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Patients' experiences of the impact of periodontal disease

Louise K. O'Dowd[1], Justin Durham[2], Giles I. McCracken[2] and Philip M. Preshaw[3]

[1]Restorative Department, Newcastle Dental Hospital, Newcastle Upon Tyne, UK; [2]School of Dental Sciences, Newcastle University, Newcastle Upon Tyne, UK; [3]School of Dental Sciences and Institute of Cellular Medicine, Newcastle University, Newcastle Upon Tyne, UK

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Abstract

Aim: To examine critically patients' experiences of the impact of periodontal disease on their daily lives.

Material and Methods: Semi-structured interviews of a purposive sample of patients with periodontal conditions were conducted using a flexible evolving topic guide. Data collection and analysis were an inductive, iterative process that occurred concurrently. The data were organized in a framework and recurrent themes identified. Interviews occurred until it was felt that no new themes or ideas were being expressed by respondents ($n = 14$).

Results: Effects of periodontal disease on patients' daily lives included impairment, functional limitation, discomfort and disability (including physical, psychosocial and social disability). A large number of the emergent themes from the analysis were relevant to the domains of Locker's conceptual model of oral health. The domain within Locker's model that had no data relevant to it in the context of periodontal disease was death. Two additional themes emerged that appeared unrelated to Locker's model, these were stigma and retrospective regret.

Conclusion: Periodontal disease reportedly affects patients' lives in a negative manner in a variety of ways. This is of relevance in the management of patients with periodontitis.

Key words: impact on daily life; patient experience; periodontal disease; quality of life

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Traditionally, research into periodontal disease has tended to focus on the clinico-pathological mechanisms of the disease rather than its impact on the patient. This is in line with the historical biomedical approach to disease and illness. It has been recognized, however, that a disease can exert more than simply biological effects and can affect both the sufferers' psychology and social functioning. It is more appropriate, therefore, to take a biopsychosocial approach to disease and illness (Engel 1977, 1980).

The biopsychosocial approach is especially important for a number of reasons. Firstly, health care systems tend to be consumer driven and evidence demands that the clinician takes a patient-centred egalitarian approach to management of disease and illness (Charles et al. 1997, Mead & Bower 2000, DoH 2004). Secondly, when dealing with chronic diseases such as periodontitis, it is important to understand the biopsychosocial effects of the disease so that attempts can be made to minimize them. This should ensure that clinicians are able to: understand patient perceptions of the impact of oral health on their lives; plan periodontal care which addresses patient needs and key concerns; and evaluate outcomes of periodontal treatment from the patients' perspective (McGrath & Bedi 1999).

The importance of patient-centred measurements in assessing periodontal treatment efficacy has been recognized (Hujoel 2004) and they were designated a research priority area at the 2003 World Workshop on Emerging Science in Periodontology (Tonetti et al. 2004). In relation to this priority area there has been research using quantitative psychometric patient-centred questionnaires, such as the Oral Health Impact Profile (OHIP), to ascertain whether or not periodontal disease has an impact on patients' daily lives including their quality of life (Da Silva et al. 1995, Croucher et al. 1997, Needleman et al. 2004, D'Avila et al. 2005, Saletu et al. 2005, Ng & Leung 2006, Cunha-Cruz et al. 2007, Lopez & Baelum 2007, Ozcelik et al. 2007, Patel et al. 2008, Jowett et al. 2009) and there are already existing models of health and illness (Locker 1988) (Table 1, Fig. 1) (Wilson & Cleary 1995). Such models seek to capture all possible psychosocial and

