Psychosocial aspects of periodontal disease diagnosis and treatment

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Abstract

Patient-reported outcomes (PROs) have attracted interest in periodontal research as our focus shifts from clinician-centric endpoints. PROs generate meaningful insight into the impact of a condition on patients. This mixed-methods study aimed to develop an understanding of the psychosocial impact of periodontitis diagnosis and treatment.

Fourteen adults with chronic periodontitis—who had been referred to a university clinic—kept diaries about their experiences. The diary information was then used as a framework for semi-structured qualitative interviews conducted at the completion of their non-surgical therapy. Inductive thematic content analysis with NVivo® was employed. Data on clinical periodontal status, self-reported oral health and the condition’s impact (the latter determined with the short-form Oral Health Impact Profile, or OHIP-14) were collected at baseline and follow-up to supplement the qualitative data. Finally, the findings were considered in the context of status passage, a sociological theory.

Three themes were identified which illustrated the detrimental impact of periodontal disease on the participants’ psychosocial wellbeing: ‘concealment’, ‘having a guilty conscience’ and ‘patient comfort as paramount’. These were related to a core underlying concept, ‘progression to a more positive outlook’, which described how the participants became more optimistic as they progressed through diagnosis and treatment. While most considered the treatment to be unpleasant, the participants not only perceived improvements in their symptoms, but described profound positive influences on their social wellbeing, self-esteem, mood, work, relationships and outlook. These findings were not reflected in the quantitative data, with a slight increase in the mean OHIP-14 score between baseline and follow-up (14.0 and 15.4 respectively). However, changes in self-reported periodontal status suggested greater periodontal awareness. Moreover, many of the findings were applicable to the notion of status passage, which indicated that this theory may be relevant to future studies investigating patients’ experiences of periodontitis.
This study illustrated the broad psychosocial impact of periodontitis. The findings suggest that the benefits of periodontal treatment extend beyond improvements in traditional biomedical indicators to those which are more relevant and desirable to patients. The findings may be reassuring for patients embarking upon periodontal treatment. In addition, this study gives clinicians valuable insights into the idiosyncratic experiences of our patients, to which we are not frequently exposed. This may improve our understanding of patients’ perspectives and facilitate the delivery of periodontal care which is sensitive and responsive to patients’ needs.
Acknowledgements

Firstly, I would like to thank my supervisors for their immense support throughout all phases of this thesis. I am honoured and grateful to have had the opportunity to work alongside you all. To Associate Professor Lyndie Foster Page, my primary supervisor, thank you for your mentorship, approachability, and for generously sharing your time and vast expertise with me. To Associate Professor Jonathan Leichter, thank you for helping me to find a thesis topic which was enjoyable and interesting. The insight I have gained from conducting this research is just one of the many ways that you have influenced me to become a better clinician. Special thanks must also go to you both for your continued involvement with this project despite moving on from the University. To Dr Ellie Knight, thank you for the many hours you spent diligently reviewing the data and manuscripts, and your insightful feedback. Finally, to Professor Murray Thomson, thank you for your wisdom and kind encouragement. Among many other things, you are a master of the English language and I have learnt so much from your careful editing.

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<tr>
<td>AAP</td>
<td>American Academy of Periodontology</td>
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<tr>
<td>BOP</td>
<td>Bleeding on probing</td>
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<td>CAL</td>
<td>Clinical attachment level</td>
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<td>CDC</td>
<td>Centres for Disease Control and Prevention</td>
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<tr>
<td>CEJ</td>
<td>Cemento-enamel junction</td>
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<tr>
<td>COREQ</td>
<td>Consolidated Criteria for Reporting Qualitative Research</td>
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<tr>
<td>CPI</td>
<td>Community Periodontal Index</td>
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<tr>
<td>CPITN</td>
<td>Community Periodontal Index of Treatment Needs</td>
</tr>
<tr>
<td>EK</td>
<td>Dr Ellie Knight</td>
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<tr>
<td>GOHAI</td>
<td>Geriatric Oral Health Assessment Index</td>
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<tr>
<td>GR</td>
<td>Gingival recession</td>
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<tr>
<td>GRADE</td>
<td>Grading of Recommendations Assessment, Development and Evaluation</td>
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<tr>
<td>HRQoL</td>
<td>Health-Related Quality of Life</td>
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<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities and Handicaps</td>
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<tr>
<td>LA</td>
<td>Local anaesthesia</td>
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<tr>
<td>LFP</td>
<td>Associate Professor Lyndie Foster Page</td>
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<tr>
<td>JL</td>
<td>Associate Professor Jonathan Leichter</td>
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<tr>
<td>NHANES</td>
<td>National Health and Nutrition Examination Survey</td>
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<td>OHIP</td>
<td>Oral Health Impact Profile</td>
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<td>OHIP-14</td>
<td>Short-form Oral Health Impact Profile</td>
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<td>OHIP-49</td>
<td>Full Oral Health Impact Profile</td>
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<td>OHIP-ADD</td>
<td>Oral Health Impact Profile- Additive</td>
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<tr>
<td>Abbreviation</td>
<td>Description</td>
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<tr>
<td>OHIP-SC</td>
<td>Oral Health Impact Profile- Simple Count</td>
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<td>OHIP-WS</td>
<td>Oral Health Impact Profile- Weight Standardised</td>
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<tr>
<td>OIDP</td>
<td>Oral Impacts on Daily Performances</td>
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<tr>
<td>OHRQoL</td>
<td>Oral Health-Related Quality of Life</td>
</tr>
<tr>
<td>OHRQoL-UK</td>
<td>United Kingdom Oral Health-Related Quality of Life</td>
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<tr>
<td>PPD</td>
<td>Probing pocket depth</td>
</tr>
<tr>
<td>PH</td>
<td>Poppy Horne</td>
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<td>PRO</td>
<td>Patient-reported outcome</td>
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<tr>
<td>SD</td>
<td>Standard deviation</td>
</tr>
<tr>
<td>SES</td>
<td>Socio-economic status</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<td>US</td>
<td>United States</td>
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<tr>
<td>SRQR</td>
<td>Standards for Reporting Qualitative Research</td>
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<td>WHO</td>
<td>World Health Organization</td>
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<td>WMT</td>
<td>Professor W. Murray Thomson</td>
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Chapter One – Introduction

1.1.1 BACKGROUND

Periodontitis is a chronic inflammatory disease characterised by progressive and irreversible destruction of the supporting tissues of the teeth. It is initiated and sustained by dysbiotic microbial biofilms, although various factors may influence its progression. In 2010, severe periodontitis was the sixth most prevalent disease worldwide, and milder forms of the disease affect a majority of adults (Kassebaum et al. 2014). This high prevalence, coupled with its undesirable consequences (which include tooth loss and putative associations with systemic conditions), has made periodontitis a significant public health issue.

In addition to its physical effects, periodontitis also has a negative impact on the oral health-related quality of life (OHRQoL) of those with the condition (Buset et al. 2016). Recently, patient-reported outcome measures such as OHRQoL scales have become a favoured method for evaluating health outcomes, because they consider the impact of disease on individuals in the wider context of their health and wellbeing. Qualitative research methods take this further because they allow individuals’ idiosyncratic perspectives to be examined in detail while preserving their context. Ultimately, a greater understanding of patients’ perspectives on periodontitis and their experiences of treatment may facilitate the provision of clinical care which addresses their needs.

1.1.2 THESIS OUTLINE

This thesis has been arranged into eight chapters. It will begin with a review of the relevant literature (Chapter two), which is presented in five parts. Part one provides an overview of periodontitis, including its clinical features, diagnosis, pathogenesis, epidemiology, and treatment. This is followed in part two by a discussion of the recent shift of the focus of healthcare to include patient-reported outcomes. In this section, the literature on patient-reported outcome measures is considered, with an emphasis on OHRQoL and its relationship with periodontitis. Part three will present an overview of qualitative research methods and the research paradigms which underpin them. Next,
previous qualitative research in periodontics is comprehensively reviewed in part four. Finally, the sociological notion of status passage is discussed in the context of chronic disease in part five.

The literature review is followed by an account of the methods used to conduct the present study (Chapter three). This includes description of the preparatory phases, the qualitative and quantitative data collection methods used, and the thematic and statistical analyses of the respective data. Chapter four comprises a descriptive account and commentary of the qualitative findings. This chapter is structured according to the four themes which were identified during thematic analysis of the qualitative data. This is followed by a presentation of the quantitative findings in Chapter five.

In Chapter six, after the limitations and strengths of the study are acknowledged, the findings are discussed and considered in the context of the existing literature. They are then used to make recommendations for clinical periodontal practice and future research. In Chapter seven, the notion of status passage is applied to the study findings. Finally, Chapter eight contains an overview of the thesis, in which conclusions are drawn from the research.

1.1.3 AIMS OF THE STUDY

The main objectives of this study were to develop an understanding of the psychosocial aspects of periodontal disease, and to gain insight into the patient experience of periodontal treatment. Secondary aims included the examination of self-reported periodontal status and OHRQoL at baseline and after non-surgical periodontal therapy, and application of the notion of status passage to periodontitis.

It was hypothesised that periodontitis would have a negative impact on patients’ psychosocial wellbeing, in addition to its clinical symptoms, and that the treatment of periodontitis would impact on individuals in different ways.
Chapter Two – Literature Review

2.1 AN OVERVIEW OF PERIODONTITIS

2.1.1 INTRODUCTION

Periodontitis is an inflammatory disease that results in the destruction of the supporting structures of teeth: the periodontal ligament, connective tissue and alveolar bone (Armitage 2004b; Lindhe et al. 1999). It is caused by dental plaque and may be largely preventable. This chapter briefly discusses the clinical features, aetiology, pathogenesis, diagnosis, epidemiology, and treatment of this condition.

2.1.2 CLINICAL FEATURES OF PERIODONTITIS

The relationship between the accumulation of bacterial plaque and the development of gingival inflammation was established in the landmark experimental studies of Löe et al. (1965) and Theilade et al. (1966). The clinical features of plaque-induced gingivitis reflect the cardinal signs of inflammation, including gingival erythema, oedema, tenderness and an increased bleeding tendency (Mariotti 1999). Upon removal of dental plaque, gingival inflammation will resolve. Persistence of the plaque biofilm and gingivitis may induce the onset of periodontitis in a susceptible host, under the influence of environmental factors (Ohlrich et al. 2009).

The clinical features of periodontitis may include periodontal pocketing, gingival recession, alveolar bone loss, furcation involvement, tooth mobility and drifting of teeth (Kinane et al. 2015). Periodontitis may be asymptomatic until it is severe, when symptoms such as discomfort, tooth mobility and even spontaneous tooth exfoliation may occur (Pihlstrom et al. 2005). In untreated patients, the extent and severity of destruction observed in periodontitis generally correlates with the amount of plaque and calculus present, or with the presence of local factors that hinder their removal - such as overhanging restorations (Armitage and Cullinan 2010). This contrasts with rapidly progressing periodontitis (previously known as aggressive periodontitis) where the
volume of biofilm deposits may be inconsistent with the severity of disease (Tonetti et al. 2018). Although children and adolescents occasionally develop periodontitis, it predominantly affects adults older than 30 years (Lindhe et al. 1999).

2.1.3 AETIOLOGY AND PATHOGENESIS OF PERIODONTITIS

Bacterial plaque is necessary for the onset and progression of periodontitis (Lindhe et al. 1973; Löe et al. 1965). Periodontitis is thought to be preceded by plaque-induced gingivitis, a reversible inflammatory condition (Löe et al. 1965). However, not all patients with gingivitis develop periodontitis, even those who carry putative pathogenic bacteria (Cullinan et al. 2003). The pathogenesis of periodontitis is largely dependent on the host immune response to bacterial plaque (Kinane 2001). As such, an individual’s susceptibility to periodontitis is primarily influenced by his/her immune response, but modified by local and systemic risk factors.

The pathogenesis of periodontitis may be modified by a number of systemic risk factors, which influence the innate immune, adaptive immune, and healing responses (Knight et al. 2016). Cigarette smoking and poorly controlled diabetes mellitus are the strongest risk factors for periodontitis (Genco and Borgnakke 2013). Other putative risk factors include metabolic syndrome, osteoporosis, immunosuppression, and emotional stress (Kinane et al. 2006).

2.1.4 CLINICAL DIAGNOSIS OF PERIODONTITIS

Clinical and radiographic assessments are central to periodontal diagnosis (Armitage 1996). Clinical assessments involve visual inspection of the gingiva for evidence of inflammatory changes, manifesting as differences in colour, contour and consistency. A periodontal probe is then used to measure the three parameters listed below, usually at six sites per tooth (Armitage 2004a):

1. Probing pocket depth (PPD), the distance from the gingival margin to the base of the probeable gingival crevice;
2. Gingival recession (GR), the distance from the cemento-enamel junction (CEJ) to the gingival margin; and
3. Clinical attachment level (CAL), the distance from the CEJ to the base of the probeable gingival crevice.

Other relevant clinical measurements include bleeding on probing (BOP), furcation involvement and tooth mobility (Pihlstrom et al. 2005).

Radiographic examination allows visualisation of alveolar bone loss (Mol 2004). Radiography also assists with the detection of local predisposing factors that hinder the removal of plaque, such as defective restorations and calculus. The most commonly used imaging modalities for periodontal diagnosis are periapical, posterior bitewing and panoramic radiographs.

The clinical and radiographic data are collated to make a diagnosis. For nearly two decades, the clinical diagnosis of periodontitis was based upon a classification system from the 1999 International Workshop on Classification of Periodontal Diseases (Armitage 1999). This classification differentiated among four phenotypes of the disease: ‘necrotising periodontitis’; ‘chronic periodontitis’; ‘aggressive periodontitis’; and ‘periodontitis as a manifestation of systemic diseases’. Periodontal diagnoses using this classification considered the disease’s severity and extent. Severity was determined using CAL and PPD, and classified as mild, moderate or severe. The extent was classified as generalised or localised, loosely based upon whether more or fewer than 30% of sites were involved (Armitage 1999).

Recently, a new classification scheme for periodontal and peri-implant diseases and conditions was proposed after the 2017 World Workshop on the Classification of Periodontal and Peri-implant Diseases and Conditions (Caton et al. 2018; Tonetti et al. 2018). It was developed to update the existing classification and incorporate current and emerging evidence. Accordingly, ‘necrotising periodontitis’ and ‘periodontitis as a manifestation of systemic disease’ remained separate forms, but chronic and aggressive periodontitis were termed ‘periodontitis’, because of a lack of evidence to support a pathophysiological distinction between them (Tonetti et al. 2018).

The 2017 World Workshop classification proposes a staging and grading system for periodontitis which incorporates multiple factors that may influence a patient’s management (Tonetti et al. 2018). The staging of periodontitis involves its severity,
complexity and extent. The proposed framework for periodontitis staging is shown in Table 2.1.

The severity of periodontitis is determined by the amount of interdental CAL, the degree of radiographic bone loss, and the number of teeth lost to periodontitis. The complexity score considers factors such as deep PPD, vertical bone loss, furcation and ridge defects, and occlusion, all of which can complicate periodontal therapy. Finally, the extent of disease is classified in a similar way to the Armitage (1999) classification; the descriptor ‘generalised’ is assigned when more than 30% of teeth are involved, and ‘localised’ is used when fewer than 30% of teeth are affected. The term ‘molar/incisor pattern’ may also be assigned when an early-onset or rapidly destructive form is suspected (Tonetti et al. 2018). Once the severity, complexity and extent of periodontitis have been determined, one of four stages may be assigned: Stage I (initial periodontitis); Stage II (moderate periodontitis); Stage III (severe periodontitis with potential for additional tooth loss); or Stage IV (advanced periodontitis with extensive tooth loss and potential for loss of dentition).

Once staged, periodontitis is graded. The grading is an appraisal of its likely rate of progression. It is unique to the 2017 World Workshop Classification. Grading aims to identify those individuals whose disease may progress more rapidly than the majority of the population, or who may respond less predictably to periodontal therapy (Tonetti et al. 2018). The proposed framework for periodontitis grading is shown in Table 2.2. Grading is primarily based upon direct evidence of progression obtained from longitudinal data, such as radiographic bone loss or CAL, if available. If direct proof is unavailable, indirect evidence such as the relationship between biofilm deposits and the level of periodontal destruction is used. The grade may then be modified by risk factors such as smoking and diabetes. Initially, all patients are assumed to be Grade B (moderate rate of progression) until the evidence is considered, when it may shift the grading towards Grade A (slow rate of progression) or Grade C (rapid rate of progression).
Table 2.1. Framework used to stage periodontitis according to the 2017 World Workshop on Classification of Periodontal and Peri-implant Diseases and Conditions, taken from Tonetti et al. (2018)

<table>
<thead>
<tr>
<th>PERIODONTITIS STAGING</th>
<th>Stage I: Initial Periodontitis</th>
<th>Stage II: Moderate Periodontitis</th>
<th>Stage III: Severe Periodontitis with potential for additional tooth loss</th>
<th>Stage IV: Advanced Periodontitis with extensive tooth loss and potential for loss of dentition</th>
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<tr>
<td><strong>Severity</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Interdental CAL at site of greatest loss</td>
<td>1 to 2 mm</td>
<td>3 to 4 mm</td>
<td>≥ 5 mm</td>
<td>≥ 5 mm</td>
</tr>
<tr>
<td>Radiographic bone loss</td>
<td>Coronal third (&lt;15%)</td>
<td>Coronal third (15% to 33%)</td>
<td>Extending to mid-third of root and beyond</td>
<td>Extending to mid-third of root and beyond</td>
</tr>
<tr>
<td>Tooth loss</td>
<td>No tooth loss due to periodontitis</td>
<td>Tooth loss due to periodontitis of ≥ 4 teeth</td>
<td>Tooth loss due to periodontitis of ≥ 5 teeth</td>
<td></td>
</tr>
<tr>
<td><strong>Complexity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local</td>
<td>Maximum probing depth ≤ 4 mm</td>
<td>Maximum probing depth ≤ 4 mm</td>
<td>In addition to stage II complexity:</td>
<td>In addition to stage III complexity:</td>
</tr>
<tr>
<td>Mostly horizontal bone loss</td>
<td>Mostly horizontal bone loss</td>
<td>Probing depth ≥ 6 mm</td>
<td>Need for complex rehabilitation due to:</td>
<td>Masticatory dysfunction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vertical bone loss ≥ 3 mm</td>
<td>Secondary occlusal trauma (tooth mobility degree ≥ 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Furcation involvement class II or III</td>
<td>Severe ridge defect</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moderate ridge defect</td>
<td>Bite collapse, drifting, flaring</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Less than 20 remaining teeth (10 opposing pairs)</td>
<td></td>
</tr>
<tr>
<td><strong>Extent and distribution</strong></td>
<td>Add to stage as descriptor</td>
<td>For each stage, describe extent as localised (&lt; 30% of teeth involved), generalised, or molar/incisor pattern</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2.2. Framework used to grade periodontitis according to the 2017 World Workshop on Classification of Periodontal and Peri-implant Diseases and Conditions, taken from Tonetti et al. (2018)

<table>
<thead>
<tr>
<th>PERIODONTITIS GRADING</th>
<th>Grade A: Slow rate of progression</th>
<th>Grade B: Moderate rate of progression</th>
<th>Grade C: Rapid rate of progression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary criteria</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct evidence of progression</td>
<td>Longitudinal data (radiographic bone loss or CAL)</td>
<td>Evidence of no loss over 5 years</td>
<td>&lt; 2mm over 5 years</td>
</tr>
<tr>
<td>% bone loss/age</td>
<td>&lt; 0.25</td>
<td>0.25 to 1.0</td>
<td>&gt; 1.0</td>
</tr>
<tr>
<td>Indirect evidence of progression</td>
<td>Case phenotype</td>
<td>Heavy biofilm deposits with low levels of destruction</td>
<td>Destruction commensurate with biofilm deposits</td>
</tr>
<tr>
<td><strong>Grade modifiers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk factors</td>
<td>Smoking</td>
<td>Non-smoker</td>
<td>Smoker &lt; 10 cigarettes/day</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>Normoglycaemic/no diagnosis of diabetes</td>
<td>HbA1c &lt; 7.0% in patients with diabetes</td>
</tr>
<tr>
<td><strong>Risk of systemic impact of periodontitis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inflammatory burden*</td>
<td>High sensitivity CRP (hsCRP)</td>
<td>&lt; 1 mg/L</td>
<td>1 to 3 mg/L</td>
</tr>
<tr>
<td>Biomarkers</td>
<td>Saliva, gingival crevicular fluid, serum</td>
<td>?</td>
<td>?</td>
</tr>
</tbody>
</table>

*These criteria require substantiation with further specific evidence, but are expected to be integrated into periodontitis grading in future.
It is expected that the 2017 World Workshop Classification will supersede the previous diagnostic classifications for periodontitis. Other case definitions exist for epidemiological purposes, and these will be discussed in the following section.

2.1.5 EPIDEMIOLOGY OF PERIODONTITIS

There are a number of challenges in estimating the prevalence, extent and severity of periodontitis. These include disparities in epidemiological methodological approaches and inconsistent case definitions of the disease.

2.1.5.1 Periodontal indices

Various periodontal indices have been developed to measure periodontal parameters. Those such as the Gingival Index (Löe 1967; Löe and Silness 1963), the Plaque Index (Silness and Löe 1964) and dichotomous BOP indices are used to assess the condition of the gingival tissues and extent of inflammation. The Periodontal Index (Russell 1956) and Periodontal Disease Index (Ramfjord 1967) were developed to measure the loss of periodontal support. These solely employed a visual assessment of index teeth, and assumed that gingivitis would inevitably develop into periodontitis, an outdated concept. These limitations of the early indices led to a decline in their use (Burt 1993).

The Community Periodontal Index of Treatment Needs (CPITN) was developed to classify the periodontal treatment needs of population groups (Ainamo et al. 1982). It was later revised to become the Community Periodontal Index (CPI), to reflect its widespread use in recording the presence or absence of periodontal disease (World Health Organization 1997). Although the CPI was simple, convenient, reproducible and superior to previous indices, it also had many shortfalls (Petersen and Ogawa 2005). Firstly, it did not record CAL and relied only upon PPD to define periodontal disease (Dye 2012). Its coding was hierarchical, assuming that sites with deepened PPDs (codes 3 and 4) also had BOP (code 1) and calculus (code 2), which may not always be the case (Leroy et al. 2010; Lewis et al. 1994). The CPI used measurements at index teeth only, and so is likely to have underestimated the prevalence of periodontitis. Moreover, it overlooked other important clinical parameters, such tooth mobility and furcation involvement. This has reportedly underestimated the extent and severity of periodontal
disease in older individuals where past disease and treatment has led to gingival recession and overestimated disease in younger individuals (Gera 2000).

2.1.5.2 CAL, PPD and BOP
In 2005, the World Workshop on Periodontology concluded that the recording of a single periodontal variable was insufficient for periodontal epidemiology (Tonetti and Claffey 2005). A combination of PPD, CAL and BOP have been suggested as the most appropriate (Leroy et al. 2010). CAL represents cumulative disease experience, whereas PPD and BOP represent the presence of current disease. Ideally, these measurements should be taken at six sites per tooth.

2.1.5.3 Full-mouth and partial-mouth recordings
Periodontal measurements may be taken from the whole mouth, or selected parts only (Leroy et al. 2010). Although partial-mouth recordings (which may range from half-mouth to specific index teeth) have the advantages of being time-efficient and economical, they assume that the condition of the examined area corresponds to that of the whole mouth. Comparisons of partial and full-mouth data have shown that partial-mouth measurements underestimated the prevalence and severity of periodontal disease (Eke et al. 2010; Kingman et al. 2008; Susin et al. 2005). The degree of underestimation depended on the number of sites examined, with a greater difference noted when fewer sites were recorded (Demmer and Papapanou 2010; Kingman and Albandar 2002; Susin et al. 2005). In order to reduce partial assessment bias, an inflation factor calculation has been suggested, but the calibrated collection of full-mouth data at six sites per tooth remains the gold standard (Demmer and Papapanou 2010; Susin et al. 2005).

2.1.5.4 Self-reported measures
Self-reporting has been used in surveillance studies of periodontal disease. It is considered simple, efficient and low-cost, and so practical for large-scale surveys (Blicher et al. 2005). Evidence suggests self-report measures may be a promising alternative when clinical examinations are not practical. In a birth cohort of 38-year-old New Zealanders, a set of four periodontal self-report questions (Appendix I) was evaluated against clinical periodontal findings (Foster Page et al. 2016). When used as a
set, these questions had moderate predictive validity, with low sensitivity but high specificity. However, relative to clinically measured periodontal disease, the self-report questions underestimated the relative risk for periodontitis in smokers.

Other studies have evaluated the performance of self-report measures to predict periodontitis. A systematic review of studies which validated such measures against periodontal examination data found that findings differed according to the population and self-report measure used (Blicher et al. 2005). One recent study compared self-reported periodontal data against the clinically-determined periodontal status of adults in the United States (US; Eke et al. 2013). When socio-demographic variables were considered concurrently, the self-report measures could predict periodontitis with moderate-strong validity. Incorporating these other predictors of periodontitis, such as socio-demographic data or risk factors may indeed improve the predictive validity of self-report measures (Blicher et al. 2005). Foster Page et al. (2016), however, questioned the wisdom of this, since self-report measures are frequently used to measure differences according to those very characteristics. The inclusion of socio-demographic or behavioural variables into the self-report measure itself would thus render it ineffective for the reporting of self-reported periodontal disease according to those variables. Nevertheless, these and other studies suggested that self-report measures alone may be appropriate for population surveillance of periodontitis (Dietrich et al. 2007; Genco et al. 2007; Taylor and Borgnakke 2007).

2.1.5.5 Case definitions for periodontitis

A universally accepted case definition for periodontal disease does not exist. Accurate estimation of the periodontitis prevalence has been hampered by large variations in case definition and difficult data comparison (Eke et al. 2012; Page and Eke 2007). Costa et al. (2009) found that the prevalence estimates ranged from 13.8 to 65.3%, depending on the periodontitis case definition, using the same dataset. In recognition of these concerns, certain groups have attempted to develop case definitions for periodontitis that limit ambiguity and allow direct comparison between studies (Eke et al. 2012). The periodontitis case definitions devised by the Centers for Disease Control and Prevention (CDC) and the American Academy of Periodontology (AAP; Table 2.3) are one such example (Eke et al. 2012). In addition, a single case definition was proposed at the recent
2017 World Workshop on the Classification of Periodontal and Peri-implant diseases and conditions (Tonetti et al. 2018). This definition considers a patient as a periodontitis case if interdental CAL is detectable at ≥2 non-adjacent teeth, or buccal or oral CAL ≥3mm with pocketing >3mm is detectable at ≥2 teeth.

Table 2.3. The CDC-AAP (Centers for Disease Control and Prevention – American Academy of Periodontology) case definitions for surveillance of periodontitis (Eke et al. 2012)

<table>
<thead>
<tr>
<th>Case</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>No periodontitis</td>
<td>No evidence of mild, moderate, or severe periodontitis</td>
</tr>
<tr>
<td>Mild periodontitis</td>
<td>≥ 2 interproximal sites with CAL ≥3mm, and ≥ 2 interproximal sites with PPD ≥4mm (not on the same tooth) or one site with PPD ≥5mm</td>
</tr>
<tr>
<td>Moderate periodontitis</td>
<td>≥ 2 interproximal sites with CAL ≥4mm (not on the same tooth), or ≥ 2 interproximal sites with PPD ≥5mm (not on the same tooth)</td>
</tr>
<tr>
<td>Severe periodontitis</td>
<td>≥ 2 interproximal sites with CAL ≥6mm (not on the same tooth), and ≥ 1 interproximal site with PPD ≥5mm</td>
</tr>
</tbody>
</table>

2.1.6 PREVALENCE OF PERIODONTITIS

Mild or moderate chronic periodontitis reportedly affects a substantial proportion of adults worldwide, with the prevalence estimates ranging from 13% to 57% (Albandar et al. 1999; Corbet and Leung 2011; Petersen and Ogawa 2012; Sheiham and Netuveli 2002). The Global Burden of Disease Study found severe periodontitis was the sixth most prevalent disease, affecting 11% of the world’s population in 2010 (Marcenes et al. 2013). Periodontitis is unequally distributed among different age, sex, racial, ethnic and socio-economic groups (Demmer and Papapanou 2010; Grossi et al. 1995). In a recent report which summarised prevalence data from the 2009 to 2012 National Health and Nutrition Examination Survey (NHANES) in the US, 46% of adults had periodontitis (Eke et al. 2015). The overall prevalence of severe chronic periodontitis was 8.9%, but
higher rates were observed in males, older individuals, current smokers, ethnic minorities, and those with lower income and education levels.

In New Zealand, periodontitis is also a common finding, where one in two adults are affected to some extent (Ministry of Health 2010). In the 2009 Oral Health Survey, PPD and CAL were measured at three sites per tooth, excluding third molars. The prevalence of any deepened PPD (≥4mm) among dentate adults was 33.5%; moderate PPD (≥5mm) was 10.5%; and deep PPD (≥6mm) was 5.1%. One in two adults were found to have some degree of CAL. The prevalence of moderate (≥5mm) and severe (≥6mm) CAL was 27.5% and 13.4%, respectively (Ministry of Health 2010). Moreover, in accordance with the global findings, there were significant disparities in prevalence: Māori and Pacific Islanders were at least twice as likely to be affected than those of European descent (Knight et al. 2015) and those of lower socio-economic status (SES) or who were long-term smokers were at a higher risk (Thomson et al. 2013).

2.1.7 TREATMENT OF PERIODONTITIS
Periodontal therapy aims to eliminate clinically detectable signs of periodontal inflammation and arrest further destruction of the periodontium, while achieving improvements in clinical parameters such as PPD, which hinder self-performed plaque removal. Periodontal treatment may be divided into three main phases. Each is briefly described below.

2.1.7.1 Phase I periodontal therapy
Phase I treatment aims to remove microbial biofilm and the local factors which hinder plaque removal, including calculus, defective restorations and root surface irregularities (Morrison et al. 1980). This phase is also known as initial, non-surgical or cause-related therapy, since the disruption of the causative agent (plaque biofilm) should lessen inflammation and help achieve periodontal stability (Dentino et al. 2013). This is achieved with thorough scaling and root debridement, which uses various instruments to systematically clean supra- and subgingival tooth and root surfaces (Pihlstrom 2001). Other individualised considerations are made, such as the medical and smoking history. Smoking cessation advice is offered at every visit, and liaison with other health
professionals may be required to assist patient management, such as in those with poorly controlled diabetes mellitus.

An important component of this stage is providing the patient with appropriate information and oral hygiene advice. Adequate daily plaque removal by the patient is decisive for successful periodontal treatment (Lindhe et al. 1982; Nyman et al. 1977). Phase I treatment is effective for reducing inflammation and PPD, particularly in mild to moderately severe cases (Heitz-Mayfield 2005). Healing after scaling and root debridement may continue for several months, so adequate time should be allowed, prior to re-evaluation and formulation of an updated treatment plan (Badersten et al. 1981).

At re-evaluation, periodontal healing is assessed using the same parameters as the initial examination. Re-evaluation includes an assessment of the appearance and texture of the gingiva, presence of plaque and calculus deposits, measurement of PPD and CAL, as well as BOP and suppuration on probing (Caffesse et al. 1995). Patients with good resolution of the inflammatory lesion may proceed to the supportive phase. Where persistent inflammation is associated with accessible residual calculus deposits, localised selective debridement may be repeated prior to re-evaluation after a further healing period (Caffesse et al. 1995). Alternatively, if localised inflammation and deep PPD persist, Phase II therapy may be considered.

2.1.7.2 Phase II periodontal therapy

Also known as the surgical or corrective phase, Phase II involves correction of aberrant changes to the oral structures caused by periodontal disease. This includes periodontal surgery to improve visual access for debridement, resection or regeneration of the lost tissues, where appropriate. Periodontal surgery is generally not indicated in patients with poor plaque control (Nyman et al. 1977). This stage may also include restorative or occlusal treatment (Pihlstrom 2001). Once active Phase II therapy is complete, the patient may proceed to the supportive phase.
2.1.7.3 Supportive phase

The supportive phase involves regular reassessment to assist in early detection of clinical changes (Renvert and Persson 2004). Each visit may consist of re-evaluation of the clinical parameters and removal of all plaque and calculus deposits (Pihlstrom 2001). Another important objective of the supportive phase is to reinforce oral hygiene advice and maintain patient motivation (Renvert and Persson 2004). Lack of appropriate supportive periodontal maintenance has been associated with failure of treatment and recurrence of disease (Axelsson and Lindhe 1981; Lindhe et al. 1984).

