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Periodontitis from the patient's perspective, a qualitative study

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Abstract: Periodontitis is an infectious disease that impacts people's oral health and can lead to the loss of teeth. There are several factors that explain why some people develop this disease. *Purpose:* The aim of this study was to describe patients' perceptions of living with periodontitis. *Method:* A qualitative method inspired by phenomenography was chosen, because the focal point was the patients' perceptions of this phenomenon. A total of 10 patients, all of whom were being treated at a specialist clinic for periodontology in the south of Sweden, were interviewed. *Results:* Two main categories were identified: *perceptions of disease* and *perceptions of having the disease under control,* together with subcategories. The first category highlights the patients' perception of what causes periodontitis, being given the diagnosis, after the diagnosis and the consequences of periodontitis. The other main category highlights the patients' perception of their own responsibility and the professionals' responsibility. The patients' oral health-related quality of life had been influenced by periodontitis. There is no guarantee that the patient has understood what is actually required of him/her during treatment, despite information about the diagnosis. It can often take some time for patients to understand the nature of their disease. *Conclusion:* Acceptance and control of the disease result in less inconvenience in the patients' daily lives. It creates an optimistic future perspective, despite feelings of anxiety about facing consequences such as tooth loss.

Key words: oral health-related quality of life; patients' perceptions; periodontitis; phenomenography

Introduction

Together with caries, periodontitis is one of two common oral diseases that affect people's oral health and oral health-related

quality of life (OHRQL; 1). An internationally accepted classification defines periodontitis as: 'an infectious disease resulting in inflammation within the supporting tissues of the teeth, progressive attachment and bone loss. It is characterized by pocket formation and/or gingival recession' (2, p. 25). According to the literature, chronic periodontitis exists within 40% of the adult population. It is estimated that more extensive and advanced attachment loss can be found in between 7% and 20% of adults. In a few cases, the disease can develop more rapidly and aggressive periodontitis, as different from chronic periodontitis, is characterized by the more rapid development of attachment loss, which usually starts at a younger age (2).

Periodontitis has been shown to be more common among men than women (3). However, a Swedish study found the reverse relationship indicating women having a more severe alveolar bone loss as compared to men (4). The periodontal status may differ between different socio-economic groups, where an individual at a lower socio-economic level appears to have poorer oral health (1, 3–5). There are significant differences in the level of disease in an age perspective due to its chronic development and the disease level also appears to be higher among smokers and individuals with diabetes (3).

Oral health and related functional, physical and psychological status influence an individual's well-being and related quality of life (Fig. 1). Figure 1 describes the relationship between OHRQL and four different main components, such as function, pain/discomfort, psychological aspects and social aspects (6). The teeth and the ability to chew are associated with the perception of oral function, which is also involved in several other important areas, such as swallowing and speech. Beyond oral function, there is also a psychosocial function where oral health has an important impact on individual appearance, with the oral functions interacting to produce the individual social adaptation. As a result, oral health is important for general well-being from a social and a psychological angle. Oral diseases such as periodontitis and subjective symptoms in the mouth can have a negative effect on an individual's well-being and quality of life (6). Studies reveal a significant association between oral health and its relationship to quality of life, specifically patients with periodontitis (7–9). Cunha-Cruz *et al.* (9) states that an association found in their study between OHRQL and a manifest periodontitis should be confirmed in other studies, as much as the disease may not be considered as a silent chronic condition.

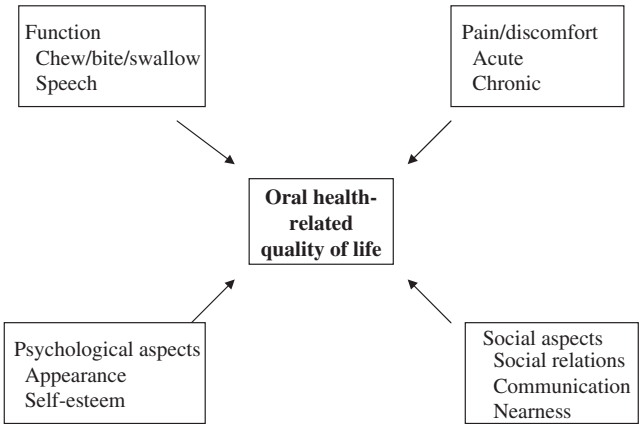

Fig. 1. Main components of oral health-related quality of life (5, p. 3).