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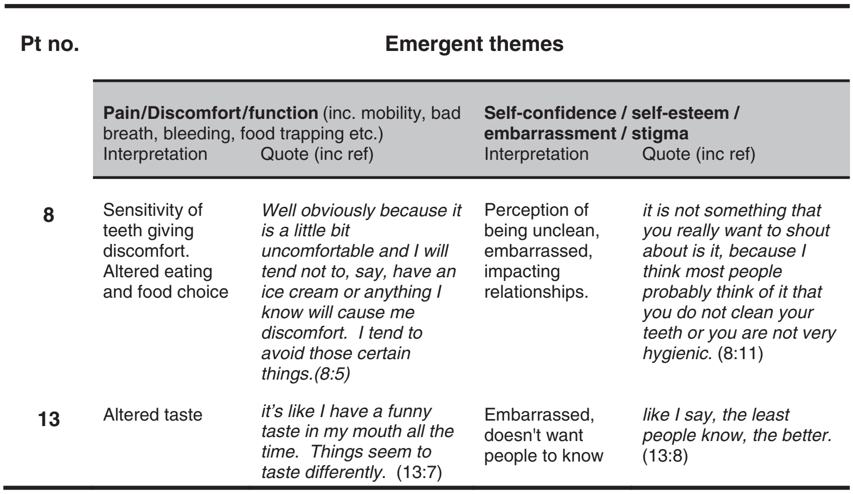
Table 1. Age, gender and periodontal diagnosis of the patients interviewed

Patient no.*	Age	Gender	Periodontal diagnosis
1	37	F	Chronic periodontitis
2	40	F	Aggressive periodontitis
3	29	M	Aggressive periodontitis
4	63	M	Chronic periodontitis
5	44	M	Chronic periodontitis
6	70	M	Chronic periodontitis
7	48	M	Gingivitis
8	57	F	Chronic periodontitis
10	57	F	Chronic periodontitis
11	50	F	Aggressive periodontitis
12	29	F	Chronic periodontitis
13	37	F	Aggressive periodontitis
14	65	M	Chronic periodontitis
15	34	F	Gingivitis

*Patient 9 data corrupted on tape and therefore discarded.



Pt no.	Emergent themes			
	Pain/Discomfort/function (inc. mobility, bad breath, bleeding, food trapping etc.)		**Self-confidence / self-esteem / embarrassment / stigma**	
	Interpretation	Quote (inc ref)	Interpretation	Quote (inc ref)
8	Sensitivity of teeth giving discomfort. Altered eating and food choice	*Well obviously because it is a little bit uncomfortable and I will tend not to, say, have an ice cream or anything I know will cause me discomfort. I tend to avoid those certain things.(8:5)*	Perception of being unclean, embarrassed, impacting relationships.	*it is not something that you really want to shout about is it, because I think most people probably think of it that you do not clean your teeth or you are not very hygienic.* (8:11)
13	Altered taste	*it's like I have a funny taste in my mouth all the time. Things seem to taste differently.* (13:7)	Embarrassed, doesn't want people to know	*like I say, the least people know, the better.* (13:8)

Fig. 1. Extract from the tabular framework used to determine the emergent themes.

functional outcomes of oral disorders and have been pivotal to the development of quality-of-life research in dentistry. There has, however, been no research that examines critically the patient experience of periodontal disease. This type of research is key to guiding the development of patient-centred tools. An examination of periodontal disease from the patient's experience of it will give the clinician an insight into the, sometimes idiosyncratic, biopsychosocial effects a specific disease or illness can cause. Qualitative research is recognized as the most appropriate method to use to achieve this as it aims to explore and understand naturally occurring phenomena and patient experiences (Pope & Mays 1995).

The aim of this study was, therefore, to examine critically patients' experiences of the impact of periodontal disease on their daily lives.

Materials and Methods

A qualitative approach to data collection was used to explore the patient's experience of periodontal disease. Semi-structured interviews were conducted by one member of the research team (L. K. O'. D). A criterion-based purposive sample (Patton 2002) of patients with various periodontal conditions attending consultant led diagnostic clinics at Newcastle Dental Hospital was used. Demographics and clinical periodontal diagnosis of the patients are represented in Table 1.

The aim of the sample was to collect detailed interview data from individual patients. Attention was given, therefore, to ensuring that the data collected reflected a range of views and experiences thus increasing the depth, breadth and richness of the data collected. The sample itself was not, however, statistically representative. The sample included both men and women of different ages with a variety of clinical diagnoses as determined from the case records. Periodontal diagnoses were assigned following consideration of the 1999 World Workshop classification system (Armitage 1999).

Ethical approval was obtained (ref: 07/Q0904/36) and written informed consent was obtained from each participant before commencing the interview. Data collection and analysis were an inductive, iterative process that occurred concurrently, broadly following the principles of the constant comparative method (Glaser 1965). Each interview transcript was analysed before proceeding to the next so that in this way each interview informed the following interview. All interviews took place in a non-clinical setting and were digitally recorded then transcribed verbatim while ensuring anonymity. Given the iterative nature of the study, a flexible evolving interview guide was used, which allowed for unanticipated issues raised by patients in earlier interviews to be explored in subsequent ones.