2.1.8 CONCLUSION

Periodontitis is characterised by irreversible destruction of the tooth supporting tissues, and is a leading cause of tooth loss. Epidemiological data suggest that periodontitis is common across the world, as well as in New Zealand. Mechanical removal of microbial biofilm underpins the basis of its treatment to prevent inflammation and immune-mediated destruction of the periodontal structures.
2.2 PATIENT-REPORTED OUTCOMES

2.2.1 INTRODUCTION

Periodontitis can affect more than one’s oral health; it may also have a significant impact on general wellbeing and quality of life. This chapter examines patient-reported outcomes, which consider the impact of a disease and its treatment on an individual.

2.2.2 MODELS OF HEALTH AND DISEASE

The provision of healthcare can be considered to be guided by models of health and illness. A disease may be defined as a somatic abnormality which affects the structure or function of a body part, which is diagnosed and treated by a clinician (Eisenberg 1977). Illness refers to an individual’s perceived state of poor health. Although disease and illness often occur simultaneously, patients may present with an illness which is not attributable to any detectable clinical pathology, such as chronic fatigue syndrome. Conversely, patients may suffer from an underlying disease, such as hypertension, without feeling ill (Eisenberg 1977; Mead and Bower 2000). While several models have been proposed, the biomedical and the biopsychosocial models of illness are most commonly adopted, usually implicitly.

2.2.2.1 The biomedical model

Western medicine in the 20th century was based upon the biomedical model of disease, which asserted that all disease arose from an underlying biochemical abnormality in the body. Health was considered the absence of disease (Wade and Halligan 2004). The mind and body were treated separately, and the body was considered a machine, which could undergo repairs (Engel 1977). The biomedical model focussed on the diagnosis and treatment of the disease, rather than understanding the illness. The correct diagnosis and treatment of the pathology was assumed to cure the patient’s illness (Mead and Bower 2000). Its focus on pathological mechanisms overlooked the impact of social and psychological factors on health and disease.
2.2.2.2 The biopsychosocial model

Since the World Health Organization (WHO) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” in 1948, the multi-dimensional aspects of health have been considered. The biopsychosocial model of disease was proposed by Engel (1977) and has since become largely accepted within the medical profession. Engel, a psychiatrist, proposed a model with a more holistic view of health and wellbeing. The biopsychosocial perspective incorporated the influence of social and psychological factors into the patient’s experience of illness, and acknowledged the reciprocal relationship between the mind and the body, while recognising that disease and illness may exist independently of each other (Mead and Bower 2000; Wade and Halligan 2004).

Engel observed that a grieving patient often had both psychological and physical symptoms. This example was used to support the theory that somatic effects may be brought about by a psychosocial event (Engel 1977). Thus, the biopsychosocial model encouraged a patient-centred approach where the unwell person was considered as a whole. This model may be used to examine the psychosocial effects of chronic diseases, such as periodontitis, as the patients’ social, psychological and biological factors are all taken into consideration (O'Dowd et al. 2010).

The paradigm shift from the biomedical to the biopsychosocial model led to the development of instruments that measure the holistic concept of health (such as health-related quality of life, HRQoL), which are used in combination with traditional clinical indicators (Testa and Simonson 1996). Since they are centred around social roles and the optimal functioning of individuals, these measures address some of the limitations of previous, biomedically-based health measures.

2.2.2.3 Conceptual models of health and disease

Conceptual models are theoretical frameworks used to measure health status, and which consider the complex relationships among the multiple dimensions that underpin health.

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One commonly referenced model, the Wilson and Cleary Model, offers a biopsychosocial perspective, by combining biomedical and socioenvironmental paradigms (Wilson and Cleary 1995). This model consists of five major dimensions (biological, symptoms, function, general health perception and HRQoL) and two less-defined domains involving individual and environmental characteristics. Ferrans and colleagues (2005) adapted and simplified the model to further define and harmonise the relationships among the various domains.

### 2.2.2.4 Locker’s conceptual model of oral health

In 1980, the WHO published its International Classification of Impairments, Disabilities and Handicaps (ICIDH), a comprehensive categorisation of various consequences associated with health conditions (World Health Organization 1980). These were organised into a hierarchy, which ranged from local symptoms and/or anatomical changes, to broader effects on interpersonal and social behaviours.

 Locker adapted the WHO ICIDH classification to oral health, in order to document the behavioural and psychosocial consequences of oral disorders (Locker 1988). This model included information about symptoms of pain and discomfort, and the impact of oral disease on the function of the oral cavity, which had largely been neglected by the clinical outcome measures. Locker’s model (Figure 2.1) consisted of the seven conceptual domains of functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicap.

![Diagram of Locker’s conceptual model for measuring oral health (Locker 1988)](image.png)

**Figure 2.1.** Locker’s conceptual model for measuring oral health (Locker 1988)
Locker’s model recognised the relationships among the above-mentioned conceptual domains, and arranged them into the above framework. ‘Disease’ may lead to an ‘impairment’, which is an abnormality or loss of anatomical structure. Examples of impairments within periodontics include CAL and tooth loss. These impairments may then cause ‘discomfort and pain’, and/or ‘functional limitation’. Pain and discomfort are self-reported and may be physical (such as tooth sensitivity) or psychological, including self-consciousness about one’s teeth or mouth (Slade and Spencer 1994). A ‘functional limitation’ is a restriction of the function(s) normally expected of the body, or its component parts (Locker 1988). Difficulty chewing is a functional limitation which commonly arises due to oral diseases. In turn, pain and discomfort and/or functional limitations may cause disability.

Locke (1988) defined disability as a limitation in, or inability to perform, the activities of daily living. This concept was further sub-divided into physical, psychological and social disability. ‘Physical disabilities’ included the impact of an oral condition on an individual’s ability to speak or eat. The term ‘psychological disabilities’ incorporated changes to emotional states (such as anxiety, depression and fatigue), as well as altered cognitive functioning (such as difficulties with concentration and decision-making; Locker 1988). Psychological effects such as these may be brought about by the experience of acute or chronic dental pain. ‘Social disabilities’ referred to the impact of disease on the frequency and/or quality of an individual’s interaction with others, such as avoiding speaking to strangers or attending social functions.

The final outcome of disease in Locker’s model was ‘handicap’. While ‘disability’ signified the direct consequences of disease for an individual, handicap considered the effects of disease in a broader social context (Locker 1988). Central to the concept of handicap was the disadvantage experienced by a disabled person in areas such as personal relationships, employment and self-esteem.

Locke’s conceptual model hierarchically described the social impact of oral disease. In essence, an individual’s progression through the above social impacts in a linear way may lead to handicap. Similarly, an individual who experienced both ‘functional limitation’ and ‘pain or discomfort’, was more likely to experience disability (Slade and Spencer 1994). Although the model depicted the relationships between impacts using...
linear arrows, Locker (1988) emphasised that these, in reality, were not always linear. For example, a facial disfigurement may cause handicap without any accompanying disability, functional limitation, pain or discomfort.

Locker’s model was central to the development of a number of OHRQoL measures, such as the Oral Health Impact Profile (OHIP), which will be discussed in more detail. Towards the end of his life, Locker favoured the Wilson and Cleary model over his one\(^2\).

### 2.2.3 THE PATIENT-CENTRED APPROACH

The paradigm shift towards the biopsychosocial model led to the development of the patient-centred approach to patient care. It is an approach which is focussed on and guided by each individual’s experience, preference and values (Barry and Edgman-Levitan 2012). Stewart et al. (1995) proposed a model of patient-centred care based upon five core principles. The first of these involved investigating the patient’s experience, understanding and expectations of their disease and illness. The second considered the broader psychosocial context, to understand the patient as a whole person (Mead and Bower 2000). The other features of the patient-centred approach included a clinician-patient partnership (which involved patients in their treatment decisions), the inclusion of health promotion elements, and a strong interpersonal relationship with the patient (wherein the power and responsibilities were shared; Little et al. 2001). This approach has shown to improve patient satisfaction and treatment outcomes (Little et al. 2001; Oates et al. 2000).

### 2.2.4 PATIENT-REPORTED OUTCOMES

Just as patient-centred care has promoted patients’ involvement in their own healthcare decisions, health outcomes research has also shifted focus to outcomes which are more relevant to patients. Patient-reported (or patient-centred) outcome measures are subjective assessments of a patient’s own health status, which are not interpreted by another person (US Department of Health and Human Services 2006). Patient-reported

\(^{2}\) Professor WM Thomson, personal communication, April 2018.
outcomes (PROs) have been used in medical research for decades, and have recently been adopted in dental research.

More than 40 years ago, Cohen and Jago (1976) advocated for the development of ‘sociodental indicators’ in oral epidemiology, in order to measure important non-clinical aspects of disease. They commented that the oral health indices available were largely concerned with the measurement of biological impact, rather than impact on function or wellbeing. In addition, recognition of the social consequences of oral diseases would aid in obtaining funding to improve oral health outcomes, through dental care and research (Reisine 1985). Some early studies that measured the social impact of oral diseases drew upon Parsons’ (1951) Sick Role theory to quantify the hours of work lost due to dental disease (Reisine 1984; 1985).

Since this time, measures of the psychosocial impact of oral health conditions have evolved, and in 2003, PROs were identified as a research priority area by the World Workshop on Emerging Science in Periodontology (Lang and Zitzmann 2012). In 2004, Hujoel argued that true endpoints should be tangible and meaningful to patients, and so they should be the focus of periodontal clinical trials, instead of surrogate outcome measures. The ultimate goal of periodontal therapy is to preserve teeth, which is directly beneficial to the patient, as opposed to the reduction of PPDs, which may be undetectable by them.

### 2.2.4.1 Overview of PROs

Although objective clinical measures of disease (such as PPD) are important and relevant to clinicians, they represent just one aspect of the holistic concept of health. PROs assess the subtle outcomes that are more significant to patients in their daily lives (Ng and Leung 2006), such as their perceptions of their illness, treatment, or the outcome of an intervention (Higgins and Green 2008).

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3 A true endpoint is an outcome which relates directly to how a patient feels, functions, or survives. True endpoints are noticed by the patient themselves, and include self-reported symptoms, or events such as tooth loss (Hujoel 2004).

4 Surrogate endpoints are substitutes for true outcome measures used in clinical trials, such as changes in PPD or CAL, which cannot be determined by a patient (Hujoel 2004).
PROs tap into various factors, all of which are subjective and can be difficult to quantify (McGuire et al. 2014). Gwaltney (2010) arranged the various types of PROs into a continuum, ranging from disease-specific to generic (Figure 2.2). The simpler PROs at the lowest end of the spectrum include reports about specific signs and symptoms, such as gingival enlargement, pain or dentinal hypersensitivity. Functional limitations include impairments related to the disease or its treatment, such as difficulties with mastication or speech (Gwaltney 2010). Treatment satisfaction is more conceptual and may concern aspects of treatment, aesthetics or adverse effects (Higgins and Green 2008). PROs at the generic end of the spectrum include global measures of health status, which consider the contribution of broader social, psychological or emotional dimensions to the patient’s perception of wellbeing. These are also organised from specific to generic, as in OHRQoL, HRQoL and general quality of life.

**Figure 2.2.** Schematic depiction of types of patient-reported outcomes, ranging from disease-specific to generic measures (Gwaltney 2010)

### 2.2.4.2 Instruments used to measure PROs

PRO data may be obtained using interviews, diaries, or, self-completed questionnaires. Many items within PRO instruments employ measurement scales, such as visual analogue or Likert scales, which may then be used to calculate a total score (Lang and Zitzmann 2012). The timing of data collection is also important, and multiple
assessments are usually required to capture differences in outcomes over time, such as in comparing pre- and post-treatment scores (McGuire et al. 2014).

As stated earlier, PRO measures are classified in a spectrum between condition-specific and generic health outcome measures. Generic health outcome measures are advantageous because they allow direct comparison with other medical or dental interventions. However, they overlook effects that are unique to particular therapies, such as non-surgical periodontal treatment (Lang and Zitzmann 2012). Condition-specific measures are often more sensitive to these subtle differences between various treatment approaches, although they cannot be easily used for comparisons with different interventions or populations (Allen 2003). These differences mean that the choice of measure may be dictated by the situation at hand (McGuire et al. 2014).

Psychometric testing is required to develop PRO measures which are reliable (free from error), valid (measure what they propose to measure) and capable of reflecting a change in patient status with a change in score (Gwaltney 2010). The OHIP is a good example of such a measure. Two reviews of PRO measures in implant dentistry reported a lack of utilisation of standardised instruments, such as the OHIP (De Bruyn et al. 2015; McGrath et al. 2012). Rather, many of the PRO instruments used were heterogeneous, non-standardised ‘ad-hoc’ measures, whose psychometric properties had not been verified. The use of these measures precludes direct comparison or meta-analysis with results from other studies. Furthermore, non-standardised measures may emphasise certain outcomes, such as pain, and thus overlook the wider physical, psychological and social impact (McGrath et al. 2012).

### 2.2.4.3 Uses of PROs

PROs have advantages both in clinical research and in practice. They are a valuable tool to help understand the patient’s perspective, as improved clinical outcomes may not necessarily align with improvements in how the patient functions or feels (US Department of Health and Human Services 2006). In clinical trials of new interventions, PROs may be used as an outcome measure, particularly when there are no other methods to measure the benefit of the treatment, such as when evaluating the efficacy of analgesics (Higgins and Green 2008).
In clinical practice, PRO data provide an insight into the patient’s perspective on their illness, and whether the provided care is fulfilling their needs (Lang and Zitzmann 2012). The data can be used to enhance communication by using examples of other patients’ experiences and involving patients in the decision-making process (Gabriel and Normand 2012). Utilisation of PRO data in practice has shown to improve patient satisfaction and adherence to the recommended intervention (Valderas et al. 2008). Further, PRO data may be valuable in gaining informed consent, and be used to inform government policymakers or third-party payors about the benefits of a particular treatment (Lang and Zitzmann 2012).

2.2.5 PROS IN PERIODONTICS

Recently, the importance and need for patient evaluation of outcomes in periodontal research has been recognised by many authors (Davies et al. 2005; Heitz-Mayfield et al. 2002; Oates et al. 2003). PROs used in periodontal research have included post-operative pain, analgesic use, aesthetics, and overall satisfaction with treatment (McGuire et al. 2014; Tonetti et al. 2004; Wessel and Tatakos 2008), but the most commonly used and well-known generic PRO is OHRQoL.

2.2.5.1 HRQoL

Quality of life is inherently difficult to define because it can have a different meaning for any given individual. Locker suggested using answers to a simple question, “how good is your life for you?” to identify the factors that embody that individual’s perspective on quality of life (Locker 1997).

HRQoL is a framework which acknowledges the importance of health in a person’s life, and can be used to inform measurement of the impact of disease on a person (Atchison 2002). There is no single accepted definition for HRQoL despite its wide use in the literature, particularly in the context of chronic diseases (Kyrkou 2014). HRQoL is a multidimensional concept, encompassing various aspects of life, including physical, functional, psychological, social, spiritual and sexual wellbeing (Ashing-Giwa 2005). HRQoL measures use patient self-report as a tool to measure self-perceived health.
HRQoL instruments measure the aspects of disease that are familiar and relevant to patients, rather than the physiological measures of interest to the health professional. They measure the impact of a disease, and/or effects on a particular population, function or problem, which may be generic or specific (Guyatt et al. 1993). They measure both negative and positive effects and can be used to evaluate treatment outcomes. HRQoL data are crucial in improving clinical care, and may have additional applications, such as screening patients for psychosocial effects, and guiding the allocation of health resources (Fitzpatrick et al. 1992).

2.2.5.2 OHRQoL

OHRQoL is a subset of HRQoL that relates specifically to oral conditions. It emerged in the 1980s with the accrual of evidence in support of a relationship between oral diseases and psychosocial wellbeing (Bennadi and Reddy 2013). OHRQoL was defined as the “impact of oral diseases and disorders on aspects of everyday life that a patient or person values, that are of sufficient magnitude, in terms of frequency, severity or duration to affect their experiences and perception of their life overall” (Locker and Allen 2007).

OHRQoL is a subjective, multi-dimensional construct of oral health, emotional wellbeing, function, and satisfaction with treatment (Sischo and Broder 2011). It is used to assess an individual’s perception and experience of an oral condition, including his/her sense of self, and its effect on his/her daily life (Bennadi and Reddy 2013). OHRQoL considers the impact of orofacial conditions on wellbeing across four dimensions: functional, psychological, social, and experience of pain and discomfort (Inglehart and Bagramian 2002). As with HRQoL, the concept of OHRQoL has a number of applications in clinical practice and research, and can be beneficial when evaluating the effects of a particular therapy.

2.2.5.3 Assessment of OHRQoL

Owing to the subjective nature of OHRQoL, data collection uses patient-self report, but can be achieved using different OHRQoL instruments.
2.2.5.3.1 Global self-ratings

Global self-ratings of OHRQoL consist of a single item, which asks participants a general question about their oral health. One common method asks participants to rank their oral health on a five-point categorical scale ranging from excellent to poor (Figure 2.3; Appendix II; Locker 2001). Despite the benefits of brevity and simplicity, ideal for large-scale epidemiological studies, global ratings have some disadvantages. As the single answer represents a summary measure of a person’s perception of their overall health (which incorporates both objective and subjective aspects) individuals may weight these aspects differently (Kaplan and Baron-Epel 2003; Locker et al. 2005). For example, some patients may perceive ‘excellent’ oral health as having no pain, whereas others may report ‘poor’ oral health based on the appearance of their teeth alone. Conversely, this freedom of interpretation can be perceived as a strength of global measures, as it allows participants to assimilate multiple dimensions and personally evaluate their important aspects of oral health (Slade 2002). Global self-ratings can be used to predict health outcomes and health care utilisation (Locker et al. 2005). They are routinely used to validate new multi-item scales, and it has been suggested that they may be as valuable as other, more comprehensive OHRQoL measures (Thomson et al. 2012).

<table>
<thead>
<tr>
<th>How would you describe the health of your teeth or mouth?</th>
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<tbody>
<tr>
<td>Excellent</td>
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Figure 2.3. Locker’s global oral health item (Locker, 2001)

2.2.5.3.2 Multi-item scales

Researchers have developed and validated multi-item scales to measure OHRQoL. These complex and sophisticated instruments explore the multiple dimensions of OHRQoL using specialised questions, and may be specific or generic (Bennadi and Reddy 2013). The former may be further classified into those specifically used for certain populations or conditions, such as the Child OHRQoL Questionnaire (Jokovic et al. 2002) and the Orthognathic Quality of Life Questionnaire (Cunningham et al. 2000). No periodontal-
specific measures have yet been validated, so generic OHRQoL measures are most commonly used in the periodontal literature (Slade and Spencer 1994). The generic questionnaires are designed to gather information on the broad impact of oral diseases on an individual’s life, and include the OHIP, Geriatric Oral Health Assessment Index (GOHAI; Atchison and Dolan 1990) and Oral Impacts on Daily Performances (OIDP; Adulyanon and Sheiham 1997).

The GOHAI was initially designed for use in geriatric populations, and is not commonly used in periodontics. The OIDP is a sophisticated and complicated measure, which may have precluded its widespread use. The OHIP is simplest and most widely used, although its prohibitive length led to the development of its short form, the OHIP-14. The OHIP and OHIP-14 (which was selected for the present study) will be discussed in greater detail below.

2.2.5.4 The OHIP

The OHIP has been used extensively to measure OHRQoL. Based upon Locker’s conceptual model of oral health (Locker 1988), it was developed by Slade and Spencer (1994) to measure the self-reported dysfunction, discomfort and disability that may arise as a consequence of an oral condition (Locker and Allen 2007). The OHIP focused on the adverse impact of oral disorders on an individual’s social, psychological and physical wellbeing, and did not include any scope to measure positive outcomes (Locker 1997).

2.2.5.4.1 Development of the OHIP

Development of the OHIP questionnaire began with a series of qualitative interviews with 64 adult dental patients in Adelaide, Australia. This group was a non-representative convenience sample, intentionally selected for maximum experience of oral conditions. Patients within this group were asked open-ended questions about their experiences of oral conditions and any resultant adverse impacts (Slade and Spencer 1994). Throughout these interviews, patients generated 535 statements which represented various ways that their oral diseases had impacted upon them. These statements were then analysed and grouped according to their common themes. This process of reduction produced a set of 46 statements, each a description of one particular impact. These were then categorised
into seven sections according to Locker’s conceptual model of health: functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability and handicap (Locker 1988). Since only 1% of the statements obtained from the interviews fit into the category of handicap (Slade and Spencer 1994), an additional three statements were incorporated from another source (Hunt et al. 1986). The resulting 49 statements formed the OHIP-49.

A strength of the OHIP is how the statements were gathered from the patient groups (Allen 2003). Asking patients directly to comment on the ways their oral health had impacted them generated patient-centred information which captured the values and opinions of the patients themselves. However, Locker and Allen (2007) argued that the subsequent reduction of the statements was expert-centred, because the statements were arranged to fit into Locker’s conceptual framework. This may have resulted in the inclusion of some redundant items, or the exclusion of some items which were, in fact, highly relevant to patients.

2.2.5.4.2 Question and response structure of the OHIP

The 49 items that make up the OHIP are phrased as questions, such as ‘Have you had difficulty chewing any foods because of problems with your teeth, mouth or dentures?’ (Slade and Spencer 1994). When participants complete the questionnaire, they are asked to record how frequently they have experienced each impact within a defined reference period. Their responses are scored on a five-point Likert scale (0 = ‘never’, 1 = ‘hardly ever’, 2 = ‘occasionally’, 3 = ‘fairly often’, and 4 = ‘very often’). Questions which pertain to dentures include an additional ‘non-applicable’ response item for those who do not wear dentures. Items left blank, or scored ‘I don’t know’ are assigned the mean response to other questions, unless there are more than nine missing items, which necessitates rejection of the questionnaire.

2.2.5.4.3 Weighting of the OHIP

During the development of this instrument, each of the 49 items was assigned a weight. The purpose of weighting was to ensure that the relative importance of each impact was reflected; a severe toothache would be recognised as a more significant impact than
temperature sensitivity (Slade and Spencer 1994). The weighting scores were derived using Thurstone’s (1927) method of paired comparisons. The items were paired in all possible configurations, and a panel of 328 residents of Adelaide were each asked to choose the most unpleasant impact from each pair. These were then mathematically converted into a positive numerical weight for each statement.

This weighting process has also been criticised as expert-centred (Locker and Allen 2007). The panel used to judge the severity of these statements was made up of community members, dental practitioners and students. These individuals were not the same initial group whom identified their own personal impacts, and may have ranked severity differently, depending on their own experiences. Although weighting may improve our ability to interpret the results of OHRQoL measures, values may differ between individuals and even within the same individual over time (Carr and Higginson 2001). Therefore, placing a static weight on an impact may be problematic, because it may not accurately reflect the true importance for a given individual.

2.2.5.4.4 Scoring of the OHIP

A higher OHIP score indicates a greater frequency of negative impacts and thus a poorer OHRQoL. Scores from the OHIP questionnaire may be calculated in three ways (Sierwald et al. 2011). First, an overall OHIP score may be obtained by counting the number of times that responses of ‘fairly often’ or ‘very often’ are selected. This method, known as the OHIP Simple Count (OHIP-SC), simplifies the scoring process into a dichotomous score by introducing a threshold level. However, the distribution of these responses in some populations may not be uniform and may preclude parametric statistical calculations (Slade 1997b). The second method, the OHIP Additive (OHIP-ADD) is the most commonly used, and is an ordinal score derived from the sum of the response items (0-4). The final method is the weight-standardised (OHIP-WS) and is the most complex. The OHIP-WS is calculated by multiplying the response score (0-4) by the weight for each statement. The resultant scores are summed to give a sub-scale score for each of the seven sections of the questionnaire. These sub-scale scores are then standardised to a mean and standard deviation of one before they are added together to produce a summary score (Allen et al. 2001).
The OHIP-WS method considers the severity of impact by incorporating the weighting of each statement (Allen et al. 2001). Moreover, the standardised OHIP-WS scores are more suitable for parametric statistical testing (Slade 1997b). However, the calculation of these scores can be complicated, and may involve additional computer programming. Allen and Locker (1997) compared the discriminant, concurrent and predictive validity of the three scoring methods. Their findings showed that the OHIP-ADD and OHIP-WS methods were similarly effective, and the OHIP-SC method was the weakest. This validated and promoted use of the OHIP-ADD in clinical situations, because it reduced complex unwarranted calculations.

2.2.5.4.5 Reliability of the OHIP

During the development of the OHIP, Slade and Spencer (1994) evaluated the reliability of the instrument in a randomly selected sample of 122 adults aged 60 and above. Reliability was tested by examining internal consistency and stability. Internal consistency ensures that similar responses arise from questions on similar topics. The internal consistency of the OHIP was measured using Cronbach’s (1951) reliability coefficient α, and high reliability coefficients (0.70-0.83) were reported for all subscales except for handicap, which was 0.37. These findings suggested that the OHIP was a reliable tool for measuring OHRQoL. Test-retest reliability, or stability, was assessed by repeating the questionnaire to a random subsample of 46 participants 3 months later. Intraclass correlation coefficients ranging from 0.42 to 0.77 were generated in all subscales, except for social disability, which gave a much lower value of 0.08. The correlation of the OHIP scores across the two administrations thus reflected questionable stability for most subscales, and poor stability for social disability.

2.2.5.4.6 Validity of the OHIP

Validity considers whether an instrument actually measures what it intends, and in the case of the OHIP, whether it measures the social impact of oral conditions. Slade and Spencer (1994) measured the validity of the OHIP using the above-mentioned group of 122 individuals, by comparing their responses from the OHIP to those obtained from another questionnaire, named Social Impacts of Dental Disease, which also measured social impact (Cushing et al. 1986). At baseline, the participant’s perceived need to visit
a dentist was correlated with a higher social impact score on the Social Impacts of Dental Disease scale. The OHIP was then administered to that sample and the resulting scores were compared between participants who felt they did and did not need to see a dentist. The OHIP subscale scores recorded by those who perceived a need were approximately double of those who did not. This difference was statistically significant in five of the OHIP subscales, with the exception of physical disability (Slade and Spencer 1994). This demonstrated high construct validity of the OHIP as demonstrated by the association between lower OHRQoL scores and a greater perceived need to visit a dentist.

Other studies supported these findings, including one in older adults in Ontario, Canada (Locker and Slade 1993). The OHIP has been translated into many languages and validated for use in these populations (John et al. 2002; Larsson et al. 2004; Lopez and Baelum 2006; Wong et al. 2002).

2.2.5.4.7 The Short-Form Oral Impact Profile (OHIP-14)
The OHIP-49 is a detailed and extensive measure, which takes an average of seventeen minutes for a participant to complete (Slade and Spencer 1994). Most clinical and research applications demand a less time-consuming instrument to facilitate administration and improve response rates. The OHIP-49 has thus been condensed into a shorter version (Slade 1997a). The OHIP-14 (Appendix III) was derived from the OHIP-49 by eliminating items unique to denture-wearers, and those which were frequently answered poorly. The remaining items were then subjected to regression analyses, generating a smaller subset of questions which captured as much information as possible. These questions were arranged in the same seven subscales as the OHIP-49, representing the domains of Locker’s conceptual model of oral health.

The remaining fourteen questions underwent validity testing to ensure that the psychometric properties were not markedly affected. This showed that the OHIP-14 was as effective as the OHIP-49 in detecting associations with clinical and social factors in the population studied (1217 adults aged 60 and above, from South Australia; Slade 1997a). Further research has been conducted in order to test the precision, reliability and validity of the OHIP-14 in other populations, including Brazilian adults (Oliveira and Nadanovsky 2005), Spanish adults (Montero-Martín et al. 2009), Malaysian adults (Saub
et al. 2005), edentulous patients (Allen and Locker 2002), patients with temporomandibular disorders (Segù et al. 2005) and for dental aesthetics (Wong et al. 2007). These and other studies conducted since then have established the OHIP-14 as the most-used oral PRO.

2.2.6 OHRQoL AND PERIODONTITIS

Studies investigating the association between periodontitis and OHRQoL aim to understand the consequences of the disease, beyond the traditional biomedical outcomes. There has been a growing interest on the impact of periodontitis and periodontal treatment on OHRQoL.

2.2.6.1 The impact of periodontitis on OHRQoL

Studies have consistently shown an association between having periodontitis and poorer OHRQoL, in small clinical samples and larger representative populations.

Numerous non-representative clinical studies have reported an association between periodontitis and OHRQoL (Aslund et al. 2008; Brennan et al. 2007; Cunha-Cruz et al. 2007; da Silva Araújo et al. 2010; Jowett et al. 2009; Needleman et al. 2004; O'Dowd et al. 2010; Patel et al. 2008; Reisine et al. 1989; Tsakos et al. 2010; Brauchle et al. 2013; Durham et al. 2013; Lopes et al. 2009). In one study, 90% of participants reported that their oral health status had impacted on their quality of life, measured with the United Kingdom OHRQoL (OHRQoL-UK) measure (Needleman et al. 2004). Moreover, an association between the number of teeth with deep pockets and lower OHRQoL scores was found. The study did not have a periodontally healthy comparison group, and it used a small private practice patient sample, so the findings’ generalisability was limited.

A recent cross-sectional study of 433 Swedish adults showed an association between radiographic alveolar bone loss and OHRQoL, using the OHIP-14 (Jansson et al. 2014). Although some probing depths were recorded, the periodontal condition of participants was classified according to a radiographic assessment of marginal bone height. Radiography is typically used as an adjunct to a full periodontal chart, rather than a lone
diagnostic tool, due to limitations largely related to the fact that a radiograph is a two-dimensional representation of a three-dimensional object (Mol 2004).

Using a birth cohort of 924 32-year-old New Zealand adults, Lawrence et al. (2008) showed an association between tooth loss, the ultimate endpoint of periodontitis, and poorer OHRQoL. The OHIP-14 was administered and the frequency of impairment (‘fairly often’ or ‘very often’) were analysed separately by sex. Periodontal attachment loss was associated with OHRQoL, which was stronger in females than males. Nearly one quarter (23%) of the participants reported frequent impairment during the previous four weeks, as a result of their oral condition. A systematic review and meta-analysis found a similar association between tooth loss and poorer OHRQoL, which was independent of the OHRQoL measure used (Gerritsen et al. 2010).

Al-Harthi and colleagues (2013) comprehensively reviewed observational epidemiological studies that examined the association between periodontitis and OHRQoL. Their analysis included seven studies of prospective and cross-sectional design that used representative samples (Bernabé and Marcenes 2010; Brennan et al. 2007; Lawrence et al. 2008; Lopez and Baelum 2006; Mariño et al. 2008; Ng and Leung 2006; Slade et al. 1996), after omitting those which did not clearly describe clinical recording methods, case definitions and OHRQoL reporting methods. Their critical analysis and comparison of the studies was impeded by the diversity of case definitions. Notably, all but one study (Mariño et al. 2008) reported a negative association between periodontitis and OHRQoL.

A recent systematic review further supported an association between periodontitis and OHRQoL, by examining 37 observational studies and clinical trials (Buset et al. 2016). Despite considerable heterogeneity between studies (including their sampling method, OHRQoL instrument used, clinical periodontal measurements and adjustment for confounding factors such as dental caries), a significant biological gradient between periodontal diseases and OHRQoL was found in 28 of the 37 studies. Further, a significant dose-response relationship between greater severity or extent of disease and greater impact on OHRQoL was observed in seven studies (Al Habashneh et al. 2012; Bernabé and Marcenes 2010; Eltas and Uslu 2013; Jansson et al. 2014; Palma et al. 2013; Saletu et al. 2005; Zhao et al. 2011).
Despite the wide variation in study methods and quality, it can be concluded that periodontitis has a negative effect on OHRQoL. A biological gradient between the severity of periodontal disease and OHRQoL appears to exist, although further research is required to confirm this.

