything was fine:

'I guess I've had it for a few years now, because I used to have a dentist, and he informed me about it and we had a few long appointments. Then I thought it was dealt with, having gone regularly to the dentist and the hygienist and all that. Everything was fine. And if you go to the dentist twice a year, you assume that they (the dental staff) will sound the alarm if there's a problem, which I don't feel like they did'.

Some of the participants mentioned irregular dental care and frequent changes of clinician or long periods without seeing a clinician at all. According to the participants, this might have been the reason why the clinicians had not mentioned their periodontitis. Sometimes, the irregular dental care was due to dental fear or changes in their life situation, for example geographical relocation, general health problems or abuse of alcohol or drugs. A poor economic situation was also a reason given for not seeing the clinician on a regular basis. The participants with irregular dental care habits were often aware of having oral problems and, although not successful, they had tried to repress the problems: *'it was always there in the back of my head'*. They had also tried to suppress their oral symptoms by various health products. The longer they had avoided professional care, the more embarrassed they felt about their situation:

'I suppose I've always had bad teeth. As early as primary school I had to go to the dentist much more often than all the other kids ... in upper secondary school, when my parents were paying my dental bills, and when I was a young adult, I think I was pretty regular about going to the dentist ... then came a period when we had a lot of money problems and I had to postpone it (going to the dentist) and give priority to other things. I would think, well, I can go in 6 months ... or in whenever ... After that I had major problems and there was a lot of shame associated with the whole thing'.

Suddenly having a shameful and disabling disease

For the participants who had visited their clinician on a regular basis and thought that there were no problems, the realisation that they had periodontitis was described as shocking. The realisation that they had the disease became obvious with the referral to the specialist: *'it feels like the last stage'*. The participants described feelings of worry and fear and questioned what would happen to their teeth, face, chewing function and self-esteem:

'Well, it's easy to be shocked ... and of course I wondered about it when she (the dentist) referred me to a specialist, and I hoped it would be ... but the specialist confirmed, instead, that it was periodontitis and told me that I might have had the problem for a long time already, for years, but it was still kind of a shock, you know'.

For the participants who had avoided dental care for a long period, the examination performed by the clinician and the subsequent information received regarding their dental status came somewhat as a relief. It confirmed what they suspected. For these participants, the biggest obstacle was overcome already (the shame of attending the dental clinic) and they were looking forward to receiving treatment and care.

The dental specialist was very clear, saying: *'the best thing is that you can do something about it, and we will take you on here at the clinic. That really meant that I had already overcome the greatest obstacle, now that somebody knew what bad shape I was in ... and who was very sympathetic and just wanted to go on taking care of me, which suddenly made it so easy'.*

A majority of the participants thought of periodontitis as something shameful; something they would rather not talk about. The reason for the disease was explained as a combination of factors including it was an inherited condition and was also linked to poor general health and due to insufficient oral hygiene. The participants considering themselves to have a poor oral status described how oral conditions affected them in their daily life, for example avoiding social interactions and holding a hand in front of the mouth when talking. Some described that they could not chew properly and they avoided certain types of food, which, in turn, affected their social life, for example avoiding coffee or lunch breaks with colleagues. The patients had developed strategies to hide their worsened state of oral health, but the worries were always there.

'Of course you worry. I didn't think it was a normal situation for my teeth to be falling out of my mouth. I definitely didn't. I also spend a lot of time out in the

world, talking to people and addressing groups and audiences, and I found it very upsetting ... the idea that my teeth were just going to disappear out of my mouth. I know they're crooked and messy, but still I have lived with them for my whole life'.

Feeling deserted and in the hands of authority

In conjunction with the first visit to the periodontist, the participants expressed worries about what would happen with their teeth such as worries about losing their teeth and whether or not it would be possible to save some teeth. The frustration and disappointment, directed towards previous dental caregivers for not having provided information about the periodontal status, was obvious for some of the participants. They expressed that they had believed they were properly taken care of by their clinician or dental hygienist and felt that they had been lulled into a 'false sense of security'. Many of the participants thought it important that clinicians or dental hygienists learned to communicate better with their patients and to ensure that the information is given in a way that the patient can understand. Some participants said since receiving the diagnosis of periodontitis, they felt that their previous clinician and/or dental hygienist had maltreated them both physically and mentally. Furthermore, some of the participants were of the opinion that the clinician or dental hygienists were sometimes too loyal to their colleagues, instead of telling the patient the 'true story'. However, the patients felt that despite their concerns, they had to continue to rely on the authority: *'He (the specialist) said that it should have been discovered much earlier ... but I think dentists stick together too much. And I don't know what I personally can do to make it clear to my former dentist. You're completely in the hands of the professionals, you know. If one of them says, well, we'll have to start by pulling that tooth, and then pull another one, all I can say is 'Okay, go ahead'. I'm not a dentist. I have no idea. But it's important that I have confidence in the specialists ... the question is whether my teeth will fall out tomorrow, or in a month, or in 10 years ... there's no way I can know that'.*

Investing all in a treatment with an unpredictable outcome

Although the patients perceived a lack of control, they were willing to invest all that was required in

the treatment. Patients were willing to invest time and money and follow treatment advice from the specialist team to save their teeth, oral function, appearance and self-esteem. Maintaining the teeth was a very high priority. If it was not possible to save certain teeth, a fixed prosthesis might be acceptable, but in most cases a removable denture was not.

'Other people have always complimented me on my winning smile, and my teeth are part of it. I can run off and hide in the woods, but my teeth are a personal matter. Yes, they are part of what make up my personality, they are a part of me . . . The first thing I worried about was what it was going to cost. I wasn't sure whether I was prepared to sell my flat to rescue my teeth and my appearance. I would have done it if it had been necessary, rather than being toothless. It's that important. Can you imagine a toothless bus driver? But the dentist said he thought he could save some of my teeth, and that it wouldn't have to cost a mint. I want to give it a try. I've decided to go for it, all the way'.