Two members of the research team (L. K. O'. D and J. D.) independently coded the transcripts and agreed the emergent recurrent themes, modifying and adding to themes as the process developed and new data emerged.

A framework approach as outlined by Ritchie & Spencer (1994) was used to manage the data and consisted of direct quotations and contextualizing information grouped together under headings representing the emerging themes. Figure 1 shows an extract from the large framework that was used for the study.

Results

Data analysis and collection occurred until it was felt that respondents were expressing no new themes and no new ideas emerged and occurred after 14 interviews. The recording for patient 9 was corrupted and therefore no data were obtained for use in the analysis. In the presentation of the results, representative quotes have been chosen to illustrate the theme and to explain the point being made. The number following the quotation in parentheses is the patient's study number and can be referenced against the patient details in Table 1 and to the supporting information Appendix S1. Information contextualizing some quotations has been added in squared brackets for clarity.

Table 2. Definitions of domains of Locker's model (Locker 1988)

Domain/ concept	Subdivision	Definition
Death		Mortality rates, life expectancy, potential years of life lost
Impairment		Extent of anatomical loss or structural abnormality
Functional limitation		Extent of loss of function of body parts or systems
Discomfort		Self-reported physical and psychological distress, including pain and other feeling states not directly observable
Disability	Physical	I. Activity restriction – acute or chronic limitation in physical activities of daily living II. Social limitation – acute or chronic problems in everyday social functioning
	Psychological	I. Affective states – emotion, anxiety, depression II. Cognitive states – problems in concentration, reasoning
	Social	I. Integration – participation in community life II. Social contacts – interaction with family, friends III. Intimacy – perceived feelings of closeness/support
Handicap	Inequality	Lack of access to social opportunities including careers, education
	Deprivation	Inequality of outcomes in terms of income, self- image, self-esteem
	Dissatisfaction	With health and/or overall quality of life

Table 3. Illustrative and representative data relating to impairment and functional limitation domains

Domain of oral health	Reported effects of periodontal disease in the domain	Representative quotation (patient identifier)
Impairment	Tooth mobility	I cannot bite into an apple and eat it that way, I have got to chop it up . . . . Because they were slack and they were getting bad at the front, whenever I bit into an apple or something hard, they used to bleed (2)
	Sensitivity of teeth	On cold days, cold air and things like that, if you breathed in you'd be like ''Aargh'', like you were eating an ice cream or an ice cube or something like that (1)
Functional limitation	As a result of tooth mobility	I cannot eat an apple how you would normally eat an apple, I would have to cut it and eat it from the side of my mouth. I cannot eat a crust or French bread because they all felt, especially the bottom ones, that they would fall out (11)
	As a result of sensitivity of teeth	If I'm eating a lolly, say if the kids have had one and I'll eat one, I won't bite it, I'll bite it at the back of my teeth (12)

A large number of the emergent themes from the analysis were relevant to the domains of Locker's conceptual model of oral health (Locker 1988) shown in Table 2. The domain within Locker's model that had no data pertaining to it in this study was death. We have therefore presented the emergent themes using the domains of the model of oral health. Tables 3 and 4 contain illustrative quotes from emergent themes in the domains of Locker's model of oral health. These tables inevitably contain quotes that cover more than one domain. This is because patients often simultaneously reported their experience in one domain along with its concomitant effects in another domain.

Two other themes also emerged from the data that were distinct from Locker's model. These were stigma and retrospective regret and these are described further below.

Data related to Locker's domains of oral health

Locker's model begins with *impairment* and this was often the first aspect of periodontal disease that patients noticed. They commonly reported that they suffered from mobility of teeth, sensitive teeth (as a result of recession) and infections. They went on to report that these experiences might limit their masticatory function (*functional limitation*). Quotations illustrating these experiences are shown in Table 3.

Discomfort was reported in two forms by the interviewees: physical and psychological. Physical discomfort was reported in relation to the sensitivity of teeth to hot and cold after gingival recession. Psychological discomfort was related to factors such as the realization that they suffered from halitosis, they might experience loss of teeth during eating due to their mobility, and that the appearance of their ''smile'' (teeth) had changed and might now be pathognomonic of ''gum'' disease, which seemingly was a stigma (Table 4).