2.2.6.2 Non-surgical periodontal treatment and OHRQoL

A large number of studies have reported short- to medium-term improvements in OHRQoL after non-surgical periodontal therapy (Aslund et al. 2008; Brauchle et al. 2013; D'avila et al. 2005; Goel and Baral 2017; Jowett et al. 2009; Makino-Oi et al. 2016; Mendez et al. 2016; Needleman et al. 2004; Ozcelik et al. 2007; Pereira et al. 2011; Saito et al. 2010; Tsakos et al. 2010). Others reported conflicting findings, where initial periodontal treatment did not have a positive effect on OHRQoL scores (Bajwa et al. 2007; Ohrn and Jonsson 2012).

Periodontal therapy may also have a dose-dependent effect on OHRQoL, since treatment may have a greater positive effect on the OHRQoL of patients with more severe disease (Brauchle et al. 2013). In a longitudinal study that compared OHIP-14 scores of a cohort of patients with moderate-advanced periodontitis to those of a dentally healthy cohort, the baseline OHIP scores were greater in the periodontitis group (Jowett et al. 2009). Once the periodontitis cohort underwent root debridement, their OHIP-14 scores improved but remained poorer than those of the dentally healthy cohort. These positive changes in OHRQoL after periodontal therapy may persist for twelve months (Wong et al. 2012). Improvements were the greatest in ‘psychological’ and ‘pain’ domains, but small positive changes were also noted within the other five domains of the OHIP. Other authors reported similar findings, but also observed significant improvements in the ‘functional’ domain (Aslund et al. 2008; Saito et al. 2010).

A recent systematic review included eleven studies to examine the impact of periodontal treatment on OHRQoL (Shanbhag et al. 2012). Nine studies showed that non-surgical periodontal therapy resulted in a moderate improvement in OHRQoL; Bajwa et al. (2007) reported a trend for improvement of OHRQoL after non-surgical periodontal therapy which did not reach statistical significance; while Ohrn and Jonsson (2012) found periodontal treatment had no significant effect on OHRQoL. Nevertheless, the authors
concluded that periodontal treatment was beneficial from a patient-centred perspective. A meta-analysis was not undertaken because of the heterogeneity of the studies.

2.2.6.3 Surgical periodontal treatment and OHRQoL

Data on the effect of surgical periodontal treatment on OHRQoL are scarce. A Japanese pilot study found that the patients’ OHRQoL did not further improve from additional surgery, after completing non-surgical therapy (Saito et al. 2011). On the other hand, in a study of 68 ‘high-risk’ Indian periodontitis patients, surgical therapy brought about improvements in OHRQoL scores (Nagarajan and Chandra 2012). A Turkish group found patients who had surgical therapy alone reported worse OHRQoL than those who underwent non-surgical treatment, or surgical therapy combined with application of enamel matrix protein derivatives, in the immediate post-operative period (Ozcelik et al. 2007). Surgical therapy was associated with more physical pain, which in turn impacted on the physical disability and psychological wellbeing of the participants.

2.2.7 CONCLUSION

There has been a shift to a more patient-centred focus in health care and research. Development of PRO instruments has allowed documentation of patients’ own perceptions of their illness and treatment; among these, OHRQoL is the most commonly used in the periodontal literature. Existing data collectively suggest that periodontitis is associated with poorer OHRQoL; however, treatment may improve OHRQoL. These data may be used to improve patient motivation and adherence (Jowett et al. 2009). However, the instruments used to measure OHRQoL are generic, and are not specifically designed to measure the psychosocial impact of periodontal disease. It is therefore possible that they may overlook the issues that are central to patients with periodontal disease. Qualitative research methods have been recommended to identify the relevant issues among patient groups, which may then be used to develop appropriate periodontal-specific OHRQoL instruments (Locker and Allen 2007).
2.3 AN OVERVIEW OF QUALITATIVE RESEARCH METHODS

2.3.1 INTRODUCTION

Conventional research was dominated by the natural sciences, often at the expense of the social sciences (Bedos et al. 2009). Quantitative research methods have been criticised, because their focus on objectivity and reproducibility meant that data were often irrelevant and inapplicable to individuals, unless applied under strictly controlled conditions (Guba and Lincoln 1994). Since quantitative research methods test existing hypotheses, they may hinder the discovery of new theories or perspectives, and are thus less applicable to the social sciences (Guba and Lincoln 1994). On the other hand, qualitative research methods may address these shortcomings, and provide an alternative approach.

2.3.2 DEFINITION OF QUALITATIVE RESEARCH

Qualitative research has been described as “a situated activity that locates the observer in the world” (Denzin and Lincoln 2000). In other words, it is the holistic examination of social or human phenomena (Creswell and Plano Clark 2011). The data collection methods are interpretive and used to create a complex representation of the world. Qualitative research is conducted in the natural setting to aid in the interpretation of phenomena as they are experienced by the participants themselves (Denzin and Lincoln 2000).

2.3.3 RESEARCH PARADIGMS

Quantitative research is generally concerned with numbers, and qualitative with words (Miles and Huberman 1994). However, the true distinction lies in the fundamental philosophies which underpin them, termed their research paradigms (Willis et al. 2007).

A research paradigm is a set of ‘worldview’ assumptions or beliefs which guide the research practice (Guba and Lincoln 1994). These assumptions are inevitable and are inextricable from the research itself, and they influence research direction, methods and
outcomes (Carter and Little 2007). A research paradigm is characterised by three branches of metaphysics\(^5\): ontology, epistemology and methodology (Guba and Lincoln 1994). These three philosophical principles differ in their assumptions. Ontology is concerned with the nature of being or existence and its assumptions reflect different views of reality (Willis et al. 2007). Epistemology questions the nature, sources and justification of knowledge. It is concerned with topics such as what comprises knowledge, and how people come to know things (Chamberlain 2015). Methodology refers to the nature of methods used to pursue this knowledge (Guba and Lincoln 1994).

Various research paradigms exist, but this discussion will be limited to the three common paradigms of postpositivism, critical theory, and constructivism. An understanding of these paradigms assists in clarification of the definition between qualitative and quantitative research methods. The key metaphysical characteristics of these paradigms are summarised in Table 2.4.

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<th>Postpositivism</th>
<th>Critical Theory</th>
<th>Constructivism</th>
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<td><strong>Nature of reality</strong></td>
<td>Reality exists but is difficult to</td>
<td>Reality exists but is difficult to</td>
<td>Reality is multiple and constructed by</td>
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<td>Knowledge is constructed by the</td>
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<td>Emphasis on subjectivity</td>
<td>Subjectivity is greatly valued</td>
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<tr>
<td><strong>Nature of methods</strong></td>
<td>Preferably quantitative methods</td>
<td>Both quantitative and qualitative</td>
<td>Preferably qualitative methods</td>
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<tr>
<td><strong>(methodology)</strong></td>
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<td>methods are acceptable</td>
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\(^5\) Metaphysics is a branch of philosophy which is concerned with the fundamental nature of reality and being. (Metaphysics [Def. 1] In Merriam Webster Online, retrieved 30 June 2017 from https://www.merriam-webster.com/dictionary/metaphysics).
2.3.3.1 Postpositivism
Postpositivism was derived from positivism, and is a dominant philosophy used in health research. The postpositivist paradigm is based upon a realist ontology, which supports the view that an external, physical reality exists, and research aims to uncover truths about this reality (Willis et al. 2007). However, it acknowledges that the knowledge obtained from research is an imperfect approximation of true reality (Guba and Lincoln 1994). Postpositivists strive to test universal laws and theories that may be applied generally to other scenarios. Its epistemology is objective, which means that knowledge is gained through precise observations and measurements taken from experiences in the real world (Creswell 2003). Since objectivity is paramount, this paradigm is well suited to quantitative methods.

2.3.3.2 Critical theory
Critical theory evolved from Marxism and is centred around power relationships in society (Willis et al. 2007). This paradigm describes and critiques unjust relationships between people, to expose and rectify power imbalances. Critical theory supports a realist ontology which believes that a material reality exists external to the human mind (Willis et al. 2007). However, its epistemology is more subjective than that of postpositivism; critical theory takes an ideological viewpoint and the research process is influenced by the values of the researchers (Guba and Lincoln 1994). This ideological focus allows some methodological flexibility (Willis et al. 2007), and critical theory may employ qualitative or quantitative methods, although those which engage and empower participants are preferred (Bedos et al. 2009).

2.3.3.3 Constructivism
Constructivism is somewhat analogous to interpretivism, a term used interchangeably by some authors. The social constructivist theory differs from the previous two paradigms in that it proposes that individuals construct their own reality, in response to their social environment. It therefore acknowledges that realities are multiple, intangible and inextricable from human perception (Green and Thorogood 2014). Constructivist research aims to understand these different realities by immersing the researcher into the participants’ social and historical context, using person-to-person interaction to gather
information (Creswell 2003). The participants and researchers use tools such as language to construct meaning from their experiences (Willis et al. 2007). The interpretation of this data is influenced by the researchers’ values and background. The epistemology of constructivism is therefore subjective (Guba and Lincoln 1994) and favours qualitative methods as it aims to understand realities, rather than explain them (Green and Thorogood 2014).

2.3.4 USES AND ADVANTAGES OF QUALITATIVE RESEARCH

The defining advantage of qualitative research is its ability to generate insight into complex social phenomena including thoughts, emotions, beliefs, attitudes and behaviours (Masood et al. 2010). Qualitative methods investigate the ‘why’ and the ‘how’ that quantitative methods may overlook (Edmunds and Brown 2012). In the health context, qualitative research may be used to identify the idiosyncratic perspectives of both professionals and laypeople (Pope and Mays 1995). The qualitative researcher is in direct contact with the participants, and immersed in their natural environment. This allows a holistic interpretation of perspectives and behaviours in an uncontrolled and context-specific setting (Bedos et al. 2009). This contrasts with quantitative methodology, where data are intentionally decontextualised.

Qualitative research is useful when investigating newly emerging or poorly understood ideas (Pope and Mays 1995). Qualitative techniques—including observation, interviews and inductive processes—may be used to describe experiences, and generate theories and hypotheses (Bedos et al. 2009). Testing of these hypotheses using quantitative methods may then follow, although the reverse is also true: where quantitative research does not fully explain a phenomenon, qualitative data may complement and enrich the findings (Stewart et al. 2008).

2.3.5 CRITICISMS AND LIMITATIONS OF QUALITATIVE RESEARCH

Qualitative research has been looked upon with scepticism, particularly from those indoctrinated with a positivist paradigm, who claim that it is fictional, or a ‘mere compilation of anecdotes’ (Denzin and Lincoln 2000; Mays and Pope 1995). The main
criticisms of qualitative research are: its subjectivity and the potential for researcher bias; its lack of generalisability; and its lack of reproducibility (Mays and Pope 1995). However, qualitative research is designed with inherent strategies to address these issues. Although qualitative data are indeed subjective, the personal accounts and impressions are systematically and critically analysed (Green and Thorogood 2014). Reliability is verified using predetermined coding frameworks and/or repeat assessments by independent examiners (Mays and Pope 1995). In qualitative research, data validation is achieved by triangulation, which cross-checks data from different methods and sources (Denzin and Lincoln 2000).

The subjectivity, diversity and flexibility inherent in qualitative research has complicated the development of formal criteria to assess its quality (Dixon-Woods et al. 2004). What constitutes rigour in qualitative research has been the subject of much debate (Barbour 2001; Mays and Pope 2000). Systematic reviews of qualitative research are known as qualitative research syntheses. O’Brien et al. (2014) conducted a qualitative synthesis of previous recommendations to develop the Standards for Reporting Qualitative Research (SRQR), a list of 21 items designed to improve the reporting of qualitative research. Further, working groups such as the Cochrane Qualitative and Implementation Methods Group (Noyes et al. 2018) and Grading of Recommendations Assessment, Development and Evaluation (GRADE; Lewin et al. 2015) have recently introduced guidelines for interpretation of qualitative syntheses.

Qualitative research can be challenging. It is labour-intensive, time-consuming and costly. Attempts to answer the initial research question may in fact uncover many more questions (Stake 2010). Its personal and exploratory nature necessitates ethical consideration with respect to anonymity, confidentiality, informed consent, and the researcher-participant relationship (Richards and Schwartz 2002). In addition, when dealing with sensitive topics, the risk of emotional challenges and intrusion is high. Recently, experts have advocated for the development of ethical guidelines specific to qualitative researchers, to mitigate these issues (Sanjari et al. 2014).

Another criticism is that qualitative methods may have little influence on professional practice or policies. However, qualitative research is useful for the development and evaluation of effective health care interventions. Reviews of qualitative and mixed-
methods data have been used for the development of evidence-based guidelines, such as for the treatment of women during childbirth (Bohren et al. 2015). In dentistry, the potential of qualitative research for comprehensive understanding of phenomena and incorporation into dental public health practice has been recognised (Bower and Scambler 2007).

2.3.6 QUANTITATIVE AND QUALITATIVE RESEARCH

Four fundamental differences between quantitative and qualitative research were summarised by Firestone (1987). These include: their assumptions about the world, their purpose, their approach, and the role of the researcher. Each will be discussed.

1. Assumptions about the world
   The major difference between quantitative and qualitative research lies in their worldviews. Quantitative research is based on a positivist/postpositivist paradigm which assumes a stable, external reality. In contrast, qualitative research is underpinned by an interpretive approach, which recognises that individuals have their own, socially constructed perceptions of reality.

2. Purpose
   Quantitative research provides quantified answers to research questions (Creswell 2003). Conversely, qualitative research aims to gain insight into the ‘what’, ‘how’ and ‘why’, to understand a phenomenon from the point of view of the participants (Green and Thorogood 2014).

3. Approach
   The quantitative approach values objectivity and use of the scientific method to obtain knowledge. Quantitative experiments are usually designed to minimise bias, and are thus inherently unlikely to represent a true version of reality (Firestone 1987). On the other hand, qualitative research aims to be naturalistic, a term used to describe the study of a phenomenon within its natural environment or context (Green and Thorogood 2014). Although a number of qualitative approaches exist, they share several common features. They are focussed on empathetic understanding of an issue, and are more flexible than quantitative research methods. The subjectivity of the researcher’s interpretation is
acknowledged, and its potential effect on the data analysis is critically scrutinised, using the principle of reflexivity (Green and Thorogood 2014).

4. Researcher role

In quantitative research, the researcher assumes a distant and impersonal role to avoid bias. In qualitative research, researchers immerse themselves into the context of their study. They effectively become the 'research instrument' by interpreting their observations (Denzin and Lincoln 2000).

In addition to these key differences, quantitative and qualitative approaches differ in other philosophical and methodological ways. A comparison of the approaches is presented in Table 2.5.

**Table 2.5. Comparison of quantitative and qualitative research approaches, adapted from Bedos et al. (2009) and Bower and Scambler (2007)**

<table>
<thead>
<tr>
<th></th>
<th>Quantitative research</th>
<th>Qualitative research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Research Paradigms</strong></td>
<td>Positivism</td>
<td>Interpretivism</td>
</tr>
<tr>
<td></td>
<td>Postpositivism</td>
<td>Constructivism</td>
</tr>
<tr>
<td><strong>Purpose</strong></td>
<td>Explain, compare, and generalise</td>
<td>Understand, explore, generate hypotheses</td>
</tr>
<tr>
<td></td>
<td>Is there a correlation or statistical difference between?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What are the strongest predictors of?</td>
<td></td>
</tr>
<tr>
<td><strong>Approach</strong></td>
<td>Reductionist</td>
<td>Holistic</td>
</tr>
<tr>
<td></td>
<td>Pre-determined design</td>
<td>Flexible design to allow emergent ideas</td>
</tr>
<tr>
<td></td>
<td>Researcher’s perspective</td>
<td>Participant’s perspective</td>
</tr>
<tr>
<td></td>
<td>Focus on objective measurement</td>
<td>Focus on subjective meaning, understanding, process</td>
</tr>
<tr>
<td><strong>Sampling</strong></td>
<td>Representative sampling (probabilistic), pre-determined</td>
<td>Purposeful sampling (select information-rich cases), flexible, diverse</td>
</tr>
<tr>
<td><strong>Sample size</strong></td>
<td>Large</td>
<td>Small</td>
</tr>
</tbody>
</table>
**Research instrument**

Uses validated instruments (eg. structured questionnaires)  
The researcher is an integral part of the instrument and uses various techniques (eg. interviews and observation)

**Data collection**

Controlled setting is ensured or assumed  
Contextual factors often eliminated  
Minimises the impact of the observer on the outcome (objective, value-free)  
Control of the environment is neither possible nor desirable  
Context is important, research often in natural setting  
Generally values the interaction between the researcher and participants (subjective)

**Data**

Numbers  
Words, images

**Data Analysis**

Occurs after data collection  
Statistical analysis, results simplified  
Imposed, predetermined categories  
Occurs throughout all stages of research  
Examination of complexities to deepen comprehension of a phenomenon  
Categories and themes may emerge from the data

**Strengths**

Indicates the prevalence of a phenomenon  
May serve to predict future phenomena  
Data collection and analysis can be conducted on a large scale in a limited amount of time  
Produces rich, detailed data  
Provides a holistic view of the phenomenon under study, taking the context into account

---

**2.3.7 MIXED-METHODS RESEARCH**

Mixed-methods research is the third major methodological approach, where components of qualitative and quantitative approaches are integrated to increase the breadth and depth of findings (Johnson et al. 2007). The rationale for using a mixed-methods approach includes triangulation, corroboration, explanation and illustration of findings (Bryman 2006). Each method may offset the weaknesses of the other, allowing the researcher to capitalise on the strengths and build more robust evidence. Ultimately, this approach assists in the development of a comprehensive picture of a phenomenon (Creswell and Plano Clark 2011). Mixed-methods studies are useful for healthcare and policymakers,
for whom undisputed, generalisable outcomes data are required, but without having had the contextual information removed (Doyle et al. 2009).

Qualitative and quantitative research methods may be combined using four basic designs: convergent parallel design, exploratory sequential design, explanatory sequential design and embedded design (Creswell and Plano Clark 2011; Pluye and Hong 2014). These designs differ by the degree of interaction between the qualitative and quantitative components, including the timing and relative priority of each. These basic designs are briefly described below, and depicted in Figure 2.4.

1. Convergent parallel design
   The collection of quantitative and qualitative data is concomitant and of equal priority. The data are analysed separately and the findings are integrated during interpretation.

2. Exploratory sequential design
   Qualitative data collection and analysis are prioritised. This stage is followed by a quantitative process, which serves to confirm and generalise the initial qualitative findings.

3. Explanatory sequential design
   The quantitative method has priority, and is used first to test a concept or theory. This is subsequently supplemented by qualitative information, which may further explore, interpret or explain the results.

4. Embedded design
   A traditional qualitative or quantitative study design incorporates the collection of both quantitative and qualitative data. The supplemental data are collected either concurrently or sequentially, and are analysed separately to the major data.

An embedded design was selected for the present study, because this allowed the qualitative methods to take priority, while incorporating some supplementary quantitative data.
1. **Convergent parallel design**  
Qualitative and quantitative methods are used in parallel

2. **Exploratory sequential design**  
Quantitative methods are used to interpret qualitative findings

3. **Explanatory sequential design**  
Qualitative methods are used to explain quantitative findings

4. **Embedded design**  
Quantitative and qualitative data are collected and analysed within a traditional qualitative or quantitative design

**Figure 2.4.** Examples of the ways that quantitative and qualitative methods may be mixed, adapted from Steckler et al. (1992) and Creswell and Plano Clark (2011)
2.3.8 CONDUCTING QUALITATIVE RESEARCH

Since it is outside the scope of this thesis to provide a comprehensive review of qualitative study design, aspects relevant to this project will be briefly introduced.

2.3.8.1 Sampling

In contrast to random sampling used in quantitative research, the sample for a qualitative inquiry is purposefully selected to include information-rich participants (Patton 2005). This is not considered a weakness or source of bias; rather it is a strength, because it focuses on those who will yield the most insight. Purposeful sampling encompasses techniques such as extreme case sampling, typical case sampling, homogenous sampling and maximum variation sampling. Maximum variation sampling selects a diverse group for their different perspectives on a phenomenon of interest. This allows comparison as well as consideration of common themes among participants (Bedos et al. 2009).

The sample size used in qualitative research is usually smaller than that used in quantitative studies. In contrast to quantitative (which use probabilistic sampling and power analyses), the qualitative research sample size is often determined by the principle of saturation, which necessitates continued data collection until no new information is obtained (Morse 1995). Saturation, or data adequacy, is fulfilled when new participants no longer contribute any new information, but instead reaffirm the ideas offered by earlier participants. When designing a qualitative study, it is not possible to preemptively determine that sample size; instead, as the study progresses and comprehensive themes emerge, data collection will cease at the appropriate point (Morse 1995).

2.3.8.2 Data collection

Qualitative researchers gather information in multiple forms: through observations, interviews, documents and audio-visual materials (Creswell 2003). Observation data are collected by the researcher in the form of field notes, as they observe the phenomenon in its natural setting. Data collection methods using interviews, audio-visual materials and document analysis will be discussed in greater detail below.
Interviews may be categorised as structured, semi-structured or unstructured (Denzin and Lincoln 2000). Structured interviews follow a predetermined set of closed questions, which usually generate one of a limited number of answers, giving rise to largely quantitative data (Masood et al. 2010). Unstructured and semi-structured interviews are more commonly used for qualitative data collection. Unstructured interviews are often used in conjunction with observational methods as the researcher incorporates informal questions while in the field (Denzin and Lincoln 2000). An unstructured interview is considered analogous to a guided conversation, because the questions are not preconceived, but they emerge as the conversation takes place.

Semi-structured interviewing is the most common type, incorporating aspects of structured and unstructured interviewing. The interview is based on predetermined open-ended questions, but has the flexibility to diverge in order to gain clarification and depth of understanding of related topics as they emerge (DiCicco-Bloom and Crabtree 2006; Gill et al. 2008). Participants are invited to expand on topics that are relevant to them that may have been overlooked by the researcher (Gill et al. 2008).

Qualitative interviewing may take place in a group setting, such as a focus group, or as a one-on-one in-depth interview. Individual interviews enable the development of rapport, which facilitates the sharing of more personal information (DiCicco-Bloom and Crabtree 2006). Individual interviews are commonly used in healthcare research, where confidentiality is important. They are therefore best conducted in person, rather than by phone or video-link (DiCicco-Bloom and Crabtree 2006). Interviews ideally take place in a quiet location where the participant feels comfortable to speak openly, and they may take between thirty minutes and two hours, depending on the topic at hand (Bedos et al. 2009). To minimise disruption by notetaking, interviews are usually audio-recorded and then transcribed verbatim before the data are analysed.

During interviews, researchers can employ interpersonal communication skills, such as active listening, open body language, encouraging noises, nodding and smiling (Gill et al. 2008). Questions asked should be open-ended, neutral, sensitive and clear. Since qualitative researchers themselves are research instruments, they must take care to
minimise their own assumptions about the data (Britten 1995). Leading questions should be avoided, and interviewers should check to ensure that they have understood correctly what the participant is trying to convey.

Qualitative interviewing is a technique whereby the participant and researcher work together to give meaning to the participant’s experiences and perspectives. The strength of interviewing lies in its ability to uncover phenomena which are otherwise difficult to obtain, such as opinions, beliefs, emotions and behaviours, in great depth and detail (Bedos et al. 2009).

2.3.8.2.2 Audio-visual material
Audio and visual materials collected for qualitative research may include photographs, maps, art, video-tapes and audio recordings, including those made during observations and interviews (Creswell 2003).

2.3.8.2.3 Document analysis
Document analysis involves the review and evaluation of raw documents to extract data and develop knowledge (Bowen 2009). These documents may include newspapers, magazines, public records, advertisements, diaries and journals. Document analysis is often used in combination with other qualitative methods for triangulating data (Bowen 2009).

Patient diaries are frequently used in healthcare research, whereby participants are asked to keep a journal of their experiences. The format of the diary may be structured, with questions or guidelines to aid entries, or unstructured (Harvey 2011). Researchers usually keep in close contact with the participants throughout the diary period to develop rapport, and help the participants feel comfortable about disclosing personal information (Day and Thatcher 2009).

The fundamental benefit of diaries is that the data collection occurs in its natural context, at or near real-time (Bolger et al. 2003). This reduces retrospection error (Stone et al. 2003). Not only do diaries expose events that researchers may not otherwise be able to access, they may also provide insight into an individual’s perception and rationalisation.
of these events (Day and Thatcher 2009; Elliott 1997). The main limitation of diaries is a lack of adherence, and/or completion of entries in a timely manner, which can negate the benefits (Stone et al. 2003). Concerns about confidentiality, perceived unimportance and literacy are other barriers to the completion of diary entries (Thomson and Holland 2005).

Once diaries have helped to identify the issues that are important to participants, follow-up interview questions can then be generated about these (Carter 2002). This technique, known as the diary-interview method, allows researchers to probe deeper into the participants’ descriptions, fill gaps, check the internal validity, and expand from specific accounts to general patterns of beliefs and attitudes (Zimmerman and Wieder 1977).

Diary studies in dentistry are relatively scarce, but have been used for quantitative pain reporting for temporomandibular joint dysfunction (Aaron et al. 2006) and burning mouth syndrome (Forssell et al. 2012). Qualitative studies in dentistry which have used diaries for data collection include one New Zealand study which investigated the lived experience of Sjögren’s syndrome (Ngo et al. 2016), and those by Rodd and colleagues (2013; 2014) in the United Kingdom (UK), which used video diaries to determine the impact of dental treatment under general anaesthetic on children and their families. Both employed a diary-interview technique, supplementing the information from the diaries with that from semi-structured interviews. No study has used diaries to investigate the impact of periodontal disease on patients.

2.3.8.3 Data interpretation and analysis

Qualitative research usually produces large volumes of text data which require interpretation and analysis. Data analysis begins during the data collection phase, whereby preliminary analysis of the data influences future data collection. The focus of data analysis is not quantification; rather, it involves analytical categorisation into themes and theories (Pope et al. 2000). The approach to data analysis is dependent on the researcher’s worldview and the purpose of the study (Creswell 2003).
2.3.8.3.1 Deductive and inductive approaches

Approaches to qualitative data analysis may be broadly classified into two categories: deductive and inductive. In the deductive approach, the researcher applies a predetermined framework to the data, based upon previous knowledge or theories (Elo and Kyngäs 2008). This approach is time-efficient and appropriate where the likely responses are already known. However, this could lead to bias if the data and themes are manipulated to fit the predetermined framework (Burnard et al. 2008). The inductive approach is more flexible and more commonly used, particularly when little is known about the phenomenon under investigation (Elo and Kyngäs 2008). Inductive analysis develops themes and categories as they emerge from the data itself (Pope et al. 2000).

A number of inductive approaches exist, but one of the most frequently used is thematic content analysis. This evolved from grounded theory, a classic method developed by Glaser and Strauss (1967) which generated theories and concepts from data. Regardless of the approach to data analysis, the general steps are similar: data coding, data display, and data interpretation/verification (Miles and Huberman 1994). These are described below.

2.3.8.3.2 Data coding

The coding process involves carefully reading through the transcribed raw data to identify meaningful sections which represent possible themes, ideas or concepts (Bedos et al. 2009). A code (a word or short phrase which summarises the meaning of the section of text) is assigned and noted in the margin (Burnard et al. 2008). These are collated, reduced and refined in an iterative process, which may see codes grouped, merged or sub-divided as data collection and analysis proceeds. The data coding, or data reduction process, is in itself analytic, as it requires the researcher to decide about which sections are to be coded (Miles and Huberman 1994).

2.3.8.3.3 Data display

In this step, the coded data are condensed and organised in a way that facilitates interpretation and analysis (Miles and Huberman 1994). Often the sections of text pertaining to each code are compiled under that heading (Burnard et al. 2008). However, visual forms of data display such as matrices and graphs may also be used and were
promoted by Miles and Huberman (1994) because they facilitated comparisons and
drawing of conclusions. Computer programs such as NVivo® are available to aid in the
coding and display process (Burnard et al. 2008).

2.3.8.3.4 Data interpretation and verification
Analysis and interpretation occur throughout the previous steps as the researcher reflects
on the possible meaning of the data. Constant comparison is made by reading and re-
reading the data to aid in the discovery and understanding of themes (Burnard et al.
2008). Further data interpretation strategies include detecting patterns, clusters, and
associations between codes (Miles and Huberman 1994). Initially, any inferences made
from the data are vague, but these gradually develop into more defined and specific
conclusions as analysis proceeds (Bedos et al. 2009). The conclusions that are drawn
should be verified, either by colleagues or by participant validation (Burnard et al. 2008).

2.3.9 CONCLUSION
The paradigm that underpins the qualitative research method differs from that of the
quantitative method, in that it focuses on comprehensive, contextual understanding of a
phenomenon. This unique methodology has advantages in the investigation of complex
personal experiences such as illnesses. Qualitative methods are under-utilised in the
investigation of dental and periodontal conditions.
2.4 QUALITATIVE RESEARCH IN PERIODONTICS

2.4.1 INTRODUCTION

The biopsychosocial effects of periodontal disease have been largely overlooked in the literature. The use of qualitative methods to investigate patients’ own views on their periodontal disease and treatment is important to understand the latter’s impact, beyond the physical signs and symptoms.

2.4.2 OVERVIEW OF PUBLISHED QUALITATIVE STUDIES

A total of five qualitative studies have investigated the impact of periodontal disease. Of these, four were Swedish (Abrahamsson et al. 2008; Johannsen et al. 2012; Karlsson et al. 2009; Stenman et al. 2009), and one involved British adults (O'Dowd et al. 2010).

Abrahamsson et al. (2008) interviewed seventeen participants after diagnosis about their views of having chronic periodontitis, and their expectations of treatment. The authors used grounded theory to identify a central concept in the diagnosis of periodontitis, which they termed ‘keeping up appearances and self-esteem’. This concept described the attempts of the patients to maintain their appearance and normative values despite their diagnosis with a chronic disease. This was further related to four additional sub-categories:

1. ‘Doing what you have to do- trying to live up to the norm’
2. ‘Suddenly having a shameful and disabling disease’
3. ‘Feeling deserted and in hands of authority’
4. ‘Investing all in a treatment with an unpredictable outcome’

These themes portrayed the significant emotional toll that their diagnoses had upon the participants, and described their concerns about the proposed treatment.

A follow-up interview study was carried out in the same group of patients upon completion of their Phase I treatment (Stenman et al. 2009). These second interviews explored the patients’ experiences and perceptions of the effects of periodontal treatment, as well as their attitudes towards oral health and their future with periodontitis. This study
identified a core concept entitled ‘understanding the seriousness of the disease condition’. This was related to several subcategories and dimensions, which together comprised a conceptual model (Figure 2.5). The model depicted the transition which occurred as patients gained an understanding of their periodontal disease, which helped them to perceive some control over the situation.

![Figure 2.5. A conceptual model depicting the key concept of ‘understanding the seriousness of the disease condition’ (Stenman et al. 2009). As participants progressed through their periodontal treatment, they developed a greater awareness of the chronic disease](image)

In 2009, Karlsson et al. interviewed ten Swedish patients with periodontitis in order to describe their experiences of living with the disease. A phenomenographic approach was used to identify two categories from the data: ‘perceptions of the disease’, and ‘perceptions of having the disease under control’. The former included subcategories which described their experiences of the peri-diagnostic period and their understandings of the causes and consequences of disease. The latter, ‘perceptions of having the disease under control’, described their own perceived responsibilities, along with those of the clinical team. This study concluded that the impact of periodontal disease was lower when the patients had a greater degree of awareness and control.

Another Swedish study used qualitative interviews to explore the experiences of patients with a history of periodontitis and who had received dental implant treatment (Johannsen et al. 2012). Although much of this work focussed on the effect of tooth loss and outcomes of implant treatment, patients reported extensively on one category, termed
‘increasing oral problems – affecting well-being’. This detailed the impact of the participants’ declining oral health on their psychosocial and functional well-being, which included feelings of shame, low self-esteem and social isolation.

O’Dowd et al. (2010) examined the impact of periodontal disease on the daily lives of fourteen patients in the UK using semi-structured interviews. Most of the themes identified in that study reflected the domains of Locker’s (1988) conceptual model of oral health. ‘Stigma’ and ‘retrospective regret’ were additional themes identified by the participants, associated with their experiences of the disease. This study focussed on the impact of periodontitis itself and did not include the effect of periodontal treatment.

Collectively, these studies reported on the broad psychosocial impact of periodontitis on patients’ lives. These findings are considered and synthesised below.