More consideration should be taken to the individual's own experience of health, well-being and quality of life (6). It is reported that the patient's perspective is missing from most of the studies of treatment of periodontitis (2). Most studies describe oral health and quality of life on the basis of quantitative methods (7–9), however few, if any, studies discuss the patient's own view of periodontitis by means of qualitative methods. Thus, the aim of this study is to describe patients' perceptions of living with periodontitis.

Study population and methodology

A qualitative method with a phenomenographic approach was chosen, as this study aimed to describe the variation in patients' perceptions of their disease. Phenomenography aims to describe how people perceive and understand different phenomena in the world around them. Phenomenography distinguishes between the first-order perspective, the actual state of something and the second-order perspective, how it is perceived. Finding perceptions from the second-order perspective is central in phenomenography (10). The use of phenomenographic method to find out the way different phenomena are experienced and understood by patients are advocated by several authors (11, 12).

Study population

The participants for the study consisted of periodontal patients, all of who were being treated at a specialist clinic for periodontology in the south of Sweden. The participants were chosen strategically in accordance with the phenomenographic tradition (13). The criteria for participation were that patients should be diagnosed with chronic periodontitis and should include both women and men of different ages to ensure a broad description of the phenomenon under study. A total of 10 patients participated, five women and five men, aged 34–78 years.

Collection of data

Interviews were used to elicit the views of respondents. This method was deemed the most appropriate to understand the participants' real-life situation as it does not limit their opportunity to convey their story. An interview guide with a semi-structured design was used to ensure that different aspects of their perspectives were addressed in all the interviews (11). Central topics of focus in the interview guide were feelings, knowledge, social aspects, function and view of the future. The participants were able to discuss the central topics in a free conversation.

The interviews were conducted in a quiet setting at the clinic and in some cases at the participant's home. The same question was asked at the beginning of the interview: 'Can you tell me what you think about your dental disease'? Afterwards, the participant was encouraged to talk more about the topics in the interview guide and things that came up during the interview. Follow-up questions designed to extend the conversation such as 'then how did that feel', 'can you tell me more about', 'what is your perception of' and so on were then asked. All the interviews were conducted by the same author and the interviews lasted for between 30 and 60 min. As a result of the time available for conducting the study, 10 interviews were conducted.

Analysis

Interviews and analyses were conducted in a cumulative manner. The interviews were transcribed verbatim and the information was analysed, as described by Sjöström & Dahlgren (12) and Dahlgren & Fallsberg (14). The first step included familiarization with the material by reading the transcribed interview over and over again. The identification and marking of the most significant elements in the answers, as well as a condensation of significant elements in the answers, then took place. Similarities and differences in the answers were noted and a preliminary grouping together of similar answers was then made, together with a comparison and naming of the categories. The last step involved a comparison of categories, so that the description of the unique character of every category could be completed.

Ethical considerations

Permission to perform the study was obtained from the director of the specialist periodontology clinic and the study was conducted under the aegis of the School of Health Sciences, Jönköping University thus ensuring that rights of participants were protected.

Results

The analysis resulted in a category system which describes the patients' perceptions of living with periodontitis. Two main categories were identified with related subcategories and dimensions: perceptions of disease and perceptions of having the disease under control (Table 1). The perceptions are illustrated by quotations from interview statements and an interview number is given after the quotation.

Perception of disease

This category includes perceptions from situations in which the patients *were given their diagnosis*, perceptions about *the reasons why they developed periodontitis*, perceptions *after they had been given the diagnosis* and perceptions of the *consequences* of their disease.