The psychological discomfort appeared closely related to *disability* reported by the interviewees (Table 4). The patients interviewed reported a range of disabilities they felt were associated with their experience of periodontal disease. These fell into the three broad groups of disability: psychological; social; and physical. Psychological disability followed on from some of the findings related to psychological discomfort and could then, it seemed, lead on to social limitation. For example, the realization of halitosis meant patients reported concern about it, and that they indulged in specific, extensive, regimens to combat it. They also reported that they felt less able to socialize because of their worry over halitosis and the fear it might be discovered.

Social disability was also reported as a result of concern over the appearance of the teeth. Several measures were reported by interviewees to try and selectively conceal the appearance of their teeth. These measures included a reluctance to smile, refusals to be photographed and positioning a hand over the mouth while talking. Difficulties in work relationships were also reported by a few in the sample and socializing in intimate situations was also reported as potentially being awkward. This intimate difficulty was reported by a few as causing strain in close relationships.

Handicap was not widely reported by interviewees. This is unsurprising as handicap is the result of very high-level impacts on patient's lives, for example, redundancy due to disease. There will, therefore, be ''ceiling''-type effects even within qualitative data. As handicap represents high-level impacts on

Table 4. Illustrative and representative data relating to physical discomfort and disability domains

Domain of oral health	Reported effects of periodontal disease in the domain	Representative quotations (patient identifier)
Discomfort	Physical discomfort related to the sensitivity of the teeth	If I go to my mum's and she's making a cup of tea I have to say put some cold water in it for us. Whereas in a café I wouldn't dream of like saying oh . . . I'd sit there for half an hour till it cools down (13)
	Psychological discomfort related to halitosis	The wife mentioned something like ''Your breath smells'' you sort of think ''Ah'' and you put your hands over your mouth . . . I feel a bit self-conscious (7)
	Psychological discomfort related to pathognomonic appearance	I am pretty confident when it comes to everything else. It is just the way my teeth look. I mean, I am thinking about that, when I am talking to people I am thinking ''Are they looking at my teeth'' (3)
	Psychological discomfort related to the worry of losing mobile teeth	I noticed with apples because we went to London a little while ago and I had an apple and I couldn't eat it, I said to my mum I think my tooth's going to fall out. I was very self conscious, I couldn't eat it (12)
Disability	Psychological disability	Like in a way it's embarrassing. Like where I've been telling my family it's not like, I don't say I've got gum disease, I'll say it's because my bone's crumbling . . . I know it's bad, but it sounds to me better than to say gum disease. Gum disease . . . well that's people who have got rotten teeth and all that and don't look after them. When I have always done all of that (13)
	Social disability	I wouldn't eat out with anybody at all. It was okay with him [husband] but I'd . . . if there was only me and him going out, I didn't bother. I was just like ''Oh no, we'll just stop in because it's too much of a hassle and I don't want anything'' (1)
	Physical disability	I couldn't go out and eat a sandwich in a restaurant or anything like that because you just hadn't got the capacity to bite. That was one of the things, you had to go somewhere where you had knife and fork and you could cut things, you know (6)

individuals' daily lives, even a few individuals reporting possible handicap is a significant finding. Handicap impacts in this study were reported as the inability to participate in hobbies (Appendix S1, 1.5), enjoy time with family (Appendix S1, 11.6), socialize (Appendix S1, 13.10) and enjoy holidays (Appendix S1, 1.3).

Data related to stigma

The effects of halitosis, tooth loss and altered appearance given in the previous discussion of the data related to Locker's model may represent examples of perceived stigma. Stigma is the process by which the reaction of others ''spoils'' normal identity (Goffman 1968). The data in this study that have been interpreted as stigma were related to the fact that if people knew you had periodontal disease it meant implicitly that you were ''unclean'' or ''unhygienic''.

''It is embarrassing because people naturally assume that it is because you have forgot your hygiene and you have not looked after your teeth and it is not always the case'' (patient 11).