2.4.3 KEY FINDINGS OF PREVIOUS QUALITATIVE STUDIES

The periodontal disease experience may be considered over three phases: the pre-treatment phase; treatment phase; and post-treatment phase.

2.4.3.1 Pre-treatment phase
The pre-treatment phase comprises patients’ experiences of having periodontitis, and throughout the diagnostic period. Pre-treatment experiences were described in the previous qualitative studies (Abrahamsson et al. 2008; O’Dowd et al. 2010; Karlsson et al. 2009; Stenman et al. 2009; Johannsen et al. 2012). The key findings from these studies are summarised in Table 2.6, and are elaborated below.
Table 2.6. Key findings from qualitative studies reporting on patients’ experiences of the pre-treatment phase

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological impact of having periodontal disease</td>
<td>Shame, worry, guilt (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Concerns about halitosis, loss of teeth while eating, and appearance (O’Dowd et al. 2010; Karlsson et al. 2009)</td>
</tr>
<tr>
<td>Social impact of periodontal disease</td>
<td>Social isolation, avoidance of social interaction (Abrahamsson et al. 2008; Johannsen et al. 2012; O’Dowd et al. 2010)</td>
</tr>
<tr>
<td></td>
<td>Holding a hand up when speaking (Abrahamsson et al. 2008; O’Dowd et al. 2010)</td>
</tr>
<tr>
<td></td>
<td>Reluctance to smile, refusing to be photographed (O’Dowd et al. 2010)</td>
</tr>
<tr>
<td></td>
<td>Difficulty with intimate relationships, work relationships (O’Dowd et al. 2010)</td>
</tr>
<tr>
<td></td>
<td>Stigma (O’Dowd et al. 2010)</td>
</tr>
<tr>
<td>Functional/physical impact of periodontal disease</td>
<td>Tooth mobility, sensitivity (O’Dowd et al. 2010)</td>
</tr>
<tr>
<td></td>
<td>Pain, bad breath (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Difficulty articulating, performing oral hygiene (Karlsson et al. 2009)</td>
</tr>
<tr>
<td>Emotions at diagnosis</td>
<td>Worry, surrealism (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Fear, shock (Abrahamsson et al. 2008; Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Astonishment, sadness, surprise (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Sensitive, worried, depressed (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Relief, confirmation (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Concern about tooth loss (Abrahamsson et al. 2008; Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Concern that treatment may be painful (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Stressed, unable to absorb information (Stenman et al. 2009)</td>
</tr>
<tr>
<td>Perceived causes of periodontal disease</td>
<td>Inherited condition (Abrahamsson et al. 2008; Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Poor general health (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Poor oral hygiene (Abrahamsson et al. 2008; Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Smoking, ageing (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Irregular dental care (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td>Blame</td>
<td>Self-blame:</td>
</tr>
<tr>
<td></td>
<td>Smoking and poor oral hygiene (Johannsen et al. 2012)</td>
</tr>
<tr>
<td></td>
<td>Retrospective regret (O’Dowd et al. 2010)</td>
</tr>
</tbody>
</table>
**Blame on previous caregivers:**
Anger, frustration and disappointment at inaction of previous caregivers (Abrahamsson et al. 2008; O'Dowd et al. 2010; Johannsen et al. 2012)
Many had sought regular dental care (Abrahamsson et al. 2008)
False security - previous clinician overlooked disease/ did not ‘sound the alarm’, told them everything was fine, ‘maltreatment’ (Abrahamsson et al. 2008)
Specialist referral sent too late (Johannsen et al. 2012; Karlsson et al. 2009)

2.4.3.1.1 Impact of having periodontitis

Patients described the ways in which periodontitis impacted on their lives, and elaborated on the psychological consequences. Many of these were common among the studies and showed the detrimental effect of periodontitis on people’s self-esteem. Most participants reported feeling worried, ashamed and guilty about their periodontal condition (Abrahamsson et al. 2008; Johannsen et al. 2012; O'Dowd et al. 2010). Many also conveyed a sense of insecurity, as they were constantly anxious about their appearance, having bad breath, or suddenly losing a tooth while eating (Karlsson et al. 2009; O'Dowd et al. 2010). In some cases, their thoughts were pre-occupied by periodontitis to the point where they almost became fixated on it (O'Dowd et al. 2010). The feelings of shame and embarrassment were often related to the perceived stigma around periodontitis. Many participants felt ashamed of their condition and were hesitant to discuss it, for fear of judgement by others (Abrahamsson et al. 2008; O'Dowd et al. 2010). They were worried that others might think that they were unhygienic because of their periodontitis (O'Dowd et al. 2010).

Patients reported resultant alterations to their social behaviours. These included avoiding social interactions and developing mannerisms to hide the appearance of their teeth, such as holding a hand over the mouth when speaking, and avoiding smiling and/or being photographed (Abrahamsson et al. 2008; O'Dowd et al. 2010).

The physical impact of periodontitis and associated effects on function were also reported similarly across the studies. Participants recorded symptoms which included tooth
mobility, halitosis, hypersensitivity and pain (Karlsson et al. 2009; O'Dowd et al. 2010). These in turn affected patients’ daily functions such as eating, speaking and performing oral hygiene (Abrahamsson et al. 2008; Karlsson et al. 2009; O'Dowd et al. 2010).

These effects of periodontitis reported by the participants across the studies can be classified according to Locker’s (1988) conceptual model of oral health, as noted by O'Dowd et al. (2010). Many of the impacts may be considered disabilities (physical, psychological or social), in addition to discomfort and functional limitations. This further reinforces the significance of the broad range of impacts that periodontitis may have on those affected by the disease.

2.4.3.1.2 Diagnosis with periodontitis
Despite the numerous ways that periodontitis affected their lives, many participants reported feelings of shock, surprise and disbelief upon diagnosis at the specialist clinic (Abrahamsson et al. 2008; Karlsson et al. 2009). The diagnosis with periodontitis was evidently a difficult time for most participants. Many felt that their disease was not severe enough to warrant the diagnosis (Karlsson et al. 2009). Others found it difficult to comprehend because they had not previously been made aware of their problems, despite regular attendance to a dentist or hygienist (Abrahamsson et al. 2008). Johannsen et al. (2012) described several participants who had been in denial about their periodontitis, although they knew, on some level, that they had the disease. Similarly, some participants in the study by Abrahamsson et al. (2008) had purposely avoided dental treatment for some time and felt relieved when the diagnosis confirmed their suspicions.

Many participants also reported feelings of worry upon their diagnosis with periodontitis. Many were worried or fearful about the possibility of tooth loss, and felt concerned that they might become edentulous (Abrahamsson et al. 2008; Karlsson et al. 2009). Some worried about the potential impact on their appearance, ability to chew, and self-esteem (Abrahamsson et al. 2008). The cost and pain associated with the proposed treatment was also a concern for some (Abrahamsson et al. 2008). Some participants reported feeling sad, stressed and sensitive at their initial appointment (Karlsson et al. 2009; Stenman et al. 2009). During the interviews, they admitted that these feelings had compromised their
ability to listen and understand the information provided (Karlsson et al. 2009; Stenman et al. 2009).

2.4.3.1.3 Blaming dental professionals for previous inadequate care

All of the studies which investigated patients’ experiences during the pre-treatment phase described participants’ frustration with and disappointment in their previous dental care providers (Abrahamsson et al. 2008; Johannsen et al. 2012; Karlsson et al. 2009; O'Dowd et al. 2010). Many had visited their dental professionals regularly but felt that they were not adequately informed about their oral condition (Abrahamsson et al. 2008; Karlsson et al. 2009). This gave them a ‘false sense of security’, because they had believed that their clinician would have told them if there was a problem (Abrahamsson et al. 2008). In addition, they were angry that referral to the specialist clinic was delayed until the late stages of the disease (Johannsen et al. 2012; Karlsson et al. 2009; O'Dowd et al. 2010). The participants described their previous dental care as incompetent and negligent (Karlsson et al. 2009) and involving physical and mental maltreatment (Abrahamsson et al. 2008). This finding is important because this frustration and blame directed towards previous caregivers was a common finding across all of the studies, and may possibly be generalised to other periodontal patients.

2.4.3.1.4 Self-blame

In addition to the blame directed at dental professionals, the participants also accepted some responsibility. This concept was termed ‘retrospective regret’ by O'Dowd et al. (2010). Although some thought that periodontitis was an inherited condition that occurred as a part of ageing, others believed periodontitis was caused by poor oral hygiene, poor general health, irregular dental care and smoking (Abrahamsson et al. 2008; Karlsson et al. 2009). Participants blamed themselves for their previous inaction and lack of awareness (O'Dowd et al. 2010). Similarly, patients regretted their former behaviour, admitting that they had been neglectful and careless with their oral hygiene (Karlsson et al. 2009) and some had avoided dental care (Abrahamsson et al. 2008). Others expressed remorse that they had continued to smoke despite being aware of its negative effect on their oral health (Johannsen et al. 2012).
2.4.3.2 Treatment phase

Patients’ periodontal treatment experiences were described in qualitative studies by Abrahamsson et al. (2008), Stenman et al. (2009) and Karlsson et al. (2009). The key findings are presented in Table 2.7.

Table 2.7. Key findings from qualitative studies reporting on patients’ perceptions of periodontal treatment

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Details详情</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of control over the situation</td>
<td>Having to trust/rely on the professionals, whether they liked it or not (Stenman et al. 2009; Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Low degree of control over treatment decisions and outcomes (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td>Expectations of treating clinician</td>
<td>To be treated with respect (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Excellent clinical skills (Stenman et al. 2009; Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Warm and positive (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Fellowship and security during treatment (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Good communication important (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Communication on an equal level (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Poor communication could influence the treatment negatively (Stenman et al. 2009; Karlsson et al. 2009)</td>
</tr>
<tr>
<td>Information given by the clinical team</td>
<td>Information should be easy to understand (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Information should be clear, motivating and inspire confidence (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Information given was enough/not enough (more may cause anxiety) (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Should be a dialogue, not too much lecturing (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Took time to understand the disease and its effects (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Appreciative of oral hygiene education/training, explanation of procedures (Stenman et al. 2009)</td>
</tr>
</tbody>
</table>

2.4.3.2.1 Lack of control

Participants initially felt that they had little control over their situation when they presented to the specialist clinic. Some were skeptical and mistrusting because they had previously been let down by the dental profession (Karlsson et al. 2009). Others considered periodontitis to be unpredictable and felt that they had little influence over
their treatment plan and outcomes (Abrahamsson et al. 2008). Nevertheless, they felt that they had no choice but to trust their new caregivers and proceed with the treatment. For some, the fact that their treatment was being done at specialist level aided the development of this trust (Stenman et al. 2009). Participants in the Karlsson et al. (2009) and Stenman et al. (2009) studies perceived increased feelings of control as they progressed through their treatment.

2.4.3.2.2 Expectations of the treating clinician

The participants expressed their feelings of humiliation upon presentation at the clinic and emphasised the importance of being treated with respect by the clinical team (Stenman et al. 2009). Participants preferred clinicians with a warm, friendly approach and a positive outlook. This aided their motivation and helped them to overcome their feelings of guilt and remorse (Stenman et al. 2009). Some perceived their relationship with the clinician to be analogous to a partnership, whereby they felt supported and secure throughout their treatment (Karlsson et al. 2009). Although the participants expected clinical skills of a high calibre, it was apparent that they also attached great importance to the interpersonal skills of the clinician (Karlsson et al. 2009; Stenman et al. 2009).

Several believed that better communication might have improved their treatment experience (Abrahamsson et al. 2008). Some participants recommended that clinicians undertake further training in psychology and interpersonal skills (Stenman et al. 2009). They preferred clear, direct communication at an adult level, rather than being treated like a child. One participant wished to be treated as a client, rather than a patient, because this commanded more respect (Stenman et al. 2009). Some also observed that poor communication might lead to negative treatment outcomes (Karlsson et al. 2009; Stenman et al. 2009).

2.4.3.2.3 Information given at the clinic

The participants noticed that their treatment involved more dedicated patient education than they had previously received (Stenman et al. 2009). This included information about periodontitis and its treatment, and oral hygiene advice. Although this was initially
difficult to grasp for some (Karlsson et al. 2009), most participants reported a gradual increase in understanding over the course of treatment (Stenman et al. 2009). While some believed the information provided to be insufficient and independently undertook further research, the others felt adequately informed, or were concerned that any more knowledge might heighten their anxiety (Karlsson et al. 2009).

The method of delivery of this information was important to the participants. They appreciated it when it was clear, easy to understand, and part of a dialogue, as opposed to a ‘lecture’ (Abrahamsson et al. 2008; Stenman et al. 2009). When they did not understand, or felt that the clinician had an unsatisfactory attitude towards the advice, their motivation and confidence in the treatment declined (Karlsson et al. 2009). Most participants appreciated the clinician taking the time to explain the proposed treatment at the start of each appointment, and provide feedback on their self-performed oral hygiene (Stenman et al. 2009).

2.4.3.3 Post-treatment phase
The post-treatment phase includes patients’ reflections on the treatment, and their outlook for the future. The key findings from this phase are presented in Table 2.8.

2.4.3.3.1 Financial cost of treatment
Most participants reported some degree of concern about the financial cost. All of the participants in the Karlsson et al. (2009) study considered their treatment to be expensive. Some recognised the ongoing costs that would be associated with regular supportive care (Stenman et al. 2009). The Swedish participants expressed frustration that their dental care was unsubsidised, while other medical conditions attracted some financial support (Abrahamsson et al. 2008; Stenman et al. 2009).
Table 2.8. Key findings from qualitative studies reporting on patients’ perceptions at the completion of periodontal treatment (post-treatment phase)

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Financial cost of treatment</strong></td>
<td>Expensive (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Injustice that dental care was not covered by the national health system (Abrahamsson et al. 2008; Stenman et al. 2009)</td>
</tr>
<tr>
<td><strong>Investment in treatment</strong></td>
<td>Time, effort, money, following advice (Abrahamsson et al. 2008)</td>
</tr>
<tr>
<td></td>
<td>Taking responsibility, no shortcuts (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Acceptance of new routines, discipline (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Investing time and effort into teeth: necessary, tedious but important (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Bad conscience (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Prepared to pay whatever the cost, saving teeth is worth the time and money (Abrahamsson et al. 2008; Stenman et al. 2009)</td>
</tr>
<tr>
<td><strong>Perception of treatment and its consequences</strong></td>
<td>Painful (Karlsson et al. 2009; Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Teeth less aesthetically pleasing (ugly, longer) after treatment (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Teeth looser, more painful, larger gaps between teeth, difficulty eating (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>A lot of effort, not much success (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>More skilfully performed than previous treatment: teeth were properly cleaned for the first time ever (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Greater understanding than before, aware of own responsibilities (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Mouth feels fresher and cleaner (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Noticed disease was improving (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Regained courage to socialise (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Smoking cessation/reduction (Karlsson et al. 2009)</td>
</tr>
<tr>
<td><strong>Future outlook</strong></td>
<td>Resignation, insecurity, anxiety about disease progression (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Worried about unpredictable outcomes of treatment (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Concerned about future loss of teeth (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Optimism/confidence about the future (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Treatment inspired hope (Karlsson et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>After treatment, possessed skills to prevent progression of disease (Stenman et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>Lack of concern because of lack of symptoms (Karlsson et al. 2009)</td>
</tr>
</tbody>
</table>
2.4.3.3.2 Investment in treatment

In addition to the financial investment, the participants invested time and effort to ensure good treatment outcomes (Abrahamsson et al. 2008; Karlsson et al. 2009; Stenman et al. 2009). For most, this was motivated by their desire to preserve their teeth (Stenman et al. 2009). While the commitment and discipline was considered tiresome, the participants understood that it was important and accepted the responsibility (Karlsson et al. 2009; Stenman et al. 2009). It weighed on the conscience of some, who felt guilty if they did not fulfil their daily oral hygiene routines properly (Karlsson et al. 2009). Despite their initial objections to the cost of treatment, many reported that the outlay had been worth it in the end (Stenman et al. 2009).

2.4.3.3.3 Perception of treatment and its consequences

The participants documented both negative and positive perceptions of the effects of periodontal treatment. Some described the treatment as painful and unpleasant, despite the use of local anaesthesia (Karlsson et al. 2009; Stenman et al. 2009). The occurrence of dentine hypersensitivity, a common post-operative side-effect, was not widely reported in either study. This is surprising, as this is one of the most commonly reported side-effects of periodontal treatment.

Some participants noticed that their teeth appeared longer and less attractive afterwards (Karlsson et al. 2009). Other negative consequences of treatment included increased mobility, pain and the development of spaces between teeth, which some felt that they were not warned about (Stenman et al. 2009). These outcomes consequently affected their physical, social and emotional wellbeing. Some participants were disgruntled that the treatment was not successful, despite their devoted time and effort (Karlsson et al. 2009; Stenman et al. 2009).

On the other hand, there was positive feedback about the post-treatment phase. A number of participants commented that the treatment was more thoroughly and expertly undertaken than before (Stenman et al. 2009). They appreciated their new understanding of periodontitis and their own responsibilities in its management. Those who smoked understood its negative impact on periodontitis - some reduced, or completely quit smoking (Karlsson et al. 2009). Many participants remarked that their mouths were
perceivably fresher and cleaner, and that their symptoms seemed to be improving after treatment (Karlsson et al. 2009). This impacted on their social wellbeing; some reported that they had resumed social activities, and others felt comfortable to share their treatment experiences with others (Stenman et al. 2009).

2.4.3.4 Future outlook
Since the management of periodontitis requires long-term follow-up, the patient’s attitude to the future may be important. In the studies which followed patients to the completion of treatment, the outlooks of the participants were divided. Some felt confident and optimistic as they believed the treatment had equipped them with the necessary skills to prevent disease progression (Stenman et al. 2009). They had accepted their responsibilities and felt they had some control over the disease prognosis (Karlsson et al. 2009). Others were ambivalent and did not perceive periodontitis to be a threatening or serious problem, due to a lack of overt symptoms and their belief that it could be easily prevented and treated (Karlsson et al. 2009). By contrast, another group of participants were anxious and worried about the potential for disease progression, and ultimately tooth loss. They lacked confidence in their ability to keep their disease under control and felt insecure because of its unpredictable nature (Stenman et al. 2009).

2.4.4 LIMITATIONS OF THE QUALITATIVE STUDIES
These five qualitative studies were bound by some limitations. All were conducted in Sweden, with the exception of the UK study by O’Dowd et al. (2010). Periodontal research from Scandinavia has documented excellent patient motivation and adherence, which may not be applicable to other populations (Löe et al. 1978). In these studies, periodontal treatment was provided by dental hygienists (Stenman et al. 2009), or unspecified providers (Karlsson et al. 2009) within a specialist setting. Total saturation of themes was reported in all studies with the exception of Karlsson et al. (2009), who suggested that the themes which arose from their final interviews were similar to those which emerged early in the study. Further, triangulation of the data was not explicitly reported and these studies did not supplement their qualitative information with quantitative data, using a mixed methods approach. Therefore, further studies are
required for corroboration of findings, particularly those using combined methods (O'Dowd et al. 2010).

2.4.5 CONCLUSION

Data from the few available qualitative studies provide treating clinicians with useful insights that can be used to improve the standard of care. The findings from the pre-treatment phase emphasise the extent of the biopsychosocial effects of periodontitis and patients’ emotional vulnerability upon diagnosis. There is a need for clinicians to act with empathy and support, while minding their manner of information delivery. Data from the treatment phase suggest that the participants perceived a low degree of control, and excellent interpersonal skills are crucial to put patients at ease. Participants’ reflections at the completion of treatment indicated that most were prepared to make a significant investment in order to preserve their dentition. Additionally, the positive and negative experiences of treatment and its consequences may be useful in other clinical scenarios, such as when obtaining informed consent. These studies collectively contribute valuable insight but have some limitations which command a need for further research in this area.
2.5 STATUS PASSAGE

2.5.1 INTRODUCTION

Status passage theory was described by Glaser and Strauss (1971), and arose from van Gennep’s (1960) ‘les rites de passage’ theory. It describes an individual’s transitions within the social system during their life. Status passages may be age-related, or pertain to one’s education, career or personal life (Tolhurst and Kingston 2013). These changes in status are often accompanied by shifts in identity, entitlement, role and behaviour (Glaser and Strauss 1971). Some examples include the transitions from adolescence to adulthood, unmarried to married, or employed to retired, as well as promotion within one’s career (Kellehear 1990). Status passage has been widely used in the literature in the context of understanding chronic illnesses (Clarke et al. 2012; Gibson et al. 2017; Kristiansen and Antoft 2016).

2.5.2 CHARACTERISTICS OF A STATUS PASSAGE

Glaser and Strauss (1971) identified that status passages were most often scheduled, regularised, and prescribed. In other words, status passages are not arbitrary in nature; they are bound by regulations and conventions which guide their timing, nature and those who may make the passage. Glaser and Strauss defined six key properties of a status passage which may be applied to the milieu of chronic illness: reversibility, temporality, shape, desirability, circumstantiality and multiplicity. These are each described below.

1. Reversibility

Because status passages are dynamic, one important consideration is whether they have the potential to be reversed (Glaser and Strauss 1971). A passage may be reversible or transient, since someone who is married may divorce, or someone who is promoted may later be demoted. Status passages may also be non-reversible, and these can be further classified into inevitable or preventable passages (Kingston 2000). Glaser and Strauss considered chronic diseases to be inevitable, irreversible passages. Tolhurst and Kingston (2013) considered
dementia in the context of status passage and reported that it was an irreversible passage which was not inevitable for all, but those with certain characteristics and lifestyle factors were predisposed to a higher risk. A similar study which examined patients with rheumatoid arthritis found that many were unfamiliar with the irreversible and inevitable nature of rheumatoid arthritis, which led to feelings of insecurity (Kristiansen and Antoft 2016).

2. Temporality
Temporal properties of status passages include the scheduling, rate and pace of the passage. Scheduled passages are anticipated, regularised and familiar, and include such events as graduation or marriage (Glaser and Strauss 1971). Conversely, non-scheduled passages are unexpected and variable, and may include the onset of a chronic condition (Tolhurst and Kingston 2013). Passage into complete tooth loss was reported to be a non-scheduled status passage which gradually became scheduled as the participants sought dental care (Gibson et al. 2017).

An awareness of the probable rate and pace of a passage is important because it informs passagees about their expected future trajectory, and it may dictate their current behaviour (Glaser and Strauss 1971). In a study of falls in later life as status passage, participants frequently asked questions of their doctor about the expected post-fall recovery (Kingston 2000). However, Glaser and Strauss emphasised that the temporality of status passages varies significantly among individuals. Expectations of an individual’s experience with a disease are guided by knowledge of its probable progression and outcomes. This is where guidance from professionals such as doctors or dentists may aid the individuals as they make the passage.

3. Shape
Glaser and Strauss (1971) described the shape of a passage as the plotted line that is formed when direction and time are named on the axes of a graph. This shape may incorporate positive and negative inclines, as well as plateaux. The person
in control of the passage attempts to regulate it, and may determine its shape. Status passages with well-defined direction and scheduling are known as prescribed passages, and are common in institutions such as schools and corporate business enterprises. Prescribed passages can be distinguished from those which lack defined direction and temporal properties, and are more difficult to control (Glaser and Strauss 1971).

The person responsible for shaping the passage may be the passagee him- or herself, or an agent with some degree of control (Glaser and Strauss 1971). In the case of chronic illness, this agent may be a health professional. During the status passage into dementia, where the direction and temporality are unpredictable, the shape of the passage is influenced by the balance of control between the person with dementia, their family and the health professional (Tolhurst and Kingston 2013). In the study of tooth loss as status passage, participants made references to the dental professionals who prescribed their status passage into complete tooth loss (Gibson et al. 2017).

4. **Desirability**

Glaser and Strauss (1971) emphasised that the desirability of a passage was largely dependent on its social and situational context. The passage may be desirable or undesirable to both the passagee and the agent, or they may take opposing views, based upon their stake in the passage. In addition, aspects of a passage may be considered separately from the passage as a whole; a largely desirable passage may have some undesirable properties.

Illnesses are mostly considered to be undesirable passages, although the passage to recovery may be seen as desirable (Glaser and Strauss 1971). The degree of control that an individual has over the passage generally increases its desirability, which may be facilitated by early diagnosis, acceptance and involvement in treatment decisions (Kristiansen and Antoft 2016; Tolhurst and Kingston 2013).
5. **Circumstantiality**

The circumstantiality of a status passage refers to the social context of the passage. Glaser and Strauss (1971) determined that passagees may proceed through a passage in one of three ways:

1. Solo;
2. As a collective, a group with defining group character; or,
3. As an aggregate, a group without common collective features.

The character of the health condition may influence the social circumstances of the passage. Stigma associated with some conditions may limit the extent to which they are discussed, and this could lead to social isolation. Alternatively, some individuals may experience a status passage in isolation because they decline professional support (Kingston 2000), or are unaware that others are experiencing the same passage (Tolhurst and Kingston 2013). In contrast, other passagees may join collectives or aggregates which are facilitated by social events such as support groups. A Danish study documented participants’ desires to meet others with the same condition (rheumatoid arthritis) to help them come to terms with their own diagnoses (Kristiansen and Antoft 2016).

6. **Multiplicity**

Individuals traverse multiple status passages at one time which may relate to one another, or exist independently (Glaser and Strauss 1971). Since many status passages are managed by institutions, the individual does not usually have to coordinate the relative priorities of the various status passages. Glaser and Strauss defined a crisis as an unexpected, undesirable status passage which takes precedence over all others. Medical events such as falls (Kingston 2000), or diagnosis with a chronic condition (Vickers 2010) have been cited as examples of crises. Once the crisis has been reconciled, passagees may resume their other passages. However, status passages in the form of chronic illnesses generally compete with these other passages, and may take priority. For example, participants with rheumatoid arthritis found it difficult to maintain the prescribed exercise regimen due to their commitments to other passages (Kristiansen and Antoft 2016). The reverse was true for many patients with dementia, who were
less able to fulfil their other passages due to limitations imposed by their condition (Tolhurst and Kingston 2013).

2.5.3 AWARENESS CONTEXT

Awareness context was documented as a separate theory by Glaser and Strauss (1964). They defined it as “the total combination of what each interactant in a situation knows about the identity of the other and his own identity in the eyes of the other”. Awareness context is closely related to status passage and was incorporated throughout the original text ‘Status Passage’ (Glaser and Strauss 1971). It has been considered by some to be an additional dimension of status passage (Tolhurst and Kingston 2013). Awareness context refers to the degree to which agents or passagees are cognisant of, or have insight into, the passage (Glaser and Strauss 1971).

2.5.3.1 Types of awareness context

Four types of awareness context were delineated by Glaser and Strauss (1964). A situation where each individual is aware of the other’s identity and/or passage, as well as their own from the other’s perspective, is referred to as an open awareness context. Early diagnosis with an illness such as dementia may increase the potential for an open awareness context, allowing patients to fully access the support available to them (Tolhurst and Kingston 2013). The pretense awareness context describes a similar situation to open awareness where both parties are fully aware, although they pretend that they are not (Glaser and Strauss, 1964).

A closed awareness context denotes a situation where one is unaware of the other’s identity, or the other’s interpretation of their identity (Glaser and Strauss 1964). In the context of status passage, a closed awareness context may occur when the passagee or agent has little knowledge or understanding of the passage (Glaser and Strauss 1971). A scenario whereby a passagee attempts to conceal his/her circumstances from family, friends or other agents may be considered a closed awareness context (Tolhurst and Kingston 2013). This may be the case for illnesses with an attached stigma, such as Human Immunodeficiency Virus (Lewis 1999).
When an individual suspects the true identity of the other, and/or the other’s view of their own identity, this is termed a *suspicion* awareness context (Glaser and Strauss 1964). This is a modification of the closed awareness context, and was reported by Gibson et al. (2017) in the context of complete tooth loss. Participants in this study suspected the reasons for their tooth loss, although these were not confirmed. The same authors introduced the concept of ‘compound awareness contexts’, which incorporated one or more aspects of other awareness contexts. An example from this study was characterised by confusion, in that participants had an open awareness that they would lose their teeth, but did not understand the underlying reasons for their tooth loss.

### 2.5.4 STATUS PASSAGE AND PERIODONTITIS

Glaser and Strauss (1971) acknowledged that the ability to arrest or prevent a passage must be considered in the context of the reversibility of that specific passage. In that regard, periodontitis is unique, because it may be considered as both undesirable (as it may be irreversible, chronic and incurable), and desirable (because it is preventable and may be stabilised with treatment and meticulous plaque control).

Using the status passage will generate insight into how it may feel to suffer periodontal disease and undergo treatment, from a patient’s perspective. As periodontitis may present with few symptoms (if any), some patients may present with a closed or suspicion awareness context, and the diagnosis with periodontitis may represent an unscheduled, undesirable passage. The shape of the passage may vary according to a number of factors, including the severity of disease and the individual’s previous experiences and willingness to adhere to treatment. The perceived stigma of periodontal disease reported by O’Dowd et al. (2010) may predispose to a reluctance to discuss their condition, rather than to undergo the passage as part of a group. Their adherence with oral hygiene and maintenance appointments may be affected by the multiplicity of their other status passages. The data collected from the participants in the present study will determine whether the concept of status passage is applicable to the diagnosis and treatment of periodontitis in this context.
2.5.5 CONCLUSION

The various dimensions of status passage have been used to gain understanding of the lived experience of some chronic illnesses and conditions, but they have not yet been applied to periodontal disease. This theory may generate further insight into the experiences of patients who are diagnosed with periodontitis.
2.6 THE PRESENT STUDY

Periodontitis is a common condition affecting New Zealanders. Previous studies have shown that its impact may extend beyond its biologic effects, since it can negatively affect patients’ OHRQoL. Gaining an insight into patients’ experiences of periodontitis and its treatment will facilitate understanding of their perspectives. Qualitative methods are beneficial for investigating such complex social and behavioural phenomena. This knowledge may be used to improve the provision of patient-centred periodontal care which is sensitive and responsive to the needs and concerns of patients. Several studies conducted in the Northern Hemisphere have investigated the effects of periodontitis on patients using qualitative interviews.

The present study aimed to investigate the individualistic psychosocial aspects of periodontitis in a New Zealand clinical sample. To the best of my knowledge, no other study has yet examined the impact of periodontitis and its treatment using patient diaries. Moreover, no single study to date has supplemented qualitative data with quantitative OHRQoL measures and clinical periodontal parameters to gain a comprehensive insight into patients’ experiences of periodontitis and its treatment. This study represents the first of its type conducted among a New Zealand sample, and the first to apply the notion of status passage, a sociological theory, to periodontitis. The next chapter will describe the methods used to conduct the research.
3.1.1 INTRODUCTION

The methods used to conduct this research are described in the following section. The steps taken in preparation for the study, including Māori consultation, ethical approval and project funding, are outlined. These are followed by a description of the data collection phase, including the mixed-methods study design, participant recruitment, the clinical periodontal appointments, and the diary and interview phases. Next, the methods used to produce and analyse the qualitative and quantitative data across these periods are detailed. Finally, the steps taken to ensure trustworthiness of the data will be considered.

3.1.2 MĀORI CONSULTATION

An application for Māori consultation was submitted to the Ngāi Tahu Research Consultation Committee in May 2016. The committee met on 7 June 2016 to discuss the research proposal and reported that this research was of importance to Māori health. The Committee made several recommendations for conducting this study, which included the collection of self-reported ethnicity data and the inclusion of a researcher experienced in data analysis by ethnicity⁶ (Appendix IV). The Committee requested a copy of the research findings and recommended dissemination of the results to relevant Māori health organisations and individuals involved in Māori dental health within the Faculty of Dentistry, University of Otago.

3.1.3 ETHICAL APPROVAL

In June 2016, an application was submitted to the University of Otago Human Ethics Committee (Health). The Committee met on 28 June 2016 and granted ethical approval conditional upon a scientific peer review of the research protocol and clarification of the proposed method of participant recruitment (Appendix V). An external peer review was

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⁶ Associate Professor Lyndie Foster Page (LFP) and Professor Murray Thomson (WMT) have extensive experience in data analysis using ethnicity information.
sought from an experienced international periodontal researcher. Responses to the peer review and an amended research protocol which explained the recruitment process were submitted to the Ethics Committee, and final ethical approval was granted on 26 July 2016 (Appendix VI; Ref. H16/072).