Some of the participants expressed anxiety over the treatment and concerns that it may become painful. Some were anxious about the communication and relationship between them and the specialist team, for example, whether or not they would receive honest information and if they would have the opportunity to take part in treatment decisions. Financial worries about treatment costs were also expressed. Although the participants said that they were prepared to pay whatever the costs the treatment would be, they expressed feelings of anger, frustration and injustice over the fact that the teeth are not considered as 'part of the body' when it comes to the financial support offered by the national medical health care system:

'I feel like my teeth are part of my body and my mouth is part of . . . Well, anyway, I think if you have an illness and have to take medication and all that, I think there ought to be a cost ceiling . . . Of course I think you should have to pay for part of it yourself, but that there should be subsidised (dental care) like there is for medical care. I really think so. I imagine there are a lot of people, even people who don't smoke and who live a healthy life, who have it (periodontitis) . . . If you are on two medications that make your mouth dry, then you can get assistance, they say, but in my case there was no help to be had, and I didn't have the energy to pursue it . . . it was easier just to pay up'.

DISCUSSION

The sample included in this qualitative study consisted of a strategically selected group of individu-

als with chronic periodontitis, who had been referred to a specialist clinic. Thus, the results describe the aspects of a specific group of patients and may not apply to all patients with chronic periodontitis. However, the aim of all research was to produce information that can be shared and applied beyond the study setting (Malterud, 2001). This present study is based on an extensive amount of data (about 250 pages of interview transcription) and the data collection and analysis included controls at all stages of the procedure, in accordance with the fundamental principles for the constant comparative method of grounded theory (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Charmaz, 2000; Delleve et al, 2002). Data collection continued until new interviews did not provide additional information (i.e. until saturation was reached). The emerging categories were all grounded in the data and the quotations given are intended to show the trustworthiness of the interpretation. Hence, the authors argue that the present results could be transferable to other patient groups with similar characteristics for the understanding of psychosocial processes in relation to periodontal health or disease.

The findings illustrate how the participants, diagnosed with a disabling oral disease that they felt ashamed of, were striving to live up to their normative values of nice teeth and a healthy mouth. They were willing to invest all they had in terms of time, efforts and financial resources to become free from periodontal disease for the purpose of their appearance and self-esteem. However, they also felt they had little control over treatment decisions and treatment outcome. Most of the informants presented a history of regular dental care. Nevertheless, the referral to a specialist and the diagnosis of chronic periodontitis meant some patients expressed feelings of shock and surrealism. Such emotions have been described elsewhere in conjunction with the diagnosis of chronic or long-term illness, and the 'crisis of illness' related to the disruption of an individual's established personal and social identity (Ogden, 2000; Kralik et al, 2001). Moreover, it has been argued that if an illness is unpredicted, the individual does not have the opportunity to consider possible coping strategies (Ogden, 2000). This may partly explain the strong emotions expressed by some of the regular dental patients in relation to the diagnosis of periodontitis. They seemed to have lived in a 'false sense of security' and expressed feelings of disappointment and anger directed to their previous dental caregivers for lack of proper information about their oral disease.

It was obvious that the patients considered periodontitis as a shameful oral disease and as something they would rather not talk about. The feelings expressed of shame and guilt were related to normative values of oral health and oral health related behaviours, as have also been described elsewhere (Abrahamsson et al, 2002; Trulsson et al, 2002). Consequently, the diagnosis of chronic periodontitis may become a threat to the patient's social identity and self-esteem. Moreover, patients considering themselves to have a poor oral status described how their oral conditions affected them in a negative way in their daily life and social functioning. For these patients the shame of attending a dental clinic seemed to be a big obstacle to overcome, and a reason for avoiding dental treatment. These findings correspond with previously described emotions and psychosocial processes related to self-perceived oral 'ill health' among dental fear patients (Abrahamsson et al, 2002) and among patients referred for treatment with implant-supported fixed prostheses (Trulsson et al, 2002). The results also support the notion that there is an association between periodontal conditions and oral health related quality of life (Needleman et al, 2004; Ng and Leung, 2006). Hence, dental professionals must realise that emotions related to oral diseases and oral conditions may be a barrier to accessing and accepting dental health care, and be sensitive to the individual patient's needs when he or she attends the dental clinic (Freeman, 1999).

The interviews revealed that the patients perceived a low degree of control over treatment decisions and treatment outcome. Furthermore, they expressed worries such as: treatment may become painful, anxiety about the communication with the specialist team and financial worries. Earlier dental experiences and perceived lack of information from previous dental caregivers seemed to influence the feelings that the outcome was out of their control and in the hands of the authority. Even so, the participants said that they had to rely on the authority, whether they liked it or not and that they were willing to follow treatment advice from the specialist team to become free from the disease. From a health psychology perspective, there are several factors that may influence patients' willingness to take part in the prevention and treatment and to follow treatment advices given, for example, individual factors including health beliefs and health locus of control, factors related to the disease and the gravity that people ascribe to a problem, the duration and the complexity of treatment and the interpersonal relationship between the patient and the caregiver (Ogden,

2000; SBU, 2004). Hence, there is a need for further studies that use a health psychology approach to periodontal health, and follow-up interviews after the periodontal therapy may lead to an increased understanding of the processes involved.

In conclusion, the results demonstrate the vulnerability of patients diagnosed with chronic periodontitis and emphasise the importance of communication in dentistry. Thus, dental professionals must be sensitive to their individual patient's needs and ensure that proper and clear information is given about oral conditions and about treatment to enhance the patient's feelings of control over the situation.

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