Being given the diagnosis

This subcategory describes the interviewees' perceptions and reactions when they were informed that they had periodontitis. Astonishment and shock was a common reaction; one of the

Table 1. **Categories, subcategories and dimensions describing patients' perceptions of living with periodontitis**

Category	Subcategory	Dimension
Perceptions of disease	Being given the diagnosis	Astonishment, shock, fear, no earlier problem, time to realize
	Causes of periodontitis	Ageing, carelessness, genetic, smoking
	After the diagnosis	Insight into what it requires, change, not serious, can be treated, expectation, dreams, seeking knowledge
	Consequences	Not feeling fresh, pain, affects speech, ugly teeth, do not want to be toothless, anxiety, what is needed, new practice
Perceptions of having the disease under control	Own responsibility	Careful dental hygiene, time, cost, stop smoking, not being careless, doing my best, bad conscience
	The professionals' responsibility	Control, give care at the right time, inform and be clear, support and motivate, be skilled and careful, do it for me

interviewees described a feeling of sadness, while others did not appear to react in any particular way. Another reaction was fear when they understood that they could lose their teeth and that the disease could lead to total tooth loss. It was clear that it often took a while before they understood their situation. The following interviewee did not react to any great degree, because the progress of the disease appeared to be slow.

The dentist called it pockets, early tooth loss, but the progress was slow and so on. I didn't react in any particular way because of that really…maybe I improved my dental hygiene just a little… (4)

The diagnosis came as a surprise as the interviewees did not feel that they had had any severe problems with their teeth; everything had been alright.

I never had much caries or anything like that…so the first time I heard it, it was like a shock…; I have always had very good teeth really… (8)

For most of the interviewees, it was not unusual for it to take a while for them to understand the disease, its scope and the effect it was going to have on them. They often dealt with it at a low level at the beginning and, if they were unable to see any difference, their motivation also declined. For the following interviewee, the situation was not evident until much later when he was sent to the specialist clinic for periodontology and it was also then that he first began to take the situation seriously.

…she was really nagging me to use interdental brushes and so on, but I was fairly neglectful at the beginning…not so frightened, I didn't know how it could end. Then when I came here and understood what it was about, then I realized that I could lose all my teeth… (9)

Causes of periodontitis

This subcategory describes the interviewees' perceptions and knowledge of why they developed the disease. Most of their knowledge came from information they had been given in relation to their treatment at the clinic. There was a general perception that periodontitis was associated with a natural process related to ageing.

…I thought only old people lost their teeth, I had no idea what it was… (1)

More than half the interviewees were or had previously been smokers for a long time. The majority of them were conscious of the negative effect smoking has on the disease. Another perception was that genetic factors were one of the causes of periodontitis, as they are in other diseases. It was common for the interviewees to believe that carelessness or insufficient dental hygiene had caused their disease.

Of course I regret being careless about my dental hygiene in the past… (4)

The interviewees also said that some people could seriously neglect their teeth without being affected. As different from some people, the interviewees thought that they have been more careful about their dental hygiene than others but still had been affected by periodontitis.

After the diagnosis

This subcategory describes perceptions of the way the interviewees saw their disease when they understood it and what is required to them. This was when they really took the disease seriously. They understood that the situation demanded a greater commitment than they had previously realized and they admitted that regularly applying new routines was a change at the beginning.

Yes, taking the situation seriously at the beginning was one thing, but brushing correctly and this, you know…I probably thought that I was doing it correctly but maybe I actually wasn't anyway… (5)

All the interviewees were anxious and afraid about losing their teeth prematurely. The worst thing that could happen was losing every tooth, something that was obvious in dreams, described by following informant.

…I dreamt that all my teeth just fell out and, when I woke up and felt, all my teeth had gone just like this – plop, plop, plop… (8)

Some interviewees were interested in looking for more information about periodontitis to obtain more knowledge about their situation. Others thought that the information they had been given at their dental visits was enough. In some cases, the interviewees thought that it would probably cause more anxiety. The majority were nevertheless optimistic about keeping their teeth for a long time. The disease can be treated and this inspired hope. The following informant therefore believed that the disease was not any real threat.