3.1.4 PROJECT FUNDING

In October 2016, a University of Otago Fuller Scholarship was awarded to the value of $4,000. An application to the New Zealand Dental Association Research Fund in April 2017 was successful, resulting in an International College of Dentists Award to the value of $4,100 in July 2017 (Appendix VII; Ref. RF8.07 2017).

3.1.5 MIXED-METHODS APPROACH

An embedded mixed-methods design was selected for this study, in which supplementary quantitative data were embedded within a primarily qualitative study design (Creswell and Plano Clark 2011). The qualitative and quantitative data were collected concurrently and analysed separately. During the interpretation stage, the data were mixed by considering the quantitative OHRQoL and periodontal information in the context of the qualitative findings.

3.1.6 PARTICIPANT RECRUITMENT

A list was obtained of patients referred to the postgraduate Periodontics clinic at the Faculty of Dentistry, University of Otago. The patient records and referral letters were screened by me (PH) for suitability. Those referred for conditions other than chronic periodontitis, who had previously undergone extensive periodontal treatment, or who were unable to communicate well in English were excluded. Owing to the exploratory nature of the study, a purposive sampling approach was selected, whereby participants were chosen for maximum variation to obtain depth and richness of data (Palinkas et al. 2015). In light of this, an attempt was made to include a group of heterogeneous participants who represented different sexes, age groups, ethnic groups, and periodontitis severity.
Once potentially eligible participants were identified, they were contacted by phone. The participants were informed that they were on a waiting list and their desire for treatment was confirmed. The nature and requirements of the study were explained, and those who expressed an interest to participate were sent a written information sheet (Appendix VIII) and consent form (Appendix IX) by post or email. After seven to ten days, I contacted them again to confirm their interest and answer any questions about the research. Those who wished to participate were given an appointment for an initial consultation with a postgraduate student in Periodontics.

The proposed sample size was flexible, in order to accommodate the number of participants required to achieve data saturation (Morse 1995). Participants were recruited from February to September 2017 as the interviews proceeded. Throughout this period, 24 potential participants were approached to take part in the study. One was excluded after the initial phone call due to difficulties with the English language. Three participants declined to participate upon initial contact, and a further two declined after receiving the written information sheet and consent form. The remaining nineteen participants signed consent forms and commenced the study, although five did not follow it through to completion. Two withdrew on their own accord: one due to work commitments, and one who sought treatment at a private practice. A further three participants were excluded from the study: one who failed to attend two appointments and subsequently could not be contacted, one who did not require any specialist periodontal input, and one who completed periodontal treatment but was non-adherent with the diary. At completion of the study, the sample consisted of fourteen individuals (nine females and five males). The participant recruitment process is depicted in Figure 3.1.

3.1.7 INITIAL APPOINTMENT AND QUANTITATIVE DATA COLLECTION

I met with each participant fifteen minutes prior to their initial appointment to discuss the research, answer questions and obtain signed consent. General demographic information, including age, self-reported ethnicity, gender and occupation was collected. The participants were then asked to complete the OHIP-14 questionnaire (Slade 1997a; Appendix III), Locker’s global oral health item (Locker 2001; Appendix II) and four self-report periodontal screening questions (Foster Page et al. 2016; Appendix I).
Figure 3.1. Schematic diagram illustrating the stages in participant recruitment, with withdrawals and exclusions at each stage
The subsequent periodontal consultations were conducted by postgraduate students in Periodontics, all of whom had undergone a calibration process at the commencement of their training. A comprehensive history and examination was undertaken for each participant according to the standard protocol of the Department, which included clinical photographs and radiographs (usually a full-mouth periapical series). A baseline periodontal examination was undertaken, with measurements taken at six sites per tooth and recorded on a physical periodontal chart. PPD (the distance from the gingival margin to the base of the probeable gingival crevice) and GR (the distance from the cemento-enamel junction to the gingival margin) were measured using a Williams probe. BOP was recorded as present or absent at six sites per tooth after measurement of PPD. Tooth mobility was also recorded for each tooth, from grade 0 to 3 according to Miller (1950). Furcation involvement was measured clinically (at two sites for mandibular molars and three sites for maxillary molars) using a Nabers probe and classified according to Lindhe and Nyman (1975).

The clinical findings were used to formulate a treatment plan for each individual. This invariably included initial non-surgical debridement by quadrant or half-mouth, and oral hygiene advice. Other treatment was planned according to each participant’s individual needs. I was not involved in the clinical treatment of any participant.

3.1.8 DIARY PHASE

At the initial appointment, each participant was issued with a research pack which contained guidelines for the diary entries (Appendix X) and their choice of diary: a portable audio recording device with instructions, or a hard-covered journal with pens and coloured pens. Participants were also given the options to record video diaries using their own smart device, or to send typed diary entries by email.

Participants were encouraged to document their diagnosis and treatment for periodontal disease in a way that might help the researchers understand their experiences. The diary guidelines were intended to help the participants get started, by providing them with a general list of possible topics they could report on, and loose suggestions for the frequency of entries. The diary entry phase continued until their Phase I non-surgical
periodontal therapy was completed. The duration of this period differed substantially among participants due to appointment scheduling. I kept in regular contact with the participants throughout this time by email, phone, or text message. The purpose of this was to discuss diary entries, answer questions, improve adherence, and maintain rapport with the participants.

Upon completion of Phase I non-surgical treatment, I collected the diaries from the participants and transcribed/typed them word-for-word into a Microsoft Word® document. The diary data from each participant were used to generate a list of key topics for their interview.

3.1.9  INTERVIEW PHASE

3.1.9.1  Quantitative data collection
All interviews were conducted within one month of the completion of Phase I therapy. Immediately prior to their interview, each participant completed the OHIP-14, four self-report periodontal questions, and Locker’s global oral health item, in the same format as those which were administered at baseline.

3.1.9.2  Semi-structured interviews
All participants completed a one-on-one semi-structured interview with me. Twelve interviews were conducted face-to-face, and two were conducted by phone, for the participants who lived out of Dunedin, to avoid additional travel and inconvenience. The face-to-face interviews took place in a neutral, non-clinical conference room and were conducted with minimal disruptions. All interviews were recorded with two high-quality recording devices used simultaneously to ensure that a back-up recording was available in the event of device failure. Upon completion, participants were given a supermarket voucher for a nominal amount as a token of appreciation for their participation in the research. Immediately after the interview, I made notes of non-verbal cues or contextual details which may not have been captured on the audio recording.

Participants were informed that the purpose of the interview was to discuss and clarify their diary entries, and to gain an understanding of their experiences of periodontal
disease diagnosis and treatment. All participants were reminded of their right to refuse to answer any questions they were not comfortable with, and ask questions of their own.

The semi-structured interviews were conducted in a conversational style using open-ended questions and a flexible, evolving interview guide. The interview questions examined participants’ views and experiences across three study periods: the pre-diagnostic phase, the treatment phase, and the future. An example of the topics included in the interview guide is presented in Table 3.1. The participants were invited to discuss the ways that having periodontitis and periodontal treatment had impacted on them. Additional topics for the interview guide were derived from each participant’s diary entries. The early interview guides were reviewed by the primary research supervisor (LFP) prior to each interview. As each interview proceeded, the data were constantly compared with those from previous diaries and interviews. The interview guides thus became more sophisticated as they were informed by the previous diaries and interviews, and themes began to emerge.

Data collection and analysis were conducted simultaneously and the interviews continued until no new information arose (data saturation). All diary and interview data were de-identified using a code number for each participant and stored on a secure cloud-based server (Syncplicity®).

3.1.9.3 Clinical follow-up appointment
Each participant attended a clinical follow-up appointment with their treating clinician to review the outcome of non-surgical therapy, after an interval determined by the clinician. At this appointment, an examination and periodontal chart were completed, whereby the same clinical parameters which were measured at the baseline examination (PPD, GR, BOP, furcation involvement and mobility) were repeated. If the participants required any further periodontal treatment, this was planned and discussed at this appointment.
Table 3.1. Overview of topics included in the interview guide

<table>
<thead>
<tr>
<th>Pre-treatment phase</th>
<th>Treatment phase</th>
<th>Post-treatment phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Becoming aware of gum problems</td>
<td>Emotions prior to the appointment</td>
<td>Mindset/ attitudes towards the future</td>
</tr>
<tr>
<td></td>
<td>Feelings</td>
<td>Positive/negative</td>
</tr>
<tr>
<td></td>
<td>Symptoms</td>
<td>Oral hygiene requirements</td>
</tr>
<tr>
<td></td>
<td>Actions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Timing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Influence of others</td>
<td></td>
</tr>
<tr>
<td>Previous dental experiences</td>
<td>Emotions upon diagnosis</td>
<td>Perceptions of the disease</td>
</tr>
<tr>
<td>Impact of having periodontitis</td>
<td>Experiences of treatment</td>
<td>Impact of treatment</td>
</tr>
<tr>
<td>Psychological</td>
<td>Positive/negative</td>
<td>Oral</td>
</tr>
<tr>
<td>Functional/physical</td>
<td>Information given</td>
<td>Extra-oral</td>
</tr>
<tr>
<td>Social</td>
<td>Cost</td>
<td>Psychological</td>
</tr>
<tr>
<td>Reasons for having gum disease</td>
<td>Side-effects</td>
<td>Functional/physical</td>
</tr>
<tr>
<td>Causes</td>
<td></td>
<td>Social</td>
</tr>
<tr>
<td>People at fault</td>
<td></td>
<td>Support from others</td>
</tr>
</tbody>
</table>

+ additional topics specific to each participant based upon topics from their diary entries
3.1.10 DATA ANALYSIS

3.1.10.1 Qualitative thematic analysis

Data analysis followed an inductive, thematic approach. Inductive analysis is preferred in exploratory research because it allows flexibility for natural theme development, without applying a pre-determined framework to the data (Elo and Kyngäs 2008). Thematic analysis is a method of qualitative data analysis used to detect and analyse key themes (Braun and Clarke 2006). Themes are important ideas or patterns within the data which are relevant to the overall research question. During thematic analysis, researchers seek themes which are common across the entire dataset (Vaismoradi et al. 2013). The key steps in thematic analysis were described by Braun and Clarke (2006) and are depicted in Figure 3.2.

All fourteen anonymised interviews were transcribed verbatim by a professional transcription service. Afterwards, I carefully checked each transcript against its audio recording file, which required close repetitive listening while concurrently reading and correcting the transcript. This allowed me to become familiar with the data and screen for important themes and ideas, while confirming the accuracy of the transcription. Key points, interesting excerpts and possible early themes were noted down for each participant. The interview transcripts were returned to the participants for member checking, to confirm that they were an accurate representation of their perceptions.

All diaries and interviews were imported into NVivo® (version 12), the qualitative data analysis software which was used to manage the data. All data were carefully read line-by-line and sections of text containing important ideas were extracted, categorised and labelled. This coding process grouped similar ideas together, which generated a set of descriptive categories and sub-categories. After I coded the data for the first three participants, LFP reviewed the coding and provided feedback for the conduct, coding and analysis of the remaining interviews.
1. **Familiarisation with the data:**
Transcription, reading and re-reading data, noting down initial ideas.

2. **Generating initial codes:**
Coding interesting features of the data in a systematic fashion across the entire dataset, collating data relevant to each code.

3. **Searching for themes:**
Collating codes into potential themes, gathering all data relevant to each potential theme.

4. **Reviewing themes:**
Checking if the themes work in relation to the coded extracts (Level 1) and the entire dataset (Level 2), generating a thematic ‘map’ of the analysis.

5. **Defining and naming themes:**
Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.

6. **Producing the report:**
The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

**Figure 3.2.** Phases of thematic analysis, adapted from Braun and Clarke (2006)
Once all data sources had been coded, the descriptive categories were revised in a second coding phase. Various categories were added, modified or removed in an attempt to interpret their true meaning and reflect their relevance to the data as a whole. This generated a set of analytical themes and sub-themes.

3.1.10.2 Data validation
The NVivo document containing the coding was independently reviewed by two research supervisors: LFP (an experienced qualitative researcher) and EK (a periodontist and clinical researcher). This involved reading the diaries and transcripts, and verifying the allocation of codes and themes. The supervisors were each invited to re-code any data if they did not agree with the coding, as well as to review and refine the themes. The researchers discussed any variances in their coding and made subsequent amendments to the coding frame.

Various appraisal criteria, such as the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al. 2007) and SRQR (O’Brien et al. 2014) are available to guide the practise and reporting of qualitative research. The latter were considered throughout the design and implementation of this study. These guidelines call for inclusion of techniques which enhance the trustworthiness of the data. One example is respondent validation, or member checking, which ensures that the researcher has recorded and interpreted the data in the way the participant intended (Mays and Pope 2000). Triangulation is another technique used to improve the validity of qualitative research findings, by combining more than one method or data source (Patton 2002). The convergence of findings which have arisen from different methods suggests validity.

Four types of triangulation have been described: method triangulation, investigator triangulation, theory triangulation and data source triangulation (Denzin 1978). Two of these were employed in the present study. Firstly, method triangulation refers to a combination of data collection methods used to study the same phenomenon (Carter et al. 2014). In this study, the inclusion of qualitative data (collected using two methods: diaries and semi-structured interviews) and quantitative OHRQoL and self-reported periodontal data represented two types of method triangulation. Investigator triangulation is the term used when the data are examined and interpreted by two or more researchers
to diversify and/or confirm the findings (Carter et al. 2014). To this end, the data in the present study were reviewed independently by three individuals.

3.1.10.3 Researcher reflexivity

Researcher reflexivity is a method of critical self-reflection which can enhance the rigour and credibility of a qualitative study (Mays and Pope 1995). It requires the researchers to consider how their personal background, perceptions, and/or motivations might impact on the research process and outcomes.

I am a female of New Zealand European descent, currently studying towards a Doctorate of Clinical Dentistry in Periodontics. The participants were aware of my role as a postgraduate student, and occasionally saw me in the clinic during their treatment appointments with my peers. Their knowledge of my clinical background and collegiality with their treating clinicians may have influenced their responses in their diaries and interviews. Conversely, my role as a postgraduate student also shaped the data collection and analysis process. My future occupation as a periodontist stimulated my interest in the patient experience, with a view to improving my clinical practice based upon the findings of this research.

The other researchers did not have contact with the participants but were involved throughout all phases of the study, including design and conceptualisation, data collection, analysis and presentation. LFP (the primary supervisor) is a specialist in dental public health, with expertise in OHRQoL, qualitative and mixed methods research. JWL and EK are periodontists, with extensive clinical and research experience. WMT is a highly experienced dental researcher and dental public health specialist. The research team thus included five individuals whose backgrounds and experience contributed different perspectives during consideration of the data.
3.1.10.4 Quantitative data analysis

The periodontal charts recorded at baseline and follow-up were transferred into a web-based digital format (Appendix XI). The clinical periodontal information was used to classify the participants’ periodontal condition according to Tonetti et al. (2018). The baseline and follow-up data were compared and used to supplement the qualitative data for each participant.

The OHIP-14 scores measured at baseline and follow-up were calculated using the OHIP-ADD method. This involved assigning a score to the response for each question, where 0 = ‘never’, 1 = ‘hardly ever’, 2 = ‘occasionally’, 3 = ‘fairly often’, and 4 = ‘very often’. These values were then summed for each questionnaire to generate a total OHIP-14 score for each participant at baseline and at follow-up.

The responses for each of the self-reported periodontal screening questions were scored as follows: 1 = ‘yes’, 2 = ‘no’, and 0 = ‘don’t know’. The responses to Locker’s global oral health item were also assigned a numerical code to facilitate the analysis, where 1 = ‘excellent’, 2 = ‘very good’, 3 = ‘good’, 4 = ‘fair’, and 5 = ‘poor’. Each participant’s responses to the self-reported periodontal questions and Locker’s item were analysed at baseline and follow-up. The raw quantitative data were entered into a spreadsheet to facilitate the statistical analysis (Microsoft Excel®).

3.1.10.4.1 Statistical analysis

The data were analysed using SPSS® (version 24). The responses to the OHIP-14 items, Locker’s global oral health item, and the self-report periodontal screening questions were considered for each participant at baseline and follow-up. Descriptive statistics, including means and standard deviations, were calculated for the OHIP-14 scores. The Locker’s global oral health item responses were used against the mean OHIP-14 scores as a concurrent validity check. The prevalence of one or more OHIP impacts reported as ‘fairly often’ or ‘very often’ was compared before and after treatment. Those, and Locker’s global oral health ratings, were cross-tabulated to determine the effect of

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treatment. Finally, a Wilcoxon Signed Ranks test was used to compare longitudinal changes in the mean OHIP-14 scores. Statistical significance was set at 0.05.

3.1.11 CONCLUSION

The methods used for participant recruitment and collection of the qualitative and quantitative data have been outlined, followed by a discussion of the techniques used for analysis of these data. The findings of this research will be presented in the subsequent sections.
Chapter Four – Qualitative findings

4.1.1 INTRODUCTION

The results from the qualitative thematic analysis will be presented in this chapter. The analysis gave rise to three themes which collectively described the psychosocial impact of periodontal diagnosis and treatment on the participants: ‘concealment’, ‘having a guilty conscience’, and ‘patient comfort as paramount’. These themes made up an underlying core theme: ‘progression to a more positive outlook’. Each theme and its constituent sub-themes will be discussed. The quantitative data, taken at baseline and follow-up (OHIP-14 scores, periodontal self-report data and Locker’s global oral health item), will be presented in the next section.

4.1.2 SAMPLE CHARACTERISTICS

Fourteen participants completed the study. Their demographic information is summarised in Table 4.1. Nine were female and five were male. The age of participants ranged from 35 to 68 years, with a mean age of 52 years. Eleven participants identified themselves as New Zealand European, while one identified as British, one as Tongan, and one as New Zealand European and Māori. A number of occupations were reported, and these reflected a range of SES. Equal numbers of participants (six) were current or past smokers, while two reported having never smoked. All had been diagnosed with periodontitis to various stages and degrees, according to Tonetti et al. (2018).
Table 4.1. Demographic characteristics of the participants who completed the study

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Occupation</th>
<th>Smoking history</th>
<th>Periodontal diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1001</td>
<td>F</td>
<td>68</td>
<td>British</td>
<td>Part-time retail</td>
<td>Smoker</td>
<td>Stage III, Grade B (localised)</td>
</tr>
<tr>
<td>1002</td>
<td>F</td>
<td>45</td>
<td>NZ European</td>
<td>Retail</td>
<td>Smoker</td>
<td>Stage IV, Grade C (generalised)</td>
</tr>
<tr>
<td>1003</td>
<td>F</td>
<td>55</td>
<td>NZ European</td>
<td>Cleaner</td>
<td>Smoker</td>
<td>Stage III, Grade C (generalised)</td>
</tr>
<tr>
<td>1004</td>
<td>M</td>
<td>35</td>
<td>Tongan</td>
<td>Teacher</td>
<td>Ex-smoker</td>
<td>Stage III, Grade B (generalised)</td>
</tr>
<tr>
<td>1005</td>
<td>M</td>
<td>54</td>
<td>NZ European</td>
<td>Site manager</td>
<td>Ex-smoker</td>
<td>Stage III, Grade B (localised)</td>
</tr>
<tr>
<td>1006</td>
<td>M</td>
<td>65</td>
<td>NZ European</td>
<td>Groundsman</td>
<td>Ex-smoker</td>
<td>Stage II, Grade A (localised)</td>
</tr>
<tr>
<td>1007</td>
<td>F</td>
<td>55</td>
<td>NZ European</td>
<td>Administrator</td>
<td>Ex-smoker</td>
<td>Stage III, Grade B (generalised)</td>
</tr>
<tr>
<td>1008</td>
<td>F</td>
<td>45</td>
<td>NZ European/Maori</td>
<td>Health and safety officer</td>
<td>Ex-smoker</td>
<td>Stage III, Grade B (localised)</td>
</tr>
<tr>
<td>1009</td>
<td>M</td>
<td>48</td>
<td>NZ European</td>
<td>Carpenter</td>
<td>Smoker</td>
<td>Stage IV, Grade C (generalised)</td>
</tr>
<tr>
<td>1010</td>
<td>M</td>
<td>60</td>
<td>NZ European</td>
<td>Lamb drafter</td>
<td>Never smoker</td>
<td>Stage III, Grade B (localised)</td>
</tr>
<tr>
<td>1011</td>
<td>F</td>
<td>45</td>
<td>NZ European</td>
<td>Compliance officer</td>
<td>Smoker</td>
<td>Stage IV, Grade C (generalised)</td>
</tr>
<tr>
<td>1012</td>
<td>F</td>
<td>59</td>
<td>NZ European</td>
<td>Caregiver</td>
<td>Never smoker</td>
<td>Stage III, Grade A (generalised)</td>
</tr>
<tr>
<td>1013</td>
<td>F</td>
<td>46</td>
<td>NZ European</td>
<td>Horse trainer</td>
<td>Smoker</td>
<td>Stage III, Grade C (generalised)</td>
</tr>
<tr>
<td>1014</td>
<td>F</td>
<td>44</td>
<td>NZ European</td>
<td>Caregiver</td>
<td>Ex-smoker</td>
<td>Stage III, Grade B (generalised)</td>
</tr>
</tbody>
</table>
4.1.3 DATA CHARACTERISTICS

A summary of the raw qualitative data, which was collected using the diaries and interviews, is presented in Table 4.2. Three participants elected to complete their diaries using a portable voice recording device, while the remaining eleven chose a hand-written format, using a hard-covered, lined journal. The number and length of diary entries differed among participants, although the diaries completed in the audio-recorded format were generally longer and more in-depth. The interviews ranged from twenty minutes to one hour and five minutes, with a mean duration of 37 minutes. The diaries and interviews collectively generated 412 pages of typed text which was used for the thematic analysis.

Table 4.2. Summary of transcribed raw qualitative data sources for each participant

<table>
<thead>
<tr>
<th>Participant</th>
<th>Diary type</th>
<th>Number of entries</th>
<th>Diary word count</th>
<th>Interview word count</th>
<th>Interview length (min:sec)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1001</td>
<td>Written</td>
<td>3</td>
<td>376</td>
<td>5342</td>
<td>31:54</td>
</tr>
<tr>
<td>1002</td>
<td>Written</td>
<td>17</td>
<td>1163</td>
<td>7853</td>
<td>33:17</td>
</tr>
<tr>
<td>1003</td>
<td>Written</td>
<td>6</td>
<td>269</td>
<td>4310</td>
<td>26:25</td>
</tr>
<tr>
<td>1004</td>
<td>Audio-recorded</td>
<td>10</td>
<td>2444</td>
<td>9062</td>
<td>55:29</td>
</tr>
<tr>
<td>1005</td>
<td>Audio-recorded</td>
<td>3</td>
<td>1064</td>
<td>5840</td>
<td>30:40</td>
</tr>
<tr>
<td>1006</td>
<td>Written</td>
<td>3</td>
<td>198</td>
<td>6232</td>
<td>33:02</td>
</tr>
<tr>
<td>1007</td>
<td>Written</td>
<td>24</td>
<td>1280</td>
<td>8676</td>
<td>46:24</td>
</tr>
<tr>
<td>1008</td>
<td>Written</td>
<td>14</td>
<td>920</td>
<td>6295</td>
<td>31:08</td>
</tr>
<tr>
<td>1009</td>
<td>Written</td>
<td>3</td>
<td>227</td>
<td>11948</td>
<td>64:44</td>
</tr>
<tr>
<td>1010</td>
<td>Written</td>
<td>14</td>
<td>689</td>
<td>6584</td>
<td>29:45</td>
</tr>
<tr>
<td>1011</td>
<td>Audio-recorded</td>
<td>6</td>
<td>3675</td>
<td>8883</td>
<td>43:07</td>
</tr>
<tr>
<td>1012</td>
<td>Written</td>
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<td>288</td>
<td>4141</td>
<td>20:23</td>
</tr>
<tr>
<td>1013</td>
<td>Written</td>
<td>8</td>
<td>140</td>
<td>4739</td>
<td>31:03</td>
</tr>
<tr>
<td>1014</td>
<td>Written</td>
<td>10</td>
<td>644</td>
<td>8780</td>
<td>42:54</td>
</tr>
</tbody>
</table>
4.1.4 CONCEPTUAL MODEL

The key themes within the data were arranged into a conceptual model (Figure 4.1). The themes ‘concealment’ and ‘having a guilty conscience’ largely pertained to the participants’ experiences in the pre-treatment and treatment phases, while the theme ‘patient comfort as paramount’ was most often related to their experiences of diagnosis and treatment. The underlying core theme ‘progression to a more positive outlook’ depicted a shift in the mindset of the participants which occurred throughout their diagnosis and treatment. In addition, the participants also described improvements in each of the above-named domains as their treatment progressed. Each theme and set of sub-themes is discussed below.
Figure 4.1. A conceptual model depicting the psychosocial impact of periodontitis diagnosis and treatment. Thematic qualitative analysis identified three themes: ‘concealment’, ‘having a guilty conscience’ and ‘patient comfort as paramount’. These were related to a core underlying theme, termed ‘progression to a more positive outlook’
4.2 CONCEALMENT

The participants indicated that having periodontal disease was an undesired burden, to which there was an attached social stigma. In order to avoid the stigma associated with having periodontitis, they went to great lengths to conceal their disease. Participants described behavioural adaptations or mannerisms which were intended to hide the fact that they were suffering from periodontitis. There was evidence of concealment throughout the pre-treatment, treatment, and post-treatment phases, although to a lesser extent in the latter, as the participants began to accept the disease and its consequences. The theme ‘concealment’ was associated with the four sub-themes of stigma, concealment of the symptoms of disease, concealment of the experience of periodontal treatment, and becoming more open after treatment. Each will be elaborated below, with supporting examples.

4.2.1 STIGMA

The participants viewed periodontitis as an adverse condition which was stigmatised by society. They feared being subjected to judgment or discrimination if others found out about their condition. This reflected their beliefs that periodontitis was caused by poor hygiene, or that it affected people of low SES. One high-SES participant remarked that she “never would have envisaged that [she] would have this problem”, suggesting that she did not feel that she fit into the stereotype she had associated with periodontal disease. Labelling it as a ‘problem’ in this way also implied her reluctance to identify and accept the disease, in a similar way to how one might describe a ‘problem child’. Other participants also used the word ‘problem’ to refer to their periodontitis, possibly because they perceived it as an annoyance or disruption to their lives which they were reluctant to address.

4.2.1.1 Stigma related to the symptoms of periodontitis

The participants feared being stigmatised because of their periodontal symptoms. The participants referred to the fact that their symptoms made it difficult for them to conform to social norms. This was usually related to their appearance:
“I hate the colour of them... I just wanted to try and get them a bit nicer looking. They were quite bad with the brown tartar and stuff on them. I would love to have a nice smile and maybe whiter teeth, and be proud to smile, as now I just avoid smiling or opening my mouth.” [1002]

This participant’s reference to a ‘nice smile’ suggests that she considered her smile to be inferior to others’, because of the impact of periodontitis on her appearance.

4.2.1.2 Stigma related to tooth loss

The participants were also concerned about the stigma related to tooth loss:

“It’s the front ones that are going to worry me more. If they have to come out, I would want them replaced with another tooth straight away, because I’m self-conscious about the way I look. I’d hate to go around [without teeth] like some people do...” [1003]

This participant’s reference to ‘some people’, with visible spaces in their smiles, suggests that she perceived them as a separate social group which she was unwilling to join.

Another participant, who had lost posterior teeth due to periodontitis, worried that her appearance might impact on the respect she commanded in the professional setting:

“You have a certain professional look and when you’re talking with people, and you’re in power, you’ve got a bit of position, you just want to feel confident, and be able to laugh and not think ‘how wide is my mouth going?’... Those sorts of things.” [1011]

4.2.1.3 Stigma related to having periodontal disease

Being diagnosed with periodontitis made participants feel more conscious of their teeth and mouths. Those who were oblivious to their periodontal condition prior to diagnosis became particularly self-conscious, as they suddenly faced a realisation that they might belong to a ‘group’ who may face stigma or discrimination. The diagnosis with periodontitis thus represented an undesired status passage, whereby the participants perceived an unfavourable change in their social standing.
Some participants discussed past instances when they had felt stigmatised because of their periodontitis. One had been a full-time student on a single parent benefit when she required an extraction for a loose tooth. Due to her limited income, she sought a financial grant for the dental treatment. The dental clinic advised her that their policy was for patients to see a hygienist first, which she did, and she described this experience as traumatic:

“The hygienist was a very unpleasant woman who, I think for the simple fact that I was a single parent, and had a grant from Work and Income, had judged me to start with. Second of all, I smoke. So, that particular appointment put me off going back to a dentist again, because I had to have a quote first, and they didn’t tell me I needed some numbing treatment for [the non-surgical therapy]. So, I had to do it without the numbing treatment and during the whole process, she just berated me for having ‘lovely teeth’, but issues with my gums due to smoking, and proceeded to lecture me. The whole thing was quite traumatic, and I was very upset.” [1011]

This experience made the participant feel so uncomfortable that she delayed the extraction of her painful, loose tooth until the following year, and subsequently did not see another dentist for a further five years, despite knowing that she had untreated periodontal disease.

Another participant felt ashamed when the dental clinic would phone her to ask whether she was interested in coming in for treatment, but she was unable to afford it:

“Yeah, like until they got to a point where they would be so sore that I wouldn’t be able to do anything, then you know… Well, it never got to that point, but I always just thought: ‘No, I can’t do it this month’. And then they’d ring again and say: ‘Can we get you’… ‘No sorry, I can’t do that’. It is quite embarrassing, because you don’t really want to… I don’t find it embarrassing now, but back then, I didn’t want to admit to people that I actually couldn’t afford to do it. I mean, you don’t know the person on the other end of the phone, but it is still telling someone that you are unable to do it, you financially can’t.” [1013]

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8 Work and Income is a government agency in New Zealand which provides unemployment, social security and student loan services.
The participants’ fears of being stigmatised and socially isolated were evident throughout the data. The participants thus carefully designed concealment behaviours to hide their periodontitis and avoid the associated social stigma. These are discussed in the next section.

4.2.2 CONCEALMENT OF THE SYMPTOMS OF DISEASE

Various symptoms of periodontitis were reported by participants in their diaries and interviews. Gingival bleeding and halitosis were the most commonly described. The participants were also highly aware of changes to their appearance which had occurred as a result of the disease process, such as gingival colour changes, gingival recession, and increased spacing of the teeth. A few participants also mentioned loose teeth which occasionally became painful or restricted their chewing function.