The stigma was either reported directly ''I've always felt there was like a stigma about it [periodontal disease]'' (patient 13), or was implied by patients' reluctance for others to know about their condition, ''it is not something that you really want to shout about is it, because I think most people probably think of it that you do not clean your teeth or you are not very hygienic'' (patient 8). Given the possible (perceived) stigma of periodontal disease, it is unsurprising that reduced self-confidence was widely reported. ''It has just affected my self-confidence really and how I feel about myself . . . I was a pretty confident lad you know before that but it has affected my confidence in a big way'' (patient 3).

Reassurance from others, including health care professionals, did not necessarily dispel this lack of self-confidence. It seems possible that for some individuals, the significance of having periodontal disease might become a fixation for them in their everyday lives, either influencing their behaviour as previously discussed, or occupying their thoughts during the day ''[I think about periodontal disease] at least 25% of the day, if not more because I was very, very conscious of it and it depends on what day it is as to how many people I have to talk to'' (patient 11).

Data related to retrospective regret

Retrospective regret was linked by the patients interviewed to past lack of understanding, personal failure to act and past behaviour. ''I wish I had maybe looked after my teeth more. When I knew . . . when I first got told that I had gum disease, you just do not worry at the time do you, you just think everything is going to be alright but then they all start falling out and they are getting slack and I sometimes wish that I had done more about it'' (patient 2).

The regret expressed by patients could also be tempered by anger or frustration. Specifically, this tended to be due to perceived inaction by members of the dental profession, ''if it had been spotted sooner, it might not have happened, but . . . nothing I can do about that now [laughter], I cannot go back and start my check-ups can I'' . . . (patient 1).

Discussion

As the interviews progressed it became clear that most of the data were related to the domains of Locker's conceptual model of oral health (Locker 1988). Locker's original model of oral health (Fig. 2) suggests a linear flow between domains but our data would suggest empirically that there may be some bidirectional links between some domains. Indeed recent studies have also suggested as much (Nuttall et al. 2006, Baker 2007).

These subtle changes in Locker's model of oral health are important to those treating periodontal disease, as a permanently functionally limited state may not necessarily always lead to discomfort, disability or handicap (Nuttall et al. 2006). Our data add to this understanding by highlighting the possible

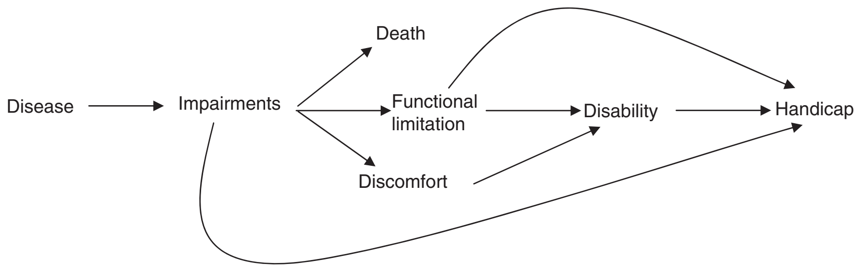


Fig. 2. Locker's model of oral health (Locker 1988).

importance of stigma (Goffman 1968) in periodontal disease. To give one example, if, as a result of successful periodontal treatment, patients have a reduced, but stable, periodontal attachment apparatus with resultant obvious gingival recession, it may be that in some patients this could lead to disability through the appearance of the teeth alone, despite a clinically ''successful'' result being obtained. Furthermore, the progression to some form of disability from a treatment outcome that would be deemed successful by the clinician could be possibly due to fear of the reaction of others to a stigma. This fear may result in strategies to combat the stigma including selective concealment, covering-up, medicalizing behaviour and condemning the condemners (Scambler & Hopkins 1986). Selective concealment, for example, covering one's mouth or reluctance to smile, may lead to social disability. A recent study has shown similar effects in that periodontal status was shown to affect sufferer's self-concept as well as their social interactions (Patel et al. 2008).