No one has threatened me with death and suffering because of this, they have instead inspired hope that it can be treated…it can be stopped for periods so I don't feel that it is really a serious disease… (4)

Another interviewee had a similar approach. He said that he did not regard periodontitis as a disease or as anything serious because he did not have any particular problems with it.

I don't have any trouble with it… I don't have any symptoms other than the ones they always talk about, the depth of

my pockets. Of course, if I felt pain from my teeth, I would be more worried… (6)

Consequences

In the following subcategory, the interviewees' perceptions of the consequences of their disease were described. They thought that the treatment which is said to halt the development of disease was good and necessary in order to have a chance of improving. Some of them said that they thought that the treatment was unpleasant and sometimes painful. According to the following interviewee, it was worse than the implant therapy he had been undergoing.

…when they have to clean deeper in the gums, you know, I thought that was worse than the operations I have recently had when I got implants… (5)

Another perception of the consequences was the feeling of not being fresh and having bad breath. One of the interviewees thought that the disease affected her speech, that it was more indistinct and that it was harder to articulate since she had lost some teeth. In other cases, some of the interviewees said that they had experienced pain in their mouth because of moving teeth and sore gums. In some cases, this had had a negative effect on their daily lives in terms of their daily oral hygiene and when chewing.

It was clear that keeping their teeth was very important when it came to appearance and function, for example. Some of the interviewees said that their teeth had become less aesthetically pleasing. Their teeth felt longer than normal and, according to the following interviewee, he had also accepted this.

It's like a daily tool that you use with joy…eating is a moment of pleasure…and they also have a major impact on appearance and so on, but I now dare to smile without feeling ashamed of my ugly teeth… (4)

It is also clear that this interviewee has accepted the use of new self-care habits. Several interviewees said that their oral hygiene routines were working and that they had become a daily routine, as well as a part of their life. They have accepted most of the things that are needed to avoid consequences such as tooth loss.

Then you have to sacrifice what it takes because of this – time, money – because…it's not fun having removable dentures… (2)

Perceptions of having the disease under control

All the patients shared the perception of feeling safe and well when the disease was under control. This comprises perceptions of the interviewees' *own responsibility* and the *professionals' responsibility*.

Own responsibility

This subcategory describes the interviewees' perception of their own responsibility and what they needed to do to control their disease. They said that they had to be really meticulous when it came to their dental hygiene and that they had to invest more time and money to maintain an acceptable level of oral hygiene. For some of them, the cost was not so high, but they all thought that their treatment was expensive. Investing more time and effort in their teeth was described as necessary and tedious but also as very important for them in order to improve. The following interviewee felt anxiety about losing control and said that she had to be much more disciplined all the time.

You really have to deal with it carefully every day, you can't neglect it, you have to be disciplined. I think that's what you feel, that it can be hard always to be like that as well…but it's necessary to achieve good oral health… (7)

It is clear that the majority of the interviewees felt that their mouths were cleaner and fresher after they had become more careful about their dental hygiene. Most of them said that they had noticed their disease was improving. The majority of the smokers were aware of the negative impact smoking had on their disease. They therefore felt that they were largely responsible for the disease prognosis. Despite this perception, most of them were still smoking, but in several cases they had reduced the level of smoking and some of them were thinking about quitting smoking. One woman described the situation as follows.

…and, yes, I am a smoker and I am thinking about it all the time…trying to reduce it in the beginning…it's one of the consequences, I know that…it has certainly affected me mentally so I have to think more about it, think more about my teeth…getting better… (2)

One interviewee said that he felt an inner need to make all his teeth clean and that he had a bad conscience if he thought about cheating with his oral hygiene. Another dimension is the experience of doing as much as they can and that this is still not enough or that they are doing it in the wrong way for it to get any better. For this reason, the interviewees had a bad conscience.