4.2.2.1 Gingival bleeding

Nearly all of the participants experienced gingival bleeding at some point. For some, this occurred frequently over long periods, such that they began to accept it:

“I knew they bled... not masses when I brushed them, but because they always had, I didn’t care”. [1008]

For others, gingival bleeding only occurred occasionally, which helped the participants to attribute it to another cause, and thus deny that they had a problem:

“Bleeding only at times, if I used a very harsh toothbrush, it created more bleeding.” [1010]

These examples illustrate the efforts of the participants to ignore this visible symptom of periodontal disease, despite being aware on some level that it was not healthy. They often tolerated gingival bleeding for months and years without actively seeking treatment. This may be considered a form of denial and concealment from oneself. One participant described how he attempted to hide his symptoms from himself by avoiding toothbrushing:

“I didn’t used to brush, like maybe once every three months or something, because every time I did it, they’d bleed, and it was just easier to have dirty teeth, ‘cause you wouldn’t know, you wouldn’t feel them. If you cleaned them and
flossed and all that, then you’d be forever feeling them... like, just hiding it under the blanket. Yeah.” [1009]

Another participant avoided seeking treatment although he knew his gingival bleeding indicated a problem:

“My gums just kept bleeding and kept bleeding and I knew something was wrong, but it’s just one of those things where you just put it in the back of your mind and think ‘Oh, it’ll go away, it’ll go away...’” [1004]

This participant also described situations where his young son had noticed his gums bleeding when he smiled, and when he spat out after brushing his teeth. Being confronted in this way prompted him to smile with his mouth closed, to hide his bleeding gums. He then explained that, although his children had become aware of his symptoms, he felt so embarrassed that he concealed them from his wife:

“So, it was just my kids that knew that my gums were bleeding, my wife didn’t know… It wasn’t a subject that we’d talk about, unless we’d start talking about the kids’ teeth, but again, I didn’t mention it to her, probably because I just felt a bit ashamed of it and was trying to hide it. Yeah, that’s what I was doing... I felt embarrassed about it, didn’t want to talk about it.” [1004]

4.2.2.2 Halitosis

Having bad breath took a significant psychological toll on the participants, bringing about feelings of embarrassment and insecurity. Those with halitosis described being constantly aware, or even ‘paranoid’ about having bad breath which others might notice. The participants made subsequent behaviour changes to conceal their breath from others. Several described how they used mints or chewing gum to hide their mouth odour:

“For a long time, I used those wee mint things, had them in my car. Just so if I knew I was gonna be in close proximity of people, that I wasn’t gonna offend them too much... if I did have bad breath...” [1010]

“You can tell when you have got bad breath, it is like, oh God. And it didn’t matter if you brushed them or whatever you did, it wasn’t the problem, it was what was going on underneath. So, I just continually sucked on mints or had gum in my mouth or something.” [1014]
As well as the attempts made by the participants to conceal their halitosis using products to freshen the mouth, some also modified their behaviour around other people. Some participants were concerned because their occupation required them to work in close proximity to others. In some cases, their anxiety about having bad breath led to them avoid speaking to other people in social situations or at work. For example, one participant described the considerable impact that his efforts to conceal his halitosis had upon him and his relationships:

“When I pushed against my mouth, at times I could feel this bad taste... and once I got that bad taste, I’d shy away and don’t talk to people, even though I want to. But knowing that bad taste is in my mouth, if I end up talking, yeah how bad it would smell... so I’d end up just nodding, and become really quiet.” [1004]

This excerpt explains how he concealed his halitosis by avoiding speaking to other people. This did not go unnoticed by his friends, who confronted him about his behaviour:

“I didn’t really think about it until [I was in] that situation and... there’s that bad taste again. So I’d just ignore people, but I’d get texts saying: ‘Oh you’re a bit stuck up today, why didn’t you talk to me?’ so I’d go: ‘Oh ok I didn’t see you there’ but really, I just didn’t want to talk because of that situation...” [1004]

This participant also described similar concealment behaviours in his work environment (as an early childhood teacher). He explained that he was happy to interact with the parents of his students in the morning, when he had recently brushed his teeth, and therefore felt confident that he had fresh breath. As more time elapsed, he became less confident, and distanced himself physically in order to avoid speaking with the parents in the afternoons when they arrived to pick up their children.

4.2.2.3 Appearance of the teeth and gums

The participants also endeavoured to hide the changes in their appearance that had occurred as a result of their periodontitis. The visible signs of periodontitis which concerned the participants included discoloration of the teeth and gingivae, gingival recession, and spaces between the teeth, or where teeth had been lost. A number of the
participants explained how they avoided showing their teeth, by avoiding opening their mouths, or smiling with their mouths closed.

One participant had been self-conscious about her appearance since a gap developed between her front teeth when she was in her thirties. In her diary, she described the impact that her efforts to conceal her teeth had upon her work and family life:

“Working in retail and being on checkouts has been hard over the years, as I don’t smile, and am very conscious of my gaps in my teeth, and the revolting colour of them (but smoking hasn’t helped either). I look at my son’s wedding last year, and am saddened to see everyone else smiling apart from me.” [1002]

Although she had avoided smiling to prevent feeling embarrassed, she was particularly confronted and upset by the realisation that she was the only person who was not smiling in the photographs from her son’s wedding. She felt that she had ruined the photographs, and this became the turning point when she decided to seek treatment for her gum disease.

Similar concealment behaviours and associated social impacts were reported by other participants. A majority described how they had modified their smile to avoid tooth and gingival display, including smiling with their mouth closed, reducing the width of their smile to limit the number of visible teeth, or holding a hand up over their mouth when smiling or laughing:

“I really wanted a plate for the top teeth that have been removed, because it’s quite noticeable when you laugh and smile that they’re missing, which I find very embarrassing. I always put my hand over the front of my mouth to hide those gaps when I’m laughing...” [1011]

For this participant, the appearance of her mouth was of such great concern that it was always on her mind, and she felt compelled to physically hide it from other people.

Some participants also limited their social interactions to hide their periodontal symptoms. Participant 1002 described how her self-consciousness about her appearance made her selective about which social events she attended, based upon who else might be there:
“You do pick the things you go to. You know, you go to the things when you know the people that will be there. If it’s strangers or whatever, I do think twice about going.” [1002]

4.2.2.4 Tooth mobility

For others, their loose, spaced or missing teeth made certain foods more difficult to eat. This affected their ability to comfortably eat out, because their food choices were restricted to those that were softer, or less likely to become stuck between their teeth:

“I went onto a soft diet, thinking that that would help. Things like meat and chicken would always get stuck in my teeth, so I would stay away from that a lot of the time if I was out.” [1014]

One participant was particularly distressed by her mobile teeth, because she considered tooth loss to be an inevitable consequence of mobility. Since it worried her so much, she preferred to be unaware of her mobile teeth:

“I haven’t even tried to see if I’ve got other [loose] ones that I don’t know about. I’d rather not know. Once I know it is loose, it makes me wonder how long I am gonna have it for. But I’ll just carry on, because I think if I was going to be more careful, it would worry me more.” [1003]

This participant’s avoidant behaviour is another example of concealing the symptoms of periodontitis, although she hid them from herself, instead of from other people.

4.2.3 Concealment of the experience of having periodontal treatment

As well as concealing the symptoms of their periodontal disease, some participants also concealed the fact that they were seeking periodontal treatment. One part of the interview guide explored whether the participants had discussed their diagnosis and treatment experiences with others. A majority of the participants admitted that they had kept these experiences private, usually mentioning them only to their spouse or a close friend. Two key reasons for this were identified in the data analysis: fear of stigma or embarrassment, and indifference. On the other hand, some participants were open about their journey
through diagnosis and treatment for periodontitis, and they had disclosed their experiences to other people.

4.2.3.1 Fear of stigma and embarrassment
Some participants described the embarrassment and fear of judgment that underpinned their decisions not to openly discuss their experiences with others. This was evident throughout the data, including the example given above where one participant was too embarrassed to discuss his periodontitis with his wife. Another participant, a well-presented female of high SES, stated this outright:

“Yeah, it is slightly embarrassing, I think in a way, but also, it’s none of anybody else’s business!” [1001]

She explained how she was unwilling to talk to others about her periodontitis, in order to preserve her self-esteem and avoid stigma:

“[It impacted on] my self-esteem, I guess. I didn’t tell any of my friends... it wasn’t something that I spoke about. I suppose I only really told one friend, and she was quite taken aback. But she was very sympathetic, I think she’s the only person that I’ve mentioned it to.” [1001]

Another participant whose periodontitis had impacted greatly on her self-confidence described how she avoided discussing her treatment with others:

“I’m not inclined to discuss the gum disease with anyone... unless someone else brings it up. Even then, I’m reluctant to talk about it. Only very close people really know of it, that it’s even happened.” [1011]

This participant went to great lengths to conceal the fact that she had gum disease, and that she was seeking treatment, sharing only selected parts of the experience with her daughter and a supportive work colleague. As part of her treatment, she had a tooth extracted, and in her diary, she described her vulnerability as she left the building afterwards:

“Having a tooth removed, and leaving the dentist with cotton in my mouth, and having had the injections, I looked like I’d had a stroke, and had no control over that side of my face. Walking back to the car, I was very conscious of people
staring at me ’cause they could see that was obviously what I’d had done, a tooth removed. I came home, and I was quite miserable, and I cried...” [1011]

This excerpt highlights the despair of this participant when she felt unable to conceal the fact that she had treatment. She believed that others had stared at her, and assumed that they knew she had had an extraction, although this was unlikely to have been the case.

4.2.3.2 Indifference

Other participants did not share their experiences with others because they did not feel that it was important enough. For some, the diagnosis and treatment was not perceived as a ‘big deal’, so they did not feel the need to obtain support from other people by discussing it with them. One participant compared her experience of diagnosis and treatment for her periodontitis to a more serious medical diagnosis that she had recently received:

“Oh, I just kept it to myself, pretty much. You know, told my husband I was going to the dentist and that sort of thing, yeah. It wasn’t as big as what we have just been through.” [1013]

Her recent health issues put her periodontitis diagnosis into perspective, making it seem less significant in comparison.

4.2.3.3 Disclosure of experiences

In contrast to those who concealed their treatment experiences, there were some participants who disclosed them more openly. In some cases, the support they received from others helped them to come to terms with their diagnoses. For example, one participant’s mother also had periodontitis and had undergone similar treatment. This participant frequently referenced her mother’s experiences in her diary and interview, and was comforted by her empathy and reassurance.

Another participant was initially quite open with others while she was awaiting treatment, but found their reactions unhelpful, because they gave her concerns about the proposed treatment:

“I talked to other people when I’d gone home, and said: “They’re going to scrape all the bottom half of my teeth and everything else. Do the front, and then the
back, and four visits and should be done.” And they said: “Oh Jesus, you know that hurts.” So, listening to other peoples’ experiences probably didn’t help.”

4.2.4 BECOMING MORE OPEN AFTER TREATMENT

In line with the core theme of ‘progression to a more positive outlook’, participants identified ways in which their periodontal treatment reduced the need for concealment. As their symptoms improved, they no longer had to hide them, and, as they became more optimistic, they shared their positive experiences with others. Having periodontal treatment did not eliminate all concealment, however, and some participants developed new behaviours to hide visible side-effects of treatment, or maintained their previous concealment habits.

4.2.4.1 Improvements in symptoms

The behavioural adaptations made by the participants to conceal their halitosis, a symptom of periodontitis, were described earlier in this section. As they progressed through the treatment, and this embarrassing symptom diminished, the participants found that their concealment behaviours were no longer required. This was, in turn, related to positive social consequences for some participants.

Participant 1004, a teacher who had previously avoided speaking to the parents after school for fear of having bad breath, described how the children and parents had noticed changes in his behaviour after his non-surgical periodontal therapy:

“At work, the kids were saying I’m talking a lot more now. And parents, especially when they’d come and pick up their kids, they had noticed that before, in the morning, I would talk to them, and in the afternoon, I’d just give them a wave, and talk from afar. Even they have noticed, saying that you’re talking to us in the afternoon, which is something they had to get used to as well (laughs)...”

[1004]

His improved confidence during social interactions as a result of his fresher breath was evident in this excerpt. In addition, the children had noticed him smiling more, and he no longer needed to use chewing gum to conceal his halitosis:
“Now I don’t actually eat that anymore, ‘cause that was one way of me disguising the taste and the bad smell... even the kids have noticed that I’m not chewing during the day...” [1004]

Others were also relieved of the behaviours they had adopted to conceal their periodontal symptoms. One noticed the impact this had on her ability to be intimate with her partner:

“I remember my partner used to say in the morning: “Don’t kiss me, don’t even come near me”. But now I am like, you know: “Come here, it’s alright”. ‘Cause I know I haven’t got bad breath. I was always conscious of that, and now I haven’t got it.” [1014]

4.2.4.2 Sharing positive experiences
As the participants noticed the positive effects of their treatment, they became less likely to conceal the fact they had sought treatment, and more likely to share these experiences with others.

One participant, who initially said that she had only ever discussed her gum troubles with her sisters, described how after treatment, it would “come up in conversation” with her friends and family. She no longer wished to hide it, but instead, brought it into the open to encourage other people to seek treatment. Another participant used his own experiences to educate and reassure others:

“...I’m more open, with new parents coming into work now, and they talk about it. I can give them positive feedback of [clinicians] and I’m letting them know that I’m getting my taste buds back, and I’m tasting food. So, it’s more trying to comfort them that it’s well worth it at the end, even though it’s a bit scary to start off with, it’s well worth it at the end...” [1004]

4.2.4.3 Concealment after treatment
On the other hand, some participants maintained their concealment behaviours after treatment. For one, the treatment caused increased spaces between her teeth, in which food would frequently get trapped. She described how she was self-conscious about this and had developed behaviours to hide it:
“My only concern is that there’s a lot more food getting caught in between my teeth now, and I can really feel it. That’s probably a more public thing, so I’ve gotta floss them and every time I have anything to eat, I’ve got to flick the food out. So, an example, yesterday in a board room similar to this, we were having morning tea and a meeting at the same time. There were little savouries there with poppy seeds and I thought shit I can bloody feel them! So, if I was talking, I might have my lips covering my teeth, just to make sure I haven’t got a big poppy seed hanging there... So yes, in a sense it’s affected me that way, I’m more self-conscious.” [1008]

Similarly, after the completion of her non-surgical treatment, participant 1011 commented that she was “still in the same position with smiling and laughing”, referring to the fact that she continued to hold her hand over her mouth to hide the spaces where her teeth had been removed.

4.2.5 SUMMARY

The theme ‘concealment’ was evident particularly in the pre-treatment and treatment phases, as the participants described the ways they hid their symptoms and experiences of periodontal treatment from others. As they progressed through treatment, some participants ceased their concealment behaviours as their symptoms improved, while others maintained or developed new mannerisms to conceal visible consequences of their periodontal treatment.
4.3 HAVING A GUILTY CONSCIENCE

Many of the participants harboured some guilt in relation to their periodontitis and treatment. ‘Having a guilty conscience’ was related to three subthemes: perceived reasons for having periodontitis, previously avoiding dental care, and keeping up with recommendations. Each sub-theme will be discussed below.

4.3.1 PERCEIVED REASONS FOR HAVING PERIODONTITIS

Some of the interview questions explored the participants’ understanding of periodontitis. Surprisingly, many of the participants struggled to define periodontitis and confidently identify what had caused it, despite having recently completed a course of treatment for the disease.

4.3.1.1 Inadequate oral hygiene

All but one participant thought that periodontitis was caused by inadequate oral hygiene. This participant was confused because she had developed periodontitis despite a history of meticulous oral hygiene habits. For the remainder of the participants, their interpretations of ‘inadequate’ oral hygiene varied significantly. Some thought they had periodontitis because they had avoided toothbrushing altogether, while others attributed it to a poor flossing technique (despite using dental floss daily). Nevertheless, a degree of guilt was evident, as the participants often indicated that they knew they should have done better:

“I probably should’ve taken a wee bit more pride in my cleaning, and flossing. I probably didn’t clean my teeth as frequently as I should, and I probably didn’t clean them correctly... I was told to floss years ago and if I had, I probably wouldn’t be where I was before I had the treatment.” [1012]

The participants who had a guilty conscience about their inadequate oral hygiene habits often also blamed themselves throughout their treatment for periodontitis:

“I’ve had my ups and downs with this treatment. I’ve gone through a bit of self-blame, because, you know, it’s me who’s put myself in this position from smoking and not really being aware of just how much you have to do to keep gum disease
4.3.1.2 Smoking

The majority of participants who smoked also identified this as a probable contributor to their periodontitis. They felt guilty because they were aware that smoking was bad for their health but had continued to smoke regardless. This was associated with self-blame upon diagnosis, as the following participant explained:

“Well I guess it’s just that whole cycle. ‘Cause you smoke. You know it’s your fault. So you’re doing that cycle thing to yourself. I don’t believe people who smoke aren’t aware of what’s going to happen to them if they continue, or the possibilities. So, you do sort of give yourself a bit of stick.” [1011]

Another participant was a heavy smoker who described smoking as an ‘old friend’ and remarked that it would be ‘borderline impossible’ for him to quit. He was not convinced that his smoking had contributed to his periodontitis, despite being informed on multiple occasions of the increased risk:

“I think I have gum disease, probably not so much from the smoking, but probably from the diet and the lack of cleaning. I don’t think the smoking’s 100%. Smoking is basically disruption of the blood supply to the gums... But my opinion is that the damage is from the food that turns into the tartar, and the bacteria that goes down under the gums and chomps away at the teeth. If a non-smoker didn’t brush, and had lots of sugar, and never flossed, surely they’d have the same effect on their gums as a smoker.” [1009]

In this excerpt, he rationalises his periodontitis and attributes it to factors other than smoking. His denial of the negative effects of smoking may be a protective mechanism to mask the guilt he feels about its contribution to his periodontal disease.

4.3.1.3 Other causes of periodontitis

When asked about the probable causes of their periodontitis, participants identified some additional factors, some of which were related to their own past behaviours. Two participants identified alcohol use as a possible cause, and several thought that a poor
diet may have had an impact. One participant was concerned that her habit of eating sweets had impacted on her periodontitis. In her diary, she mentioned that the process of diagnosis and treatment had made her more conscious about her diet. She described herself as having poor self-control, and became remorseful when she ate sweets:

“Of course, teeth and gums decide to be sore now. Ate lollies yesterday so obviously now got to stage where I can’t eat crap w/out suffering consequences. Bit depressing.” [1007]

Although the pain she described was probably not related to the fact that she had consumed sweets on the previous day, this excerpt highlights the guilt and self-blame experienced by this participant.

The participants also identified other contributing factors, which were beyond their control. Several believed that periodontitis was related to the ageing process. Others, particularly those whose family members had experienced similar problems, inferred that periodontitis was a hereditary condition. Some participants thought that their medical conditions or medications may have impacted on their periodontal health:

“I’ve always had trouble with my teeth with the pills I’ve been on…. which cause all the plaque, and all the enamel [to] come off…” [1002]

While these additional factors may indeed have impacted on their periodontitis, the participants’ willingness to identify them suggested that it helped them to overcome their guilt about those factors they did feel responsible for.

4.3.2 PREVIOUSLY AVOIDING DENTAL CARE

Many of the participants admitted that they had avoided dental care in the past. Although they justified this with legitimate reasons, they felt guilty or remorseful upon their diagnosis, as summarised by one participant:

“That [diagnosis with periodontitis] was not a great feeling, ‘cause I never came to the dentist unless I really had a problem, and I think that’s why my teeth are so bad, and my gums... If I had done the yearly treatment or check-ups, then my teeth would be in better condition.” [1003]
The most common reasons for avoiding dental care included financial concerns, fear of dental treatment, and no perceived need for treatment. Each will be briefly discussed below, with supporting examples.

4.3.2.1 Financial reasons

For most adults in New Zealand, dental care is not publicly funded, and the cost of private care is prohibitive for many. A majority of the participants explained that dental care was a lower priority for them than other expenses, such as study, medical care and travel. Those who had children described how they would prioritise their children over themselves:

“If you’ve got children, you always put their needs before your own. So, you would leave your teeth, you’d be like: ‘Oh hang on, the kids need a uniform’, and that’s more important than me getting my teeth fixed.” [1014]

As a result, most participants had delayed seeking treatment for as long as possible. Most recognised that seeking treatment earlier would have left them in a more favourable position. One participant, a single mother, did not see a dentist for fourteen years after first being diagnosed with periodontitis, because she was unable to afford it:

“Maybe if I had gone to the dentist more regularly, things might not [have] got to this stage. But there was always something the kids needed, or another bill to be paid.” [1002]

Despite being aware of the negative consequences of delaying treatment, this participant and some others were matter-of-fact about their past circumstances and did not feel guilty about it. On the other hand, others regretted not attaching higher priority to their oral health in the past, and blamed themselves accordingly:

“It’s my own fault, I should’ve spent more time worrying about my teeth and not about travelling...” [1005]

4.3.2.2 Fear of dental treatment

Some participants explained that they had avoided dental treatment because they were fearful of dental work. Most often, their fears stemmed from previous negative dental
experiences. These included occasions where the local anaesthesia was ineffective and previous dental treatment had been painful. Others recalled traumatic dental treatment as children, which had translated to dental phobias in their adult lives. Several participants referred to ‘the murder house’\(^9\), vividly describing experiences which included receiving treatment without anaesthetic along with restorations or tooth extractions which the participants considered to be unnecessary.

Others avoided seeking treatment because they were embarrassed or ashamed about their periodontal condition:

“It was one of those things where I just kept in the back of my mind... and I didn’t want to do anything about it because I’m a bit shy.” [1004]

Similarly, the participant who felt judged and demoralised during her previous visit to a dental hygienist was put off by this experience and subsequently avoided dental treatment.

### 4.3.2.3 No perceived need

Another sub-group of participants did not visit the dentist simply because they did not perceive a need to. One participant justified her previous non-attendance for this reason:

“I think that’s why I’ve stayed away, because I don’t feel like I’ve got any problems and I don’t come here.” [1003]

One participant, who had few symptoms prior to diagnosis, stated “ignorance is bliss”. These participants had believed that the absence of pain corresponded with the absence of a problem, while some admitted that they had noticed and ignored their symptoms during this time.

### 4.3.3 KEEPING UP WITH REQUIREMENTS

During the treatment and post-treatment phases, the participants described their efforts to adhere to the recommendations made by their treating clinician. The recommendations

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\(^9\) ‘The murder house’ is a colloquial term sometimes used by New Zealanders to refer to the School Dental Clinics, where dental therapists provided dental care to school children (Cartwright 2010). This term is often associated with negative and painful dental experiences.
mainly consisted of oral hygiene advice and included other advice on a case-by-case basis, such as wearing an occlusal splint or undergoing smoking cessation.

4.3.3.1 Oral hygiene routines

Most of the participants reported that they had adopted the recommended oral hygiene regimes (including toothbrushing techniques and the use of interdental brushes). They appreciated that maintaining their oral hygiene was their personal responsibility, and they recognised its importance for successful treatment outcomes. Those who successfully maintained their oral hygiene practices spoke about how they had adapted their daily routines to incorporate new habits. These included carrying interdental brushes in their cars or in the pockets of their work uniforms, or cleaning their teeth immediately after dinner, before they became too tired to do it thoroughly.

Nevertheless, participants generally took a positive approach to these changes, while recognising that they required dedication and perseverance:

“I guess the education that she has provided me has made me spend a lot more time on my oral hygiene practices and just take a bit more care. I have a new regime now, it takes a lot longer, so I factor that in to my morning, and especially, when I’m going to work, to make sure I’m doing that every day. I think when you put it in the big picture though, it’s like anything else. You know, some people do their makeup, it takes an hour. So, it’s putting it into perspective. If it takes you ten more minutes to do your teeth, then just get up ten minutes earlier. You know, it’s just life.” [1011]

The participants were motivated by the noticeable improvements in the way their mouths felt, as well as their desires to achieve successful treatment outcomes. Many also communicated a desire to impress their treating clinician with their self-performed oral hygiene, as they felt they might disappoint them if they didn’t maintain their responsibilities:

“I just don’t want to get back to that point again, to where they were... you guys have done the hard work and done the scraping, so it’s up to me now to continue and keep the hygiene side of it up. So hopefully, when I see someone again next year they will be like, “Oh gosh, your teeth are looking good!”” [1014]
Some of the participants were so self-disciplined with their new routines that they felt guilty if they occasionally did not keep up with their oral hygiene; they would compensate by doing a more thorough job the next day. On the other hand, some were poorly adherent to the oral hygiene recommendations, because they forgot, felt too tired, hadn’t established the habits, or found the interdental brushes too expensive. However, of those who did not adhere to the recommendations, most appreciated their importance and described their intentions to improve their habits in the future.

4.3.3.2 Other clinical recommendations

The theme ‘having a guilty conscience’ was also evident in relation to participants’ nonadherence to other clinical recommendations. One participant was issued an occlusal splint which she struggled to wear comfortably due to the thickness of the acrylic. She described herself as “a bit naughty” for not wearing it, and she resolved to persevere in the hope that it became more comfortable. Similarly, those who had been given smoking cessation advice knew that their treatment was less likely to be successful if they continued to smoke. One participant, who was not successful in her quit attempts, used additional oral hygiene products to those that had been recommended by the clinician, in an attempt to mitigate the effects of her continued smoking.

4.3.4 SUMMARY

A guilty conscience was evident throughout the pre-diagnostic phase, with participants reporting their guilt about the factors which had had contributed to their periodontitis, and for avoiding treatment. During the treatment and post-treatment phases, guilt was also a common finding, when participants did not adhere to the recommendations made by their clinicians.
4.4 PATIENT COMFORT AS PARAMOUNT

The participants frequently identified situations where they experienced physical and/or emotional discomfort throughout the pre-treatment, treatment, and post-treatment phases. ‘Patient comfort as paramount’ thus became an important theme within the data. The factors which relieved the participants’ physical and emotional discomfort have been included in this section.

4.4.1 PHYSICAL DISCOMFORT

4.4.1.1 Pain during the pre-treatment phase

Periodontitis is usually painless, and so physical discomfort was not widely reported in the pre-treatment phase. A few participants described pre-treatment pain arising from tooth mobility, which compelled one to cut his food into small pieces in order to eat comfortably. Another participant’s pain was exacerbated by smoking, which worsened her guilty conscience about her smoking habit. After treatment and once her pain had been resolved, she remarked:

“I don’t have that pain. If you live with pain, you’re quite undertone grumpy. You probably don’t even realise.” [1011]

This perceptive comment highlighted her awareness of the negative effects that her constant pain had upon her mood.

4.4.1.2 Pain during the treatment phase

The participants recounted their experiences of physical pain during their treatment. Several experienced discomfort during the initial diagnostic appointment, usually during radiography, clinical photography, or periodontal probing, although the degree of discomfort experienced varied greatly. Some participants did not mention anything untoward, while one described pain which disrupted his sleep that night, and another described the discomfort from the photographic retractors as the “worst experience [he] had here”. Other participants struggled with the radiographs, commenting that the apparatus was too big, inducing pain and gagging.
Physical discomfort during non-surgical periodontal therapy was almost universally experienced by the participants. The use of local anaesthesia (LA) made it comfortable for most people, most of the time, although many disliked the delivery of the LA. Where the LA was ineffective or the clinician worked on an area which had not been adequately anaesthetised, the participants vividly described the resulting pain:

“If you imagine you’re numb, but there’s a point that’s not... if she touches that with anything, it’s like lightning...” [1009]

Once the LA had subsided after treatment, some participants described how the affected area felt bruised, swollen or tender. Occasionally, they required analgesics for several days to manage this discomfort.

Some participants found their non-surgical therapy uncomfortable despite the use of LA. They used strong adjectives such as ‘horrendous’ and ‘hideous’ to describe the treatment process. When asked to elaborate further, it became apparent that their discomfort was multifactorial, and pain (or potential pain) comprised just one aspect:

“Imagine if you magnify that what you thought was painful by 100, that’s what you feel. But not only me, probably everyone that’s in that chair ’cause it mentally is a hard 45 minutes to get through. The whole, stuck in the chair with the lights... the bite block... the noise... the scraping and the pain.” [1009]

This participant found the treatment particularly difficult to tolerate. He described himself as a person who was sensitive to noise, and he struggled with the sound of the ultrasonic scaler and hand curettes, which he likened to nails on a blackboard. He disliked the treatment process so much that he almost abandoned it partway through. He explained that this was largely because of the pain he was experiencing during and after each appointment. His decision to complete the treatment process was motivated by his desire to preserve his teeth.

Another participant identified a similar combination of factors which made her treatment unpleasant. These included her small mouth, the sounds and the ‘scraping’ sensations. She noticed that her treating clinician was very thorough, remarking that they were “determined to keep going until there was nothing left”. While she described the treatment as ‘rough’ and ‘brutal’ at times, she denied that it was painful:

“It was hideous. I just loathe the drill with a passion, if I could have general anaesthetic I’d be happy. It’s just a horrible process... it’s a funny thing isn’t it?
They say: ‘Does it hurt? ’ and it doesn’t hurt, but you’re waiting for it to hurt... it always feels like they’re using so much force on what you think is a fragile part of your body.” [1007]

This example suggests that, while the treatment itself may not have been painful, her anticipation of pain contributed to her discomfort and aversion to treatment. Several other participants also commented on the ways that auditory, olfactory and gustatory stimuli impacted on their comfort during treatment.

Conversely, some participants did not find the treatment to be unpleasant. One described her treatment as ‘brilliant’, remarking that she “did not feel one piece of anything painful”. Another even explained how she was so comfortable during the treatment that she fell asleep:

“I came up expecting the worst. And it wasn’t the worst. I’ve had three kids so yeah, it was nothing like that. No, most times it was pleasurable. As I say, I fell asleep a couple of times.” [1002]

Despite all participants receiving similar treatment, the variation in the level of pain and discomfort reported may reflect their different pain thresholds, mindsets and coping mechanisms.

4.4.1.3 Pain during the post-treatment phase

In the post-treatment phase, the most significant discomfort identified by the participants was due to dentine hypersensitivity. Some participants remarked that, although they had been warned about this beforehand, they had not expected it to be so unpleasant. A degree of sensitivity was mentioned by most participants, while some were more severely affected:

“Teeth are very sensitive and I am having a lot of pain eating and drinking anything hot or cold. I know it will get better, but at the moment, that seems a long way off, and I am not enjoying eating or drinking... I have started brushing with warm water because I can’t handle the cold water. I really hope it settles down, ‘cause I’m starting to wonder why I even started trying to get my teeth fixed. I know they were horrible before, but at least there was no pain.” [1002]
The above excerpt highlights the extent of the functional limitation that can be caused by severe dentine hypersensitivity, to the point where this participant questioned whether the treatment was worthwhile. Another participant commented that the sensitivity was not helpful for his motivation to adhere to the treatment and self-performed oral hygiene regime.

The participants’ coping mechanisms included using warm water to clean their teeth, and waiting for their drinks to get to room temperature. For some, desensitising toothpaste prescribed by their clinician helped, while others were frustrated that it did not work as quickly or effectively as they would have liked. One participant reported taking multiple daily doses of paracetamol and codeine for a month post-operatively (sometimes exceeding the maximum daily dose), in order to comfortably drink hot or cold fluids.

Over time, however, the participants found that their dentine hypersensitivity reduced, and this facilitated the development of more positive attitudes towards their treatment.

4.4.2 EMOTIONAL DISCOMFORT

The participants experienced a variety of emotions during their diagnosis and treatment for periodontitis. These included anxiety, confusion, embarrassment, disappointment, shock, frustration and anger. Some participants, however, were not surprised by their diagnosis and looked upon it as a positive step as they embarked upon treatment.

4.4.2.1 Anxiety

Anxiety was the most commonly reported emotion throughout the pre-treatment and treatment phases. It was predominantly associated with the initial consultation and non-surgical treatment appointments.

4.4.2.1.1 Anxiety in the pre-treatment phase

Most of the participants felt anxious or worried prior to their initial appointment, because they did not know what to expect. Many were unaware of their periodontal condition prior to the initial consultation, and they were unsure of what the appointment might
entail. Others, especially those referred from private dental clinics, were nervous about the prospect of seeking treatment at the University clinic (a teaching hospital), and the level of experience of their student clinician:

“I was surprised by the level of autonomy, just ‘cause I didn’t know anything about her, but I did realise she obviously knew what she was doing. I didn’t know what to expect... and I suppose being a teaching hospital and my experience with medical or anything like that, in a teaching environment... those people are always accompanied by [someone] more senior... so that was my model, that’s what I was thinking.” [1007]

During the initial examination appointment, the participants were concerned about what the clinician might find, particularly when they heard them relaying information to their assistant or the supervising periodontist. In some cases, the participants felt so overwhelmed by their nerves that they were unable to fully absorb the information provided. For example, one participant overheard her clinician ask the dental assistant to note down a tooth that required an extraction. She was so upset by this news, and the fact that it was not delivered directly to her, that she was unable to process any other information given to her on this day. As a result, she had a poor understanding of her diagnosis and proposed treatment until the next appointment, when she was able to engage in a dialogue with the clinician and ask questions.

Another participant was anxious that the dentist would confirm his fears and suspicions at the initial consultation:

“I think getting told what I already knew... and it’s just a new environment. I think it hit me more when [clinician] told me that, what I’ve already known... about the gum disease, about this colour... why it’s bleeding and that if I don’t start the treatment now, there’s a possibility that at least four of my teeth will fall out...” [1004]

This excerpt implies that this participant felt anxious about having to confront the reality, after concealing it from himself and others.

After the diagnostic appointment, many participants commented that they were not looking forward to the treatment. Although they had been informed about their diagnosis and treatment plan, many seemed unsure of what it would involve and were concerned
about the potential cost. Their lack of understanding about the proposed treatment may have also been related to the amount of information given at the consultation appointment, which overwhelmed some participants and affected their ability to retain the clinician’s advice.

Moreover, after diagnosis, the possibility of tooth loss was another source of anxiety for the participants. Many seemed preoccupied by the suggestion that untreated periodontitis might lead to tooth loss. Despite having a treatment plan, some were also concerned that they had left it too long to save their teeth, which they considered to be a ‘worst-case scenario’:

“Sometimes all I could think about was having no teeth and both my lips sunken in like a dirty old man on the street... Just look at someone trying to take a bite out of an apple with no teeth.” [1006]

4.4.2.1.2 Anxiety in the treatment phase

Anxiety was also frequently reported during the periodontal treatment phase. One participant explained the physical effect of her anxiety, despite having treatment with LA:

“I was anxious throughout the whole process: body tensing, holding my breath, clenching my hands. [Clinician] was great, she kept reassuring me: ‘I’m doing well, well done’” [1008]

Generally, as the participants built rapport with their clinicians and became familiar with the procedures, their anxiety reduced as their treatment progressed. However, one participant found that simply arriving at the Dental School made him feel anxious, even after he had completed his treatment:

“Even though I didn’t get that much treatment in my last visit, I’m still a bit nervous. I think just initially walking through the door, you’re just instantly nervous.” [1004]
4.4.2.2 Confusion
Some of the participants felt confused after their consultation appointment, and could not recall being explicitly informed about the diagnosis and what to expect during the treatment. One participant described how she had to deduce this information for herself by listening to her dentist speak to other members of the team, and this was complicated by their use of jargon. Some felt that visual aids, or some written information about periodontitis might have helped them to understand better. Those who felt confused about their diagnosis indicated that they would have preferred the clinicians to spend more time discussing the diagnosis and proposed treatment with them.

4.4.2.3 Embarrassment
In the pre-treatment phase, many of the participants were ashamed of their periodontitis, which was closely linked to the theme ‘concealment’. Since this was discussed earlier in this chapter, it will not be repeated here, other than to emphasise that feelings of shame and embarrassment were common among the participants. Moreover, many of the participants felt embarrassed about their condition during the treatment phase. Those who were ashamed of their teeth—and who were accustomed to concealing them—felt uneasy revealing them in such close proximity to the clinician and assistant. The physical layout of the clinic in the Faculty of Dentistry was not helpful in this regard, because some found it difficult to relax in the open and busy environment, due to concerns about their privacy.

The participants were also worried that the clinician might judge them on their oral hygiene or think that they were unhygienic. Upon hearing his clinician recording PPD, one described the disappointment he felt in himself for letting his mouth deteriorate:

“I felt a bit let down in myself, thinking I’ve got you know, 12s and 9s and that... Because it’s not good when she’s telling the assistant... I’m not stupid, and I felt embarrassed...” [1005]
4.4.2.4 Disappointment

As well as being disappointed in themselves for letting their periodontitis progress, a few participants expressed disappointment in their past dental providers. This disappointment was related to previous unsuccessful periodontal treatment, or inadequate information about their condition:

“I used to go to the dentist quite often, my dentist, and I would go in maybe once a year and get them scaled. But that sort of annoyed me a bit when I found out, like when I came here and they actually told me, that I have got, I mean, I did have a small problem. That dentist, getting me to go, without explaining stuff... ‘It’s alright, I’m paying the bill...’ and it’s ongoing... so it’s like you know, ‘We’re not going to tell you, we’ll just keep getting you in.’” [1006]

4.4.2.5 Frustration and anger

One participant was angry with herself for neglecting her periodontal health, while another felt frustrated at being diagnosed with a problem which he thought would affect older people. A majority of the participants became more conscious of the disease after their diagnosis. It remained at the forefront of their minds for some time, as a heightened awareness of the way their teeth looked and felt, what they ate, and how they cared for their teeth. For one participant, however, this increased awareness bordered on obsession, which became distressing:

“I can clearly say that 95 or 96 percent of the time, I am constantly thinking about the disease every day, more than when I didn’t know [about it]. Especially in the mornings, and at nights... I constantly think about it, due to brushing [my] teeth and [my] gums bleeding. Back then, when I wasn’t told, it didn’t concern me, but I did have thoughts about it, and getting told [about the diagnosis] after that check-up, I’m constantly thinking about it.” [1004]

This diary excerpt depicts the incessant psychological impact that the diagnosis had upon him. This was explored further in the follow-up interview:

“There was a period of the process that I was constantly thinking about it, and it made me slightly depressed that I actually did have this gum disease... and I just couldn’t stop thinking about it. That was one of the reasons why I just had to push it away, just leave it alone... ’cause everything that I was doing, I was thinking
about it, and it just got to the point where I started feeling angry, I started feeling ashamed that I didn’t do anything about it. You know how you put things in the back of your mind and then you can forget about it? Yeah, I couldn’t forget about it.” [1004]

As well as the profound and relentless impact of the diagnosis on the patient himself, he reported its effect on his family. The realisation that his anger affected his wife and children almost caused him to withdraw from the treatment:

“I think even my kids knew that I had a different anger that came out... I wasn’t engaging before like what we usually do... and [my wife] did ask me, she goes: ‘Oh, this is a different wairua10. ’ She knows when I’m angry and she knows when I’m angry at sports... or at studying and that, but she was saying this one’s slightly different...” [1004]

This participant noted that his anger and preoccupation improved once he began to discuss his feelings about his diagnosis with other people. He first disclosed them to a dental assistant (in the clinic) who had supported him throughout his appointments. She reassured him and remarked on his progress, which improved his confidence and encouraged him to continue with the treatment. While he believed that her reactions to the physical effects of treatment were ‘over the top’, he believed that if they were noticeable to her, they might also be perceptible to others, which further motivated him to persevere with the treatment.

4.4.2.6 Shock
As discussed in relation to the sub-theme of stigma, the diagnosis of periodontitis was a shocking revelation for some participants, who did not consider themselves the ‘type of person’ who might suffer from this disease, as well as those who had not experienced any symptoms. On the other hand, some were relatively unperturbed by their diagnosis, usually because they had been expecting it. Some of the participants who had been ‘expecting the worst’, felt relieved upon diagnosis, because it represented the first step towards managing their periodontitis. Nevertheless, many of the participants who were

10 Wairua is a New Zealand Māori word which translates to the spirit or soul of a person.
unsurprised by their diagnosis still reported emotional discomfort throughout the diagnosis and treatment appointments, as described in the preceding section.

4.4.3 SUMMARY

Their physical and emotional comfort was of paramount importance to the participants as they progressed through their diagnosis and treatment. Most considered their non-surgical therapy to be unpleasant, and many struggled with the physical discomfort associated with post-operative dentine hypersensitivity. While anxiety was the most common emotion in the pre-treatment and treatment phases, the participants’ emotional discomfort decreased over the treatment phase.
4.5 PROGRESSION TO A MORE POSITIVE OUTLOOK

The underlying core theme ‘progression to a more positive outlook’ described how the participants’ attitudes improved as they transitioned from the pre-treatment phase, through diagnosis and treatment, to the post-treatment phase. This was closely related to the three main themes, as their ‘need to conceal’, their ‘guilty consciences’, and ‘physical and emotional discomfort’ also reduced as they progressed through treatment. This core theme was related to the three sub-themes of the participants’ pre-treatment and post-treatment attitudes, and the patient-dentist relationship (which played an important role in the participants’ improved outlook). Each of these sub-themes is discussed below.

4.5.1 PRE-TREATMENT ATTITUDES

The participants’ attitudes to their disease prior to treatment have been discussed in detail in the preceding sections, so this section will serve as a summary to which their post-treatment attitudes can be compared.

Prior to diagnosis and treatment, many of the participants felt ashamed and guilty about their symptoms, and the behaviours that may have contributed to their periodontitis. They were aware of the social stigma attached to periodontitis and thus attempted to conceal their disease from those around them. Most of the participants kept their concerns private from others, and this might have exaggerated their magnitude.

Initially, a negative outlook was common among the participants. Anxiety was the most widely reported emotion, and it was usually related to the participants’ fears of the unknown: the extent of their disease; what the treatment would entail; and the prognosis for their teeth. Some expressed defeatist or fatalistic views:

“I would be like: ’Okay, there is another one gone’… I came to the conclusion that maybe my teeth were all just going to fall out.” [1014]

Although the majority began with a relatively negative mindset, several participants maintained a positive outlook throughout the whole experience of diagnosis and
treatment for periodontitis. One who had been oblivious to his periodontal issues before diagnosis kept it in perspective by comparing it to something worse:

“Well, it’s not as if you’ve got cancer and you’re dead by Christmas really, so you know, you just get on and get the job done. If that’s the worst thing that happens to me in the next twenty years, I’ll be doing pretty good.” [1010]

Participants were generally nervous about taking the first step towards seeking treatment, but attending the initial diagnostic appointment put some of the participants at ease:

“[I was] a bit anxious, nervous. But sort of proud in a way that I was finally getting something done about it. I was more anxious of what they were going to do, really. And how they were going to fix my problem that I created. I didn’t know what the outcome was going to be, but at least something was going to happen, and I might feel you know, start feeling a bit better about myself.” [1002]

Although this participant identified that she was afraid of the unknown, she (and others) was motivated by the prospect of moving forward and facing the issues which had bothered her for a long time.

Similarly, participants whose ruminations had inflated their expectations of their disease severity were relieved to discover the reality upon their diagnosis:

“In my mind, I thought that my teeth were just stuffed and they were going to pull them all out and that would be it, and I would get false teeth. So, it was probably a little bit of a relief to know that it was something that could be saved, my teeth could be helped. And if I looked after them and got these things done, then it would make it better for me in the long run. I mean, they said my front teeth are actually really good, because I think I thought I had the worst teeth in the world.” [1014]

### 4.5.1.1 Summary

Before their diagnoses, many of the participants catastrophised about the severity of their disease. They were anxious and worried about how their periodontitis would be managed. While the initial diagnostic appointment provided some relief, the prospect of treatment remained a concern for most.
4.5.2 POST-TREATMENT ATTITUDES

Although the participants did not find the treatment process pleasant, their outlook became increasingly positive as they moved through it. This shift in mindset was evident in the contrasting ways in which the participants described their experiences before and after treatment.

4.5.2.1 Effects of treatment

Upon completion of their non-surgical therapy, the participants recognised some resulting physical changes. Many commented that their teeth felt cleaner than before, a sensation which they enjoyed:

“*My teeth do feel better for it. I couldn’t get over the difference, when I rub my tongue along them, I actually feel individual teeth, when I haven’t felt that for years...”* [1002]

The participants also noticed that they had fresher breath, and an improved sense of taste. The resolution of their halitosis allowed the participants to break the habits they had developed to hide it (as described in the ‘concealment’ section), which, in turn, had positive social implications for them.

4.5.2.1.1 Gingival bleeding

Pre-operatively, gingival bleeding was nearly unanimously reported by the participants. After treatment, nearly all of the participants also described a significant reduction in their gingival bleeding. Many considered it a gauge of treatment success:

“The bleeding was the main concern right from the kick-off. Even now, some nights, instead of doing the dental brushes, I’ll floss, just to really test the gums out and see if they bleed. I think a couple of nights ago, there was a faint trace of a bit of blood and then last night, there wasn’t, so I’m telling myself that it’s working.” [1010]

Since the reduction in bleeding was tangible to the participants, they could clearly see the positive effects of the treatment, and this motivated them to continue with their self-performed oral hygiene routines.
4.5.2.1.2 Improved appearance

The participants also commented on the aesthetic effects of their periodontal treatment. They noticed their teeth were cleaner and whiter than before, and this had a positive impact on their self-esteem:

“Looking at my teeth, they’re beautiful, in comparison to when I first came, and the gums do look good, none of that disgusting black stuff on the teeth, so I feel quite nice in that respect.” [1011]

Another participant did not consider her teeth to be perfect but felt uplifted by the difference made by the treatment all the same:

“They’re still not perfect, they’re always going to be discoloured, but they feel clean, they don’t have that furry feeling. I can see that I’ve had treatment for my teeth and my gums, they look a bit cleaner, and that makes me feel happier.” [1012]

4.5.2.1.3 Increased interdental spaces

Increased spacing between teeth is a common side-effect of periodontal treatment. While the majority of the participants found this to have occurred, they did not dwell on it; rather, they approached it with a positive mindset:

“I would rather have a gap than the plaque. And they are probably a wee bit whiter even.” [1014]

Another participant mentioned “being able to have the gaps”, as if she considered it to be an advantage. She felt that the increased spacing facilitated her cleaning with interdental brushes, and this was satisfying to her, because she described herself as a ‘clean person’.

Even when faced with the annoyance of food entrapment in the increased spaces, the participants were not resentful but remained positive:

“I do feel now, if I have got food trapped, a lot more than what I did. But it is easy to poke out and get rid of it. I am a bit more pro-active in the mouth hygiene area these days.” [1013]
One participant who took a lot of pride in her appearance was more perturbed by her larger interdental spaces than some of the others. While she disliked them, she had accepted them regardless, because she considered them to be a trivial annoyance relative to tooth loss:

“They’re gappier, the gaps between are bigger. I do notice it, but then again, it’s just something that is. So, I’m sort of resigned to the way they look, and I just hope that I can keep them.” [1001]

4.5.2.1.4 Dentine hypersensitivity
The participants’ struggles with post-operative dentine hypersensitivity were discussed in relation to the theme ‘patient comfort as paramount’, so they will not be repeated here. However, it is noteworthy that they had a more positive perspective on this topic during their interviews, than in their diaries. Many of the participants were experiencing severe sensitivity during the diary phase, and their entries reflected their frustration. By the time of the interview, however, the severity of their symptoms had reduced, and other positive effects of treatment were evident, so they placed less emphasis on their negative experience of dentine hypersensitivity.

4.5.2.2 Reflections on the treatment process
4.5.2.2.1 Positive post-treatment attitudes
The participants’ reflections after treatment were appreciative and optimistic. The tangible physical improvements in their symptoms led to improvements in their self-esteem, mood and social relationships:

“I started opening up about it and the process that I’m going through. That process, coming here, made me more confident.” [1004]

As discussed previously in this chapter, the periodontal treatment empowered the participants and allowed them to cease the concealment behaviours which had affected their psychological and social wellbeing in the past. While they admitted that, at times, the process was not pleasant, they felt that the resulting improvements had been worth it. The participants were proud that they had taken steps to address their periodontitis, and felt optimistic about the future:
“It’s quite nice to not give a shit, excuse my language, about what people think now. I think I just had to get to that point. I just think the only way to get them fixed is to go through the process and that might be a bit embarrassing and what have you. But you know, in a few weeks, I should have some teeth. And that is pretty cool. So, I think it’s worth going through a bit of whatever… I think I just probably have a bit more positive outlook. ‘Cause I know that it’s being dealt with, and soon we’ll have some other ones in there. Moving forward, I can try and just maintain it, and keep it. So, I feel my approach to it is different, ‘cause I don’t feel helpless.” [1011]

4.5.2.2.2 Pathways to a more positive outlook

Each participant’s trajectory towards a more optimistic state was not always straightforward. After commencing treatment, the periodontal diagnosis had such a profound impact on one participant that it became all-consuming and depressing, such that he almost withdrew from the treatment. However, he was encouraged and motivated to continue by the improvements he (and others) had noticed to date, and by becoming more open about his experiences. Upon completion, his mindset and attitude towards the future were overwhelmingly positive, since he had noticed the wider benefits of the treatment upon him and his psychosocial wellbeing.

Another participant described how he almost quit treatment partway through, due to the severe discomfort it was causing him, and his aversion to dental treatment:

“You’re in a compromised position, you’re under the light, you’re stuck, it’s not easy to open your mouth, I use the bite block[11]. Sometimes you feel like jumping up and saying, you know… “My teeth aren’t worth that…” ” [1009]

He later decided to complete his treatment, motivated by his own integrity to see it through:

“I did have a tizzy fit half way through and really felt like chucking it in... But I’d like to see myself as someone who can handle things and not quit... and she’s just trying to do stuff to make my teeth better. You know, you sign up for something, you go through with the whole thing, I just don’t waste people’s time.” [1009]

[11] A bite block is a device which is used to prop the mouth open during dental procedures. It is used when an individual finds it difficult to hold the mouth open.
The different experiences reported by the participants reflected a range of personalities and coping mechanisms. One participant remarked on the little impact that the process had upon him, because he considered himself a confident person:

“If you’re a confident person, you don’t let things like that knock you back anyway... you go forward don’t ya? That’s why the eyes are in the front of your head...” [1005]

4.5.2.2.3 Reflections on the financial costs

The participants unanimously considered the financial cost of treatment to be worthwhile (including those who were particularly conscious about money and had frequently mentioned it in their diaries and interviews). Many were surprised that the costs were so low, and considered themselves fortunate to be able to access treatment through the Faculty of Dentistry. Despite the lower costs, some were so pleased about the fact that they were finally receiving treatment that they would have been prepared to pay more:

“I didn’t really care, just because I was having the treatment. I didn’t really care how much it was going to cost.” [1001]

They considered the financial outlay for treatment to be insignificant when they contemplated the benefits they had gained from the experience, which included improvements in their periodontal health, as well as their increased awareness and knowledge. Some thought it might even save them money in the long term, because having better periodontal health might reduce their future need for more complex dental treatment:

“It was really worth it ‘cause I learnt so much about my teeth, so it’s probably gonna save me a few dollars in the long run.” [1006]

4.5.2.3 Thoughts about the future

The interviews explored the participants’ views towards their future with periodontitis, and most expressed a positive outlook. A majority considered that their disease was under control, while recognising that their own behaviours had a significant bearing on their future periodontal outlook:
“As long as I keep doing what I’m doing, I think they said they will be alright. I mean, by the time I am 70, I am probably not going to be too worried... I want to keep my teeth as long as I can... and by having this done, I think it has enabled me now to be able to do that. Otherwise, I would’ve left them too long and I would have had to probably take them all out.” [1014]

The participants recognised their role in maintaining periodontal health, accepting that they were responsible for preventing disease progression through self-performed oral hygiene, avoiding smoking, and seeking regular professional care. Thus, their motivation was largely internal, and this was often related to their concerns about tooth loss:

“I don’t want to lose any more of the bottom teeth either, because I’ve had it explained to me that that’s quite different, a bit harder to deal with if you do lose those, so let’s hope I can be disciplined.” [1011]

This excerpt illustrates how, instead of feeling worried and resigned to inevitable tooth loss (as they were at the start of treatment), their outlook became more positive by converting their concerns into motivation to continue with their home care regimes.

The participants’ optimistic attitudes at the completion of non-surgical treatment were also linked to the possibility of replacing their missing teeth. One described her excitement at the prospect of receiving prosthetic tooth replacements:

“I think the main thing is excitement now. I feel like I have a clean mouth, and that’s quite nice not to have bad breath, or those sorts of things. I just really want to have some new teeth in there, so that I can smile and be happy and eat properly, on both sides of my mouth, not just rely on the right side of my mouth. Life will be probably a lot easier, and I don’t think I’ll take it for granted, my teeth for granted so much in the future, because once they’re not there, you just don’t realise how important they are.” [1011]

4.5.2.4 Summary

The participants underwent a mindset shift as they progressed through treatment, and a contrast between their pre- and post-treatment attitudes was apparent. While they expressed negative and resigned feelings at the outset, they became more optimistic as they perceived more control over their periodontitis. Their attitudes towards the future
were positive, as were those to some side-effects of treatment, which can be poorly tolerated by other periodontal patients. Upon reflection, the participants were grateful and proud of the changes it had made in their lives. While they recognised that it had not been easy, they were self-motivated to maintain their treatment outcomes, and the improvements in their symptoms and psychosocial wellbeing had made it worthwhile.

4.5.3 PATIENT-DENTIST RELATIONSHIP

The participants described the ways which the relationship with the clinical team helped them throughout the diagnosis and treatment phases. This relationship was instrumental to their transition to a more positive outlook as they underwent periodontal treatment.

4.5.3.1 Communication

The participants identified good communication as the most important skill they would like their treating clinicians to possess. Since many felt anxious, it was important for the clinician to have a kind, non-judgemental, and understanding manner. This facilitated the development of trust and rapport between the participant and dentist:

“To me, particularly, it’s having an understanding, or being able to empathise with- because I always explain how nervous I am, and my fears and all that sort of stuff. Some people take it on board and some don’t.” [1001]

Most participants were satisfied in this regard and described ways that the clinicians used their interpersonal skills to put them at ease throughout their treatment:

“I think she’s got my best interests. At times, she’s had to tell me stuff I don’t want to hear, and we’ve obviously both gone away and had a think about the reaction to some of that, especially from the beginning. So, she definitely takes my concerns or my dislike for the environment into consideration and she passes that onto whoever else is working with her, and I think that’s really cool. She started explaining everything too, and it wasn’t patronising, so that’s nice.” [1011]
4.5.3.1.1 Information delivery

Participants also described the importance of being fully informed about the treatment. They were highly appreciative when their clinician took the time to thoroughly explain the diagnosis and proposed treatment plan in a way that they could understand:

“[Clinician] told me everything that she was going to be doing and what was going to happen before she started, which was a good thing. All dentists need to tell you what’s going to be happening, instead of just diving right in.” [1003]

Many others echoed this, and they considered the delivery of information to be an important part of the treatment. The participants found it reassuring to have their treatment explained in a stepwise fashion, so they knew what to expect:

“The two who looked after me explained what was happening, so they calmed my nerves a wee bit. They took it step-by-step, and they were constantly asking me if I was alright, which was quite good. It took the scary thoughts of what was happening away, and made the poking around in the mouth quite relaxing for me.” [1004]

Several also recalled analogies that had been used to aid their understanding; the participants thought these were an effective communication tool. Others appreciated the use of a mirror or other visual aids to reinforce the information. Some of the participants admitted that they had sought further information independently (such as conducting an internet search about periodontitis), and this helped them to come to terms with their diagnosis.

4.5.3.1.2 Inadequate communication

Some participants described situations where the communication was not satisfactory. They described the use of jargon as ‘unsettling’ and felt that clinicians sometimes assumed that they understood what was happening, instead of explaining it properly. The participants highlighted the importance of being fully informed, since it involved them in the treatment process:

“I like to be told what’s going on. Especially when it’s your body, your mouth. I’m one of those people that just needs to know stuff, and then I get my head around it, and then it’s cool. It’s when there are surprises, that I’m not at one with it. So, I think it’s quite good to discuss the plan. And I think it was a couple
of weeks in before that happened, and that worked better for me. Knowing exactly and just maybe having some of the decision-making.” [1011]

One participant who had a fear of dental treatment was initially assigned to a clinician who she struggled to understand:

“’I just couldn’t understand him. He spoke really quickly, and I wasn’t sure what he was doing, it was probably because he wasn’t explaining as he was going what was happening. So, I always kept having questions, and thinking ‘Well what... so what am I doing, what’s happening here?’ And he probably couldn’t explain to me either, it just was an unusual situation, because I was like oh God, I don’t know what this man’s actually doing...which is terrible. I mean he was a lovely man, don’t get me wrong, but I just could not understand a word he was saying and I don’t know whether he thought I already knew what was happening...but he probably didn’t think to tell me... and it sort of put me off, because then the next time I was like, ‘Oh I don’t really want to go back there now!’” [1014]

The participant explained how the communication difficulties (in part due to a language barrier) caused her to lose confidence in him as a clinician because she did not feel he could adequately inform her about the treatment she required. After seeing him for two appointments, she asked to see a different clinician.

Her experiences with the second clinician were much more positive, and the participant was immediately put at ease. She was grateful to be involved in conversations on an equal level, and to receive clear information which was easy to understand:

“’Straight away I felt like: ‘Oh, okay it’s fine’. She’d say: ‘We’re just going to do the top left, and then you can have a break and then we’ll do, the bottom, it may hurt a wee bit along the front here because it’s a bit more sensitive.’ I just felt so much more comfortable. Her and the other lady also just chattered away, they were just chatting about their day and so I felt really comfortable. I suppose I just related to them a bit easier. And I could ask her questions and know that she would answer them, and I would understand what she was saying.’” [1014]
This participant went on to explain how she no longer had a fear of dentists and was looking forward to her next appointment:

“Honestly, she was fantastic. I don’t even have a slight fear now of even going to the dentist, that’s completely gone... I have a completely different view now, than what I would’ve had before. Next time I get an appointment it will be like, yep definitely keep it, go, get it done, because this is going to be so much better for my teeth. And they feel so much better.” [1014]

These excerpts depict the change in this participant’s attitude which occurred during her treatment, and they highlight the significant impact that communication may have on a patient’s experience of treatment.

4.5.3.2 Power and control

The participants also referred to the power dynamics of the patient-dentist relationship. Since many of the participants were anxious and afraid of the unknown at the start of their treatment, they appreciated being treated with respect by the professionals. When the participants perceived a degree of control over the treatment, they were more satisfied.

For many, simply being told by the clinician that they could raise their hand whenever they wished to take a break during the treatment gave them some control:

“I think it’s being heard, when you’ve had enough. And I’ll give you a credit there, she always listened. So, it’s having that trust that they’ll listen to you when you need to stop. Or you don’t feel bad that you need to have a spit. So, I think you’ve got to have that reassurance of that person that’s the lead person.” [1011]

The participants found that having some involvement in their own treatment decisions, as well as noticing improvements in their symptoms, helped to motivate them to complete the treatment.

One participant who found the treatment uncomfortable and difficult to manage described his coping mechanisms:

“I’d rather have the sucker where I know it’s being effective, not the assistant just sitting there thinking they’re doing it, but deep down, I’m nearly choking.
and she’s not really doing it, so I’d rather just hold it. It’s anything to get you through it. Like the bite block, I’ve gotta have it pulling the chain, I dunno why, but it helps... it just kind of makes me feel like I’m more totally in position, I’ve got the chain.” [1009]

This suggests that this participant perceives a greater degree of control, and thus copes with the treatment better, when he is holding the suction or the chain for the bite block.

The participants also described situations where they felt powerless or belittled during their interactions with their treating clinicians. A booking error meant that one participant had an appointment with a different clinician to her regular one. She compared them, noting that one clinician talked to her throughout the treatment, even though she couldn’t respond, while the other spoke only to the dental assistant, without stopping to check whether she was all right. The latter left her feeling unimportant and vulnerable, while being involved in the treatment process by the first clinician made her feel valued and empowered. Similarly, this participant described how she felt belittled and humiliated about her oral hygiene:

“It’s like being called into the principal’s office and told off because I’m not brushing my teeth properly. Well, I sort of know I’m not brushing my teeth properly. Because that’s why I’m here. I know I haven’t been doing it, but after 46 years it’s hard to change habits.” [1002]

On the other hand, the participants also expressed a desire to please their treating clinician. They recalled the positive feedback they had received and frequently recounted this in their diaries or interviews. This helped them to remain motivated to keep up their oral hygiene routines. One participant felt concerned that if he did not maintain his oral hygiene, he would be personally letting his clinician down:

“If I come back in here next year, and they say ‘you’ve got gum disease’, I’ll be really pissed off with myself. I’d be letting [clinician] down, and this place down, basically, and myself.” [1006]

4.5.3.3 Summary

The participants recognised the importance of effective communication with their clinician throughout their periodontal treatment. They also described their perceptions of
the power dynamics within this relationship. A positive relationship with their clinician was central to their comfort and motivation, and played an important role in their progression to a more positive outlook.
CONCLUSION

The qualitative data analysis gave rise to the three key themes of ‘concealment’, ‘having a guilty conscience’ and ‘patient comfort as paramount’, which collectively demonstrated the broad psychosocial impact of periodontitis and its treatment on the participants. These themes were underpinned by a core theme, termed ‘progression to a more positive outlook’, which depicted a positive shift in the participants’ mindsets which occurred alongside their treatment. These findings suggest that the effects of periodontal treatment may surpass the traditional biomedical outcome measures, by improving patients’ attitudes and psychosocial wellbeing.
Chapter Five  – Quantitative Findings

5.1.1 INTRODUCTION

This chapter will present the quantitative findings of this study. These include the fourteen participants’ responses to Locker’s global oral health item, the four self-report periodontal screening questions, and their OHIP-14 scores.

5.1.2 LOCKER’S GLOBAL ORAL HEALTH ITEM

The participants’ responses to Locker’s global oral health item at baseline and follow-up are presented in Table 5.1.

Table 5.1. Responses to the Locker item, at baseline and follow-up

<table>
<thead>
<tr>
<th></th>
<th>N (%)</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>0 ( - )</td>
<td>0 ( - )</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>0 ( - )</td>
<td>0 ( - )</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>3 (21.4)</td>
<td>7 (50.0)</td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>8 (57.1)</td>
<td>4 (28.6)</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>3 (21.4)</td>
<td>3 (21.4)</td>
<td></td>
</tr>
</tbody>
</table>

No participant scored their own oral health as ‘excellent’ or ‘very good’ at either baseline or follow-up. At baseline, just over half reported their oral health to be ‘fair’, while at follow-up, half reported their oral health as ‘good’.

These scores were cross-tabulated to compare the changes in self-reported oral health status which occurred after the treatment. The findings are presented in Table 5.2.

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Table 5.2. Responses to the Locker item at follow-up, by baseline response

<table>
<thead>
<tr>
<th>Baseline score N (%)</th>
<th>Follow-up score N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>3 (100.0)</td>
</tr>
<tr>
<td>Fair</td>
<td>0 (–)</td>
</tr>
<tr>
<td>Poor</td>
<td>0 (–)</td>
</tr>
<tr>
<td>Good</td>
<td>2 (25.0)</td>
</tr>
<tr>
<td>Fair</td>
<td>3 (37.5)</td>
</tr>
<tr>
<td>Poor</td>
<td>3 (37.5)</td>
</tr>
<tr>
<td>Good</td>
<td>2 (66.7)</td>
</tr>
<tr>
<td>Fair</td>
<td>1 (33.3)</td>
</tr>
<tr>
<td>Poor</td>
<td>0 (–)</td>
</tr>
</tbody>
</table>

None of the three participants who originally rated their oral health as ‘good’ reported a worse score after treatment. Of the eight individuals who scored ‘fair’ at baseline, at follow-up, three improved, three remained ‘fair’, and three worsened to ‘poor’. These were the only three individuals in the sample whose Locker’s global oral health rating was worse at follow-up than at baseline. The self-rated oral health of those who scored ‘poor’ at baseline all improved. Two scored ‘good’, and one scored ‘fair’ at follow-up.

5.1.3 SELF-REPORT PERIODONTAL SCREENING QUESTIONS

The participants’ responses to the four self-reported periodontal screening questions at baseline and follow-up are presented in Table 5.3.
Table 5.3. Responses to the self-reported periodontal questions at baseline and follow-up

<table>
<thead>
<tr>
<th>Self-reported questions</th>
<th>Responses</th>
<th>Baseline N (%)</th>
<th>Follow-up N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think you have gum disease?</td>
<td>Yes</td>
<td>9 (64.3)</td>
<td>13 (92.9)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2 (14.3)</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td></td>
<td>Do not know</td>
<td>3 (21.4)</td>
<td>0 (–)</td>
</tr>
<tr>
<td>Has a dental professional ever told you that you have lost bone around your teeth?</td>
<td>Yes</td>
<td>7 (50.0)</td>
<td>10 (71.4)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2 (14.3)</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td></td>
<td>Do not know</td>
<td>5 (35.7)</td>
<td>2 (14.3)</td>
</tr>
<tr>
<td>Have you ever had scaling, root planing, surgery for gum disease?</td>
<td>Yes</td>
<td>6 (42.9)</td>
<td>13 (92.9)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>7 (50.0)</td>
<td>0 (–)</td>
</tr>
<tr>
<td></td>
<td>Do not know</td>
<td>1 (7.1)</td>
<td>1 (7.1)</td>
</tr>
<tr>
<td>Have you ever had teeth that have come loose by themselves without some injury (not baby teeth)?</td>
<td>Yes</td>
<td>7 (50.0)</td>
<td>8 (57.1)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>6 (42.9)</td>
<td>6 (42.9)</td>
</tr>
<tr>
<td></td>
<td>Do not know</td>
<td>1 (7.1)</td>
<td>0 (–)</td>
</tr>
</tbody>
</table>

Prior to their consultation appointments, just under two-thirds of the participants believed that they had gum disease. After treatment, all but one participant (92.9%) considered themselves to have gum disease. Similarly, at follow-up, thirteen participants responded positively to the question about previous treatment for gum disease. The remaining participant responded ‘do not know’. A greater proportion of participants also responded positively to the questions pertaining to periodontal bone loss and tooth mobility at follow-up than at baseline.