The emergence of data in our study that are broadly relevant to the domains of Locker's model could be considered promising for the development of an oral health-related quality-of-life measure specific to periodontal disease based on OHIP-49. This is because the structure of OHIP-49 (Slade 1997) is based upon Locker's original model of oral health and is therefore likely to capture a large amount of what our data show in relation to patient experiences. Despite recent changes to both Locker's model and the WHO classification on which it is based (WHO 2001, Baker 2007), OHIP has been shown to be a valid measure of oral health-related quality of life (Allen & Locker 1997, Nuttall et al. 2006). Given the data presented in this paper, it is unsurprising that in trials with periodontal patients, OHIP measures an impact on patients' quality of life and also appears to be responsive to changes in periodontal status (Ng & Leung 2006, Cunha-Cruz et al. 2007, Lopez & Baelum 2007, Jowett et al. 2009). However, it is possible that the full version of OHIP-49 contains a number of redundant items for those suffering from periodontal disease and lacks focus on domains or areas of particular importance to those sufferers.

Our data support the assertion that periodontal disease affects patient's everyday lives, often in a negative manner, and also provide greater insight into the idiosyncratic nature by which it can do so. The reasons for this variation cannot be answered from the small cohort in this study but the data do emphasize the challenges associated with: (a) truly capturing all the impacts of a disease such as periodontal disease on oral health-related quality of life; and (b) designing a tool that can fully examine and quantify these impacts. Further combined methodology studies specifically examining quality-of-life measures, perhaps OHIP-49, and periodontal disease are required to ensure that whichever quality-of-life measure is accepted by the wider research community, it has the degree of content validity required for periodontal disease.

The reported impacts of periodontal disease that emerged in our study included a large psychosocial component. It is important that the clinician understands and, if possible, addresses these issues as clinical-psychological studies suggest negative life events and depressive mood themselves may be a pathogenic factor for periodontal disease (Da Silva et al. 1995, Croucher et al. 1997, Saletu et al. 2005). It is possible, therefore, that if these factors are left unaddressed, sufferers of the disease may find themselves in a vicious circle in which their periodontal disease triggers low mood, which subsequently contributes to the disease process.

A limitation of this study is that it used a relatively small sample, from one country, in a secondary care setting. This may mean that the data are not necessarily translatable to other populations. We did, however, reach a position where no new themes were identified and achieved our aim of providing depth and detail of how this cohort was affected by periodontal disease. The data presented may now act as a platform for further combined methodology studies attempting to create a patient-centred tool to measure change as a result of periodontal treatment. Our data may point towards the further investigation of the efficacy of OHIP-49 in measuring change in oral health-related quality of life.

Conclusion

Periodontal disease reportedly affects sufferers' lives in a negative manner in a variety of ways that could be mapped to Locker's conceptual model of oral health, including particularly impairment, functional limitation, discomfort and disability (physical, psychosocial and social disability). Some of these negative effects are mediated through the perceived stigma of periodontal disease. Further combined methodology studies are required to ensure any patient-centred measurement tool for periodontal treatment has the necessary content validity to be sensitive for periodontal disease.

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Supporting Information

Additional supporting information may be found in the online version of this article:

Appendix S1. Patient quotations and illustration of domains covered within Locker's conceptual model of oral health (Locker 1988).

Address:
Louise K. O'Dowd
Restorative Department
Newcastle Dental Hospital
Richardson Road
Newcastle upon Tyne, NE2 4AZ
UK
E-mail: louise.odowd@nuth.nhs.uk

Clinical Relevance

Scientific rationale for the study: Periodontal research has traditionally focussed on clinical aspects of disease and treatment, but has rarely examined the impact of periodontal disease on patients' daily lives. Patient-centred management approaches require investigation of the biopsychosocial effects of periodontitis to improve our understanding of patient perceptions of the impact of periodontal disease.

Principal findings: Periodontal disease has reportedly wide-ranging negative impacts on patients' daily lives in multiple oral health domains. These include impairment (e.g. difficulties eating), functional limitation (e.g. as a result of tooth mobility or sensitivity), physical discomfort (e.g. sensitivity), psychological discomfort (e.g. embarrassment and worries about halitosis or possible tooth loss) and disability, including psychological disability (e.g. embarrassment), social disability (e.g. a negative impact on socializing) and physical disability (e.g. as a result of difficulties eating). Furthermore, there appears to be a stigma, that is, negative associations and impressions of periodontal disease for the patient.

Practical implications: Our findings will help health care workers understand the wider impacts of periodontal disease on the sufferer and have relevance for improving understanding of patients' experience of their disease. A central tenet of successful periodontal therapy is behaviour change, and improved understanding of patient experiences regarding their disease is therefore relevant to help effect such change.