…it's a question of always having a bit of a bad conscience about not doing as much as you really should do, I think…but now I am quite good but maybe not as good as I should be…I am balancing a little, keeping it under control, you know… (3)

The professionals' responsibility

In the following subcategory, the interviewees' perceptions of what is important for the professionals are described. All the interviewees felt it was important to be called for regular check-up, that the professionals are supportive and motivating so they can feel that they have their disease under control. They want to know what they have been doing well and not so well to be able to improve their condition.

…I come here and they tell me that it's getting better and then I feel much better, I think, it makes me more motivated, so now I am going to continue fighting and not be careless… (9)

Several interviewees talked about the importance of being well informed about their condition and being given information at an early stage. Some of the interviewees said that they had been given the right care and information too late. The following interviewee felt disappointed when the disease had progressed so far and he felt that he had not been given the right care, despite regular dental visits.

It was easy for me because I was always told that I didn't have any caries in my teeth…so I thought everything was all right…later, when my gums and teeth started to be sore, I understood it had to be something else…of course the dentist should have sent me to a specialist, but he was negligent, I suppose… (5)

It was clear that information and instruction in treatment situations should be confidence inspiring and clear. The following interviewee did not understand the importance of using the interdental brushes because she did not feel that the professionals' attitude to this recommendation was important. They did not motivate her sufficiently.

…they didn't make me understand that this was necessary…it was a question of simply 'take these and use them when it's OK for you', something like that, and that didn't motivate me at all because then I just kept going for 3 weeks or something… (7)

The professionals should also be skilled and careful and it is important that there is a feeling of fellowship and security during the treatment. The patient wants to feel that the professional is doing this for his/her best and that they can solve these problems together. Otherwise, it has a negative impact on the treatment situation.

Discussion

This study was designed to obtain an insight into the perceptions of periodontitis described by patients with the disease. This insight could help oral health professionals to understand the way patients react and think about the disease and treatment and thereby be better prepared to give individualized, quality care.

A qualitative method with a phenomenographic approach was chosen, because the patients' perceptions of this phenomenon were the focal point. Interviews were used to avoid setting any limits for the patients' story. To support credibility requirements, the research procedure was carefully performed and described (14). Quotations from the interviews are presented in the results section to provide evidence for the relevance of the categorization. While the sample was strategically chosen, more perceptions of this phenomenon may have been elicited by a larger sample and perhaps a more diverse sample. While a total saturation of perceptions may not have been reached, the themes from the last interview were very similar to previous ones. One interviewer conducted all the interviews and performed the initial analysis, but, at a later stage, the result was discussed continuously with the other authors. The researchers were striving throughout the analysis to maintain the most objective profile possible to prevent the result being affected by their own subjective perceptions (11).

The most important results from this study are periodontitis influences the patients' OHRQL from psychological and social aspects as well as physiological aspects. The patients' insight into their disease can appear within a short or long period and, in the worse case scenario, not at all. Just because patients have been informed about the diagnosis and restrictions relating to treatment, there may be no guarantee that they have understood what is actually required for him/her. Oral health professionals must be supportive and thereby motivate patients to control the disease. When the patients have accepted their disease and learned to control it, periodontitis seems to be less in an inconvenience in their daily lives. Despite inner anxiety about facing the consequences, like tooth loss, the patients' perception of periodontitis as something that can be treated and controlled produces an optimistic future perspective, given that dental treatment tailored for the disease is provided for the patients.

In general, the interviewees particularly felt that periodontitis was related to age and also that oral hygiene, heredity and dental care habits are factors that have an impact. Moreover, the patients had a fairly good knowledge of the reasons for developing periodontitis, probably due to the amount of information they had obtained during their regular dental visits. Naturally, they experienced the causes differently; one more frequent opinion was that they thought that they had neglected their dental hygiene.