5.1.4 OHIP-14

5.1.4.1 Total OHIP-14 scores

A scatterplot of total OHIP-14 scores at baseline and follow-up is shown in Figure 5.1. A lower OHIP-14 score represents better OHRQoL.
At baseline, the total OHIP-14 scores ranged from 0 to 34. At follow-up, the total OHIP-14 scores ranged from two to 33. On the above scatterplot, the data points that lie beneath a line drawn to bisect the x and y axes represent the five participants whose OHRQoL improved (that is, the OHIP-14 score decreased) after periodontal treatment. Those above the line represent the seven participants whose OHRQoL worsened (their OHIP-14 score increased). One participant’s total OHIP-14 score remained the same on both occasions.

The mean OHIP-14 scores were compared at baseline and follow-up. The mean baseline OHIP-14 score was 14.0 (SD 12.5). At follow-up, the mean OHIP-14 score increased to 15.4 (SD 11.0). No statistically significant difference between these scores was detected ($p = 0.34$). The increase in mean OHIP score represents an effect size of 0.1, which is small.
5.1.4.1.2 Prevalence of 1+ OHIP-14 impacts

The number of participants who scored ‘fairly often’ or ‘very often’ for one or more impacts in the OHIP-14 questionnaire are presented in Table 5.4.

**Table 5.4.** Prevalence of one or more OHIP-14 impacts ‘fairly often’ or ‘very often’ at baseline and follow-up

<table>
<thead>
<tr>
<th>1+ OHIP-14 impact</th>
<th>Baseline</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes N (%)</td>
<td>7 (50)</td>
<td>8 (57.1)</td>
</tr>
<tr>
<td>No N (%)</td>
<td>7 (50)</td>
<td>6 (42.9)</td>
</tr>
</tbody>
</table>

At baseline, half of the participants reported experiencing one or more OHIP-14 impacts ‘fairly often’ or ‘very often’. At follow-up, the number of participants reporting one or more impact increased by one. The changes which occurred within these groups as a result of treatment are presented in Table 5.5.

**Table 5.5.** Prevalence of one or more OHIP-14 impacts at follow-up by baseline prevalence

<table>
<thead>
<tr>
<th>Follow-up</th>
<th>Baseline</th>
<th>No OHIP-14 impacts, N (%)</th>
<th>1+ OHIP-14 impacts, N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>No OHIP-14 impacts, N (%)</td>
<td>5 (71.4)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td></td>
<td>1+ OHIP-14 impacts, N (%)</td>
<td>1 (14.3)</td>
<td>6 (85.7)</td>
</tr>
</tbody>
</table>
Of the participants who reported no OHIP-14 impacts before treatment, just over two-thirds also reported none after treatment. However, the remaining individuals in that group reported more than one OHIP-1 impact at follow-up, reflecting a worse OHRQoL. Similarly, the majority of participants in the group who reported one or more OHIP-14 impacts at baseline also reported these impacts at follow-up, while one participant did not, whose OHRQoL score had improved after treatment.

5.1.4.1.3 OHIP-14 by Locker’s global oral health item

The participants’ mean OHIP-14 scores, and the mean number of OHIP-14 impacts at baseline and follow-up were compared against their Locker’s global oral health ratings as a concurrent validity check for the OHIP-14. The data are presented in Table 5.6.

Table 5.6. Mean OHIP-14 scores and mean number of OHIP-14 impacts by Locker’s item at baseline and follow-up

<table>
<thead>
<tr>
<th>Locker’s item</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Baseline</td>
<td>Follow-up</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>3</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Mean OHIP-14 (SD)</td>
<td>2.3 (1.5)</td>
<td>17.0 (13.6)</td>
<td>17.7 (13.6)</td>
</tr>
<tr>
<td>Mean no. of OHIP-14 impacts (SD)</td>
<td>0.0 (–)</td>
<td>2.6 (2.9)</td>
<td>3.0 (2.7)</td>
</tr>
</tbody>
</table>

The mean OHIP-14 scores and mean number of OHIP-14 impacts showed a consistent gradient across the responses to Locker’s global oral health item. Participants who responded ‘good’ had the lowest mean OHIP-14 score, and no OHIP-14 impacts, both at baseline and follow-up. Conversely, those who rated their oral health as ‘poor’ had the highest mean OHIP-14 score, and greatest mean number of OHIP-14 impacts.
5.1.5 CONCLUSION

The quantitative data collected from the participants at baseline and follow-up were used to supplement and enrich the qualitative findings. In the following section, these data will be interpreted and related to the qualitative findings.
Chapter Six – Discussion

6.1.1 INTRODUCTION

This chapter will examine and interpret the findings of this research. The study’s strengths and limitations will firstly be addressed, followed by a consideration of the findings in the context of the existing literature. Finally, the implications of these findings will be discussed, and recommendations for the future will be made.

6.1.2 LIMITATIONS

Acknowledgement of the limitations of this investigation is appropriate before the findings are considered. These relate to the participants, and the researcher. Each will be explained below.

6.1.2.1 Limitations related to the participants

The findings from this study were generated from a small sample of participants, located in or near to the city of Dunedin, in the South Island of New Zealand. All participants underwent periodontal treatment at the postgraduate Periodontics clinic at Faculty of Dentistry, University of Otago, a secondary care facility where treatment is provided at a substantially lower cost than in private practice. Thus, the findings were obtained from a specific group of patients, and their transferability to other settings is unclear.

Attempts were made to include a variety of participants with respect to age, sex, ethnicity and SES. However, the final sample reflected only a moderate degree of variation: there were more female than male participants; the majority identified as New Zealand Europeans; and high SES groups were under-represented. The participants available for recruitment into the study were limited to those on the waiting list for periodontal treatment at the clinic. The 2009 New Zealand Oral Health Survey found that males and Māori and Pacific adults were significantly less likely to have visited a dentist in the previous twelve months than females and non-Māori or non-Pacific adults, respectively (Ministry of Health 2010). In addition, the participants in the present study were
distributed towards more severe forms of periodontitis (stages III and IV), which may be characteristic of those referred to an institution. Thus, this sample may be considered to be a reasonable demographic representation of the patients seeking periodontal care at the University of Otago clinic.

That a small number of participants declined to participate, withdrew, or were excluded from the study during the recruitment phase may represent a source of bias. The contribution that these individuals would have made to the findings cannot be known. Their individual characteristics and/or reasons for withdrawal may have contributed different perspectives to those of the participants who did complete the study. Irrespective of this, data saturation and redundancy of themes was achieved, which suggested concordance among the included participants.

I aimed to recruit ‘periodontally naïve’ participants who were unaware of their periodontal status, so that their experiences could be captured from the beginning. In reality, this was difficult to achieve; the majority of participants had either been aware of their diagnosis (to some extent) for many years or had been informed by their treating clinician prior to their referral for specialist care at the periodontal clinic. Nevertheless, upon questioning, their level of understanding of their condition was judged to be minimal, such that I believed that they fit the criterion of being ‘periodontally naïve’.

I made regular contact with the participants during the diary recording phase to encourage their adherence. Despite this, the number of entries produced by participants varied significantly (from three to 24), with an average of nine entries. Most were relatively short and described participants’ oral hygiene routines, rather than being an introspective account of the psychosocial impact of their periodontal disease. The duration of the diary phase differed among participants due to the scheduling of their clinic appointments. For some, this period became more protracted than anticipated, and this had a negative effect on their interest and adherence with their diaries. Moreover, entries made using an audio recording device were noted to be more in-depth than the hand-written diaries. It is possible that the use of an audio recorder was less cumbersome than a written diary, and this should be considered for improving data richness and adherence in any such future research. Overall, the interviews generated a greater volume of meaningful data than the diaries.
The limitations related to the participants included the unclear transferability of the findings, the limited demographic variation of the sample, and the unknown contribution of those who did not take part. In addition, the participants’ prior knowledge of their conditions and adherence with diaries may have impacted upon the findings, to some extent. Several limitations related to the researcher will be discussed in the following section.

6.1.2.2 Limitations related to the researcher

In qualitative research, the subjective influence of the researcher’s personal characteristics on the data is accepted and valued, but it must be acknowledged. In the present study, since I developed and maintained rapport with the participants, I conducted the interviews and data analysis. The limitations of this are considered below.

First, prior to the present study, I was inexperienced in qualitative research methods and interviewing techniques. To ensure that the research was conducted appropriately, two supervisors with extensive qualitative research experience were included on the team. These co-investigators provided supervision and advice, including training on qualitative interview techniques and careful checking of the interview guide prior to the first three interviews.

Second, the initial data analysis and coding were conducted by a single researcher (PH). This allowed the data analysis to proceed soon after each interview, so that it could be used to inform the next one. To counteract bias arising from analysis by a single researcher, I met with an experienced supervisor (LFP) after each of the first four interviews to discuss the findings and refine the line of questioning. Once the initial coding of the dataset was complete, it was submitted independently to two members of the research team (LFP and EK) who carefully reviewed the coding and the thematic analysis, noting any different perspectives. In addition, while the research team comprised five individuals with diverse clinical and research experience, all of them were dentists. The inclusion of another researcher with a non-dental background may have provided a different perspective on the data.
Next, I am a postgraduate student in the Periodontics clinic at the Faculty of Dentistry, University of Otago. While I was not involved in the clinical treatment of any of the participants, I worked in close proximity to the other postgraduate students with whom the participants underwent treatment. Some participants may have observed interactions among my colleagues and I which might have prevented them from considering me to be completely impartial. The participants were encouraged to give both positive and negative responses, and advised that they would be kept strictly confidential. Despite this, their awareness of my relationship with their clinician may have prevented some participants from disclosing negative or private feelings.

Finally, it is possible that the participants modified their responses in the diaries and interviews because of their relationships with (and desires to please) me, the primary investigator. This form of response bias has been termed the ‘Hawthorne effect’, and recognises that people may change their behaviour because they are being observed. At the beginning of the interviews, when I thanked them for their diary entries, some of the participants asked whether their entries had been appropriate, or apologised for the number of entries they produced, which suggested their wishes to gratify me. However, their diary and interview responses seemed genuine, and included supportive examples. Little can be done to minimise the Hawthorne effect, although the participants were advised that the aim of the research was to understand their own unique thoughts and experiences, so any information they wished to share was relevant and gratefully received.

In summary, the limitations related to the research team included the limited experience of the primary investigator, the initial coding by a single researcher, the possibility that participants may not have perceived the investigator as impartial, and the Hawthorne effect. While it is important to acknowledge these limitations, the study also had many strengths, and these will be discussed in the next section.

6.1.3 STRENGTHS

The design and conduct of the present study underpin its strengths, and contribute to the trustworthiness of the data. The study design allowed consideration of the impact of
periodontitis across the pre-treatment, treatment and post-treatment phases, and this contributed to the breadth of the findings. Other strengths included the relationship between the participants and the primary researcher, the data collection and analysis, and the transferability of the data; each will be discussed below.

6.1.3.1 Relationship between the participants and researcher
Developing rapport with participants is critical when conducting qualitative research (Gill et al. 2008). In the present study, I was closely involved with the participants from the recruitment phase to the completion of the study. This fostered a relationship where participants felt valued, which encouraged their trust and honesty. The diary recording phase (during which I made regular contact with the participants) preceded the interview phase, and this meant that our relationship was well developed before the interview took place. In addition, I transcribed each participant’s diary entries prior to their interview to familiarise myself with the content. When points from the diary were raised in the interviews, the participants recognised that their thoughts were being heard and were encouraged to continue to share them. At the completion of the study, a number of the participants commented that they had enjoyed taking part in the study and expressed gratitude for the opportunity to be involved.

As discussed previously, I was not involved in the participants’ clinical care; this was a strength of the study because it reduced the risk of bias in their responses. My background as a postgraduate student in Periodontics was appropriate for my role as the interviewer, because having a general understanding of the treatment process aided the development of follow-up questions.

6.1.3.2 Data collection
The present study employed two different qualitative data collection methods. This study was the first to use patient diaries to examine patients’ experiences with periodontitis. While participants’ adherence to their diaries was lower than expected, the diaries were a valuable part of this study for several reasons. Patient diaries may give the researcher ‘a view from within’, because participants tend to emphasise the topics which are most important to them (Zimmerman and Wieder 1977). The diaries gave an insight into the
participants’ thoughts, feelings and experiences during their diagnosis and treatment, capturing detailed information which may have otherwise been overlooked, and reducing retrospection error. Several diary formats, including written, typed, audio-recorded, or video-recorded, were offered to include options for those with literacy issues.

The advantages of semi-structured interviews in qualitative methodology are well documented. In the present study, the interviews were carefully conducted to confirm the interpretation of diary data through participant checking, while expanding and adding to them. The combination of these two data collection methods, according to the diary interview technique described by Zimmerman and Wieder (1977), represented one method of triangulation, used to increase the trustworthiness of the findings.

A mixed-methods approach with an embedded design was selected for the study (Creswell and Plano Clark 2011). Quantitative OHRQoL data was collected alongside the qualitative data and used in a secondary role to create a more comprehensive picture of the participants’ experiences. The inclusion of quantitative measures of periodontal disease impact imparted another dimension to the findings, allowing further triangulation and validation of the qualitative data, along with a clear conventional periodontal research reference point.

6.1.3.3 Data analysis

The inductive approach to data analysis allowed themes to naturally emerge without the application of preconceived frameworks or ideas. The thematic analysis, which was conducted concurrently with data collection, facilitated a meaningful consideration of the true essence of the data.

The subsequent data validation process involved independent critical review of the coded data by two other members of the research team, each with slightly different viewpoints and experience. This ensured that important information had not been overlooked, and it reduced bias arising from the subjective perceptions of a single researcher. This validation process generated discussion which resulted in conceptualisation and adjustment of the thematic framework until the research team considered it to be an honest and balanced representation of the data. Moreover, these themes and sub-themes
were supported by direct quotations from the transcripts, in order to emphasise the trustworthiness of the analysis.

6.1.3.4 Data transferability

While the findings were obtained from a small and specific sample, this did not necessarily preclude their transferability to other groups. There was high concordance among the data obtained from the fourteen participants, who had been purposively selected for maximum variation. The recruitment of participants ceased when the final few interviews no longer generated any new information, indicating data saturation. These factors suggest that the findings may have some applicability beyond the setting in which the present study was conducted. In particular, the insight gained into the psychosocial effects of having untreated periodontitis and receiving a diagnosis might be generalisable to others, irrespective of their personal characteristics or the setting in which they receive periodontal treatment.

The strengths of the study were largely related to its careful design and conduct. These included the rapport between the participants and researcher, methods used for data triangulation and validation, and the attainment of data saturation. These contributed to the trustworthiness of the findings, which will be discussed next.

6.1.4 DISCUSSION OF FINDINGS

The findings illustrate the profound psychosocial impact of having periodontitis and undergoing periodontal treatment. The key themes identified in the present study will be considered in the context of other related literature.

6.1.4.1 Concealment

The participants perceived a degree of social stigma against periodontitis. This finding echoes those of other studies which have investigated patients’ experiences with periodontal disease. Participants in one study, which reported stigma as a key theme, perceived stigma in relation to halitosis, tooth loss and changes to their appearance, as they believed that these factors implied they were unhygienic (O'Dowd et al. 2010). This
was related to low self-confidence, which was widely reported by the participants in that study. Social stigma was not explicitly reported in any of the other qualitative studies of periodontal disease experience. It was, however, suggested in the study by Abrahamsson et al. (2008), in which the core concept ‘keeping up appearances and self-esteem’ described how the participants desired to maintain their self-image, dignity, and position in society, despite their diagnosis with periodontitis.

The shame and perceived stigma associated with periodontitis led to ‘concealment’, an important theme identified in the present study. The behavioural modifications made by the participants to conceal their periodontal symptoms from others were extensive and impacted on their daily lives. These behaviours were particularly detrimental to their social wellbeing, because they avoided smiling, intimacy, attending social functions, and speaking with others. A similar concept was termed ‘social disability’ which described the ways that those concerned about the appearance of their teeth tried to hide them (O'Dowd et al. 2010). These included avoiding smiling for photographs and covering their mouths with a hand. Abrahamsson et al. (2008) also documented similar strategies which the participants used to conceal their disease in the social context.

These findings are consistent with those from a quantitative study which examined the effect of periodontal disease on smiling patterns (Patel et al. 2008). It found that participants were less likely to smile widely when they had a greater PPD, or missing or mobile teeth. When considered together, this and other studies indicate that the theme ‘concealment’ was not an isolated finding and is probably relevant to other periodontal patients.

6.1.4.2 Having a guilty conscience

Many of the participants in the present study had been aware of their periodontal problems for some time but did not seek treatment, largely because of their fears about what it might involve, and the cost. Their untreated periodontal disease had a significant impact over this time. Many reported feeling embarrassed, worried and insecure, but preferred to ignore or deny their problems than face the reality. Reluctance to seek periodontal care, despite awareness of a problem, was not unique to this study. Abrahamsson et al. (2008) described how some participants had unsuccessfully tried to
suppress thoughts about their disease, in an attempt to convince themselves that professional care was not required. On the other hand, several of the participants in the present study had few or no symptoms, and were surprised at their diagnosis. These participants reported little to no psychosocial impact in the pre-diagnostic phase but experienced shock and worry upon diagnosis. Similar findings were reported by Karlsson et al. (2009).

Irrespective of whether they were aware of their disease prior to diagnosis, the participants in the present study had a guilty conscience for failing to recognise, or failing to act upon their symptoms. Self-blame has been reported by other periodontal patients upon diagnosis, usually in relation to avoiding treatment and behaviours which increased their risk for periodontitis (Johannsen et al. 2012; O'Dowd et al. 2010). In addition to self-blame, previous studies have identified that patients also blamed their previous dental clinicians for their failure to recognise or manage their periodontitis (Abrahamsson et al. 2008; Johannsen et al. 2012; Karlsson et al. 2009; O'Dowd et al. 2010). This was not a common finding among the participants of the present study. Since many were irregular dental attenders anyway, it was likely that they did not have the same expectation that their oral problems would have been detected early.

The findings showed that the participants had a guilty conscience about avoiding dental treatment, smoking, and failure to adhere to oral hygiene regimes. When treating patients with periodontitis, clinicians should anticipate that they may feel guilty and be sensitive to this when discussing the causes of disease and providing oral hygiene and smoking cessation advice.

6.1.4.3 Patient comfort as paramount
This theme encompassed the participants’ experiences of physical and emotional discomfort related to periodontitis and its treatment. Since periodontitis is usually painless, physical discomfort was not a common finding in the pre-treatment phase. However, almost all participants considered their non-surgical therapy to be unpleasant and/or painful, to some extent. It is possible that some were not expecting the treatment to be so thorough or intensive, because their expectations were based upon their prior experiences of scaling. Patients may therefore benefit from careful pre-operative advice.
which prepares them for the treatment, so that they are aware that specialist periodontal treatment is intense because it is aimed at removing tenacious deposits from a large surface area. Post-operative dentine hypersensitivity also had a considerable impact on the comfort of the participants in the post-treatment phase.

While pain during non-surgical therapy was mentioned in the earlier studies, it attracted relatively little attention in those reports (Karlsson et al. 2009; Stenman et al. 2009). It is therefore unclear whether pain during treatment was infrequently experienced and/or reported, or whether this finding was considered less relevant to their research questions. Similarly, post-operative dentine hypersensitivity was not discussed in their findings, despite being a common complication of periodontal treatment. These differences in findings may be related to the amount of time elapsed between the treatment and the interviews (since patients’ recollections of their discomfort might reduce over time), the experience of the operator(s), and/or the expectations of the patients.

The data suggested that the participants’ physical discomfort during treatment was multifactorial; it was linked to smells, tastes, sounds, the physical environment, and the tactile sensation of debridement. This became apparent through the experiences of participants who found it particularly difficult despite having profound LA. It is understood that pain is not an exclusive reflection of the intensity of nociceptive input but is a subjective experience which is modulated by cognitive and emotional factors (Wiech et al. 2008). Thus, an association between anxiety and greater pain perception has been demonstrated (Rhudy and Meagher 2000). One study, which examined the effect of dental anxiety on pain perception after dental scaling, found that those with greater anxiety perceived it to be more painful (Sanikop et al. 2011). Moreover, in the present study, this relationship appeared to be bidirectional, whereby pain affected participants’ emotional states. The association between pain and negative affect has been reported elsewhere (Feldman et al. 1999).

The participants’ emotional discomfort (predominantly anxiety) during the diagnosis and treatment appointments was consistent with findings from other studies (Abrahamsson et al. 2008; Karlsson et al. 2009; Stenman et al. 2009). In some cases, their emotions impaired their ability to retain the information provided by the clinician, a finding which has been previously noted (Abrahamsson et al. 2008). Since their anxiety was generally
related to a fear of the unknown, it appeared to abate as the participants became more familiar with the clinical team and the treatment process.

Consistent with other studies, anxiety about future tooth loss featured in the present study (Abrahamsson et al. 2008; Karlsson et al. 2009; O'Dowd et al. 2010). These concerns persisted despite diagnostic and prognostic information from clinicians. This might suggest that those affected perceived little control over their treatment outcomes. Anxiety is prevalent among patients with chronic diseases (De Ridder et al. 2008; Taylor and Aspinwall 1996). Further, patients’ inflated concerns about undesirable consequences of other chronic diseases, such as chronic obstructive pulmonary disease (Sutton et al. 1999) and inflammatory bowel disease (Mussell et al. 2004), have been reported. It is possible that clinicians emphasise the risk of negative disease endpoints, such as tooth loss, in order to improve patients’ adherence to their recommended behavioural interventions. While it is not known whether this occurred in the present study, clinicians treating patients with periodontitis should avoid using threats of negative consequences to motivate, because it may heighten their anxiety.

After their diagnosis, the participants experienced other emotions, such as disappointment, frustration, anger, shock and confusion. It is recognised that patients’ management or regulation of their emotions can influence their adjustment to illness; while the acknowledgement and expression of emotions can aid adaptation, emotional suppression can have an opposite effect (De Ridder et al. 2008). Participants in the present study recognised and articulated the benefits of discussing their emotions with others in order to help them accept their diagnosis. Clinicians should be aware of the potential negative impact of periodontal diagnosis and treatment on patients’ emotions, and encourage them to discuss their experiences with others. It may also be helpful to inform the patients that their negative emotions will subside with treatment progression, as reported by participants in the present study.

This study gave the participants an opportunity to provide feedback about all aspects of their clinical care, and these findings should be noted by clinicians. Although their personal accounts formed the key thematic findings, some powerful lessons arose from the raw data, specifically in relation to participants’ comfort during treatment. One example concerned clinicians interacting with dental assistants without actively
involving the patient. Clinicians should be discreet when reporting their clinical findings to dental assistants because patients overhearing this information may become distressed. Similarly, the participants felt more relaxed when the clinician and dental assistant chatted during their non-surgical treatment but became uncomfortable if they perceived the conversation topics to be inappropriate or ‘gossipy’. Some also felt disappointed if negative comments were made about their previous treating clinicians. A particularly moving insight was the extreme emotional impact of a tooth extraction. Since the experience of tooth loss has been described as a crisis analogous to amputation of a body part (Johannsen et al. 2012), clinicians should be sensitive to this when proposing or providing extractions as part of a treatment plan. Although these findings may seem insignificant to some, they act as a reminder for clinicians to treat patients with the utmost care and respect. Having a greater awareness of these experiences might improve the delivery of patient-centred periodontal care.

6.1.4.4 Progression to a more positive outlook

Positive changes in the participants’ outlooks occurred during treatment. This confirmed the findings of Karlsson et al. (2009) and Stenman et al. (2009), where patients’ acceptance of their periodontitis depended on perceived control and treatment success. In the present study, tangible improvements in periodontal symptoms translated to improvements in the participants’ psychosocial wellbeing. At the completion of their non-surgical treatment, participants reported improvements in their confidence, mood, and social relationships. This finding confirms that periodontal treatment has additional benefits for patients which supersede those measured using traditional biomedical indicators.

Accordingly, the participants appreciated and valued their periodontal treatment highly. Their perceptions of its benefits, including symptom resolution, preservation of teeth, and psychosocial effects underpinned their motivation to adhere to treatment. Thus, they considered the financial costs to be well worthwhile. This finding contrasts with those from Swedish studies, in which participants expressed frustration about treatment costs and a lack of public funding (Abrahamsson et al. 2008; Karlsson et al. 2009; Stenman et al. 2009). It must be borne in mind that the current study participants received their treatment in a teaching hospital, at a substantially lower cost than in a private practice.
setting. Since dental care for adults is not publicly funded in New Zealand, it is likely that a study conducted in a private practice would yield similar comments to the above-mentioned studies about the financial costs of treatment.

The participants’ rapport with their clinicians facilitated their progression to a more positive outlook. Interpersonal communication skills were highly regarded by the participants, because this helped them to feel fully informed. Having a good understanding of the disease aetiology and the treatment plan empowered them and alleviated some of their anxiety. The role of the clinician thus extended beyond the provision of periodontal treatment. It involved forming an alliance with the individuals (on an equal power level), treating them with respect and empathy, and supporting them emotionally. Problems with communication or power within the relationship were detrimental to the participants’ motivation and emotional investment in the treatment. This was not a unique finding; a meta-analysis showed that patients were more than twice as likely to adhere to medical recommendations if their physician was an effective communicator (Haskard-Zolnierek and DiMatteo 2009). It was also consistent with other qualitative findings which have highlighted the importance of the clinician-patient relationship in periodontal care (Abrahamsson et al. 2008; Stenman et al. 2009).

According to the biopsychosocial and patient-centred perspectives, the patient should be treated as a whole person, and the psychosocial impact of their illness should be considered (Mead and Bower 2000). Those providing periodontal care should therefore strive to build rapport with patients on an individual level. This is particularly relevant in the public setting, where individuals may be more inclined to feel overlooked due to a greater number of patients seeking care, and the demands placed on clinicians. Nevertheless, it was encouraging that the participants in the present study recognised the broader impact that their periodontal treatment had upon their lives and completed their non-surgical treatment with a more optimistic outlook than at the outset. These findings might provide some reassurance to other individuals who require periodontal treatment but have concerns at the outset about the process.
6.1.4.5 Quantitative findings

While the qualitative data described substantial improvements in participants’ attitudes after treatment, these findings were not reflected in the quantitative data. Just five of the fourteen participants had improvements in their OHRQoL scores after periodontal treatment. The mean OHIP-14 score at follow-up was slightly worse than that at baseline, although the difference was not statistically significant.

This study was essentially qualitative in nature, and the quantitative data were collected to complement the rich qualitative findings. The small sample size precluded meaningful statistical analysis of the quantitative data. Nevertheless, the quantitative findings provided another dimension to the results and highlighted some limitations of the current OHRQoL measures when applied to periodontitis.

Aside from the small sample size, the disparity between the quantitative and qualitative findings may also be related to the reference period and timing of the administrations of the OHIP-14 questionnaire. The baseline questionnaire was given before the clinical examination (prior to diagnosis). The follow-up questionnaire was given at the time of the interview, which was usually conducted within eight weeks of the completion of treatment. A four-week reference period was used. Since the second questionnaire was completed relatively soon after treatment, it is likely that the participants had continued side-effects within that period (such as dentine hypersensitivity), which may have influenced their OHIP-14 scores. While many studies have shown that periodontal therapy can improve OHRQoL, the follow-up periods vary substantially (Shanbhag et al. 2012; Tsakos et al. 2010).

Moreover, the impact of diagnosis and greater periodontal awareness was not captured in the baseline questionnaire, because the diagnoses were given after its completion. This may have affected the participants’ responses to the follow-up questionnaires, due to their increased understanding and awareness of periodontitis. This was evident in their responses to the self-report periodontal questions at follow-up, which showed that they were more cognisant of their periodontal issues than at baseline. It is possible that this heightened awareness may have negated some of the beneficial effects of treatment on the participants’ OHRQoL at follow-up.
In the interviews, the participants expressed positive attitudes towards the treatment and its residual side-effects which were not captured by the OHIP-14. Others have advocated for the development of a condition-specific OHRQoL measure for periodontitis (Shanbhag et al. 2012). The minor inconsistencies found between the qualitative and quantitative findings in the present study suggest that the OHIP-14 (a generic measure) may not be sensitive to some aspects of periodontal disease and its treatment.

On the other hand, the self-report oral health data collected using Locker’s global item at baseline and follow-up suggested that many of the participants did indeed perceive an improvement in their oral health after treatment. Only a small minority rated their oral health as worse at follow-up. The responses to the single item were consistent with the scores obtained using the more sophisticated OHIP-14 instrument, which suggested it was a valid measure of OHRQoL in this sample. Such global measures have the advantages of simplicity and flexibility, allowing individuals to consider the dimensions which are relevant to their personal OHRQoL.

While a detailed examination of the participants’ clinical periodontal status was outside the scope of this study, it is relevant to note that, at follow-up, the majority of the participants had improved with respect to the periodontal parameters recorded at baseline. The improvements in their BOP, PPD and CAL were likely linked to their more positive perspectives at follow-up. The participants’ periodontal charts are presented in Appendix XI. These confirm the clinical improvements.

In summary, the quantitative data provided an additional dimension and allowed further triangulation of the qualitative findings. While the OHRQoL scores measured using the OHIP-14 were not directly correlated with the underlying theme, ‘progression to a more positive outlook’, the self-reported measures suggested that the participants did perceive some improvement in their oral health, and that they had greater awareness of their periodontal condition.
6.1.5 RECOMMENDATIONS FOR FUTURE RESEARCH

This investigation generated an insight into patients’ experiences through diagnosis and non-surgical therapy for periodontitis. Since the interviews were conducted relatively soon after the completion of treatment, future studies using longer follow-up periods would expand on the findings. Such studies might examine whether the participants’ motivation and positive outlook were maintained in the longer term, along with the impact of other treatment modalities including surgery.

This study was conducted in a convenience sample of patients who underwent specialist periodontal care in a public teaching hospital. The findings thus may not be transferable to those seeking private specialist periodontal care in New Zealand. Similar research conducted among patients treated in private practice may provide a different perspective, due to SES differences and greater treatment costs. Future research might also focus on patients’ views about how the management of their periodontal conditions could be improved, to help clinicians adopt a patient-centred approach to periodontal practice.

Findings from current and future qualitative and mixed-methods studies about patients’ experiences with periodontitis may be used to develop a periodontitis-specific OHRQoL measure. Although extensive psychometric testing would be required before use, a measure based upon qualitative foundations would be specifically relevant and sensitive to periodontal conditions.

6.1.6 CONCLUSION

This study offered valuable insights into the experiences of a small group of New Zealanders undergoing periodontal diagnosis and treatment. Despite the study limitations, the findings are comparable to those of the other qualitative studies which have examined patients’ experiences of periodontitis and periodontal treatment. The three themes identified (‘concealment’, ‘having a guilty conscience’, ‘patient comfort as paramount’, and the underlying core concept ‘progression to a more positive outlook’) illustrated the psychosocial processes related to the participants’ experiences from untreated periodontitis through to periodontal diagnosis and treatment. These qualitative findings were mostly corroborated by the quantitative data, but the lack of improvements
in self-reported OHRQoL after treatment might have been due to their greater periodontal awareness. In the following chapter, the notion of status passage will be applied to the findings.
7.1.1 INTRODUCTION

This study’s findings highlighted the profound social impact of periodontitis. Since status passage is a theory which examines individuals’ passages through the social status system, it is relevant to consider these participants’ journeys through diagnosis and treatment for periodontitis as a status passage. While this is an interesting topic which deserves further study, the findings from this research will be briefly discussed in the context of the six key properties of a status passage: reversibility, temporality, shape, desirability, circumstantiality, and multiplicity (Glaser and Strauss 1971). Finally, since awareness context is closely linked to status passage, its relevance to the findings will also be considered below.

7.1.2 REVERSIBILITY

Although Glaser and Strauss (1971) regarded chronic illnesses as inevitable, irreversible passages, this may not hold true for periodontitis. Many of the participants recognised its preventable nature, and were regretful about past behaviours which they believed may have contributed to their disease. Those behaviours included poor oral hygiene habits and smoking, and were associated with the theme ‘having a guilty conscience’. On the other hand, the participants understood that periodontal destruction was irreversible, and this may have motivated them to prevent further attachment loss by adhering to treatment. The irreversibility of the passage into having periodontitis may have been perceived differently among the participants, since some sought treatment earlier than others. Control of the disease with early treatment and establishment of preventive routines might have translated to a degree of reversibility for some, or at least a ‘reversal-of-decline’, which was described by Tolhurst and Kingston (