The different reactions that were expressed when they were given their diagnosis, such as astonishment/shock, emotional calm or showing their feelings by crying, are described as typical patterns of coping from the approach of health psychology (15). In fact, it took a while for the patients to understand their situation. This study showed that patients do not have an insight into their disease and are less involved at the beginning of the disease process. Sometimes, after a short or long period of time following the diagnosis, they realize what they have to do, what it takes to make any progress. In several cases, it was clear that this was a significant change in their daily lives. In general, the patients did not understand that periodontitis was a serious disease, even if they had begun to take the situation seriously. It was clear that they experienced feelings of fear and inner anxiety about conceivable tooth loss. The fact that periodontitis is a disease that can often be treated and may also be under the patients' own control presumably helps to explain why the patients still felt hopeful about their situation. It can also explain why some of the patients were interested in finding out more about their disease. From the perspective of health psychology, this can also be described as coping, where cognitive and emotional strategies reduce external or internal requirements by focusing on something else (15).

Like other studies (7–9) in which quality of life related to oral health has been researched, this study also confirmed that the patients were influenced to a greater or lesser degree by their physical, psychological and social situation. In an observational study, Needlemann *et al.* (8) found that periodontitis affected patients' OHRQL in several dimensions. Major areas that contributed to this result were psychological aspects (mood, self-confidence), physical aspects (eating, appearance) and symptoms (comfort, breath odour). In addition, the authors showed that treatment of periodontitis eventually increased the level of OHRQL. A cross-sectional observational study analysed the relationship between periodontal attachment loss and OHRQL measured by the Oral Health Impact Profile questionnaire (OHIP-14). The results revealed significant associations between severe attachment loss and higher scores on the OHIP-14 (total sum of scores and for the dimensions of functional limitation, physical pain, psychological discomfort and disability and physical disability) (7). The results of this qualitative study reveal similar experiences among periodontal patients as these quantitatively oriented studies.

It has been shown that subjective symptoms like pain and discomfort have been experienced in relation to the treatment of periodontitis. In a study by Cunha-Cruz *et al.* (9), patients with periodontitis reported how frequently pain was experienced in relation to their periodontal disease. Over 10% of the sample reported pain fairly or very frequently.

Furthermore, it is clear that mobile teeth and sore gums caused by the periodontal disease have been experienced as painful and have restricted some patient' daily lives, as well as their speech and ability to chew (9). Periodontitis has been found to have changed the patient's appearance. Otherwise, none of the patients thought it had prevented them smiling, which has been reported in another study (8). However, it is also clear that they experience a feeling of shame about smiling in public. The patients therefore appear to understand that this change in appearance and function has been incorporated in some kind of new self-image. It is possible to interpret this as the patients accepting the situation, even if they were aware of the circumstances. Other consequences of their disease were feelings of not being fresh and experiences of bad breath. A connection can therefore be seen between the patients' perceptions of their OHRQL and their own well-being (Fig. 1). The establishment of new dental habits and routines is also a consequence of their disease. Their general apprehension was that the situation had developed into something they had to accept. According to studies, perceptions like this are described as a strategy of adaptation (5, 13).

Their overall perceptions were also that they wanted to have control their disease. To obtain control, they said that the periodontitis disease demanded more of their time and money and, not least, meticulous oral hygiene. The patients explained during the interview that living with periodontitis may be difficult in a cognitive sense due to continuous thoughts about their teeth and daily oral hygiene. If they did not spend enough time cleaning their teeth as they should, they experienced both a bad conscience and not feeling fresh. Factors like smoking are a typical example of areas in which the patients felt they could do more to improve their oral health. The patients said that, in order to maintain a high level of oral hygiene, the involvement and support of the professionals was essential. This underlines just how important it is that the dental professionals actually do follow up the patients regularly to motivate them to continue their interest in their own dental hygiene. The opportunity to offer the patient help to quit smoking is also an important issue. In general, successful treatment also depends on good communication between the professionals and the patients.

In conclusion, two main categories were reported by the patients: perceptions of disease and perceptions of having the disease under control, together with subcategories. The patients' OHRQL had been influenced by periodontitis, thus implicating that chronic periodontitis may have an impact on

individuals' life situation and not merely being a 'silent' disease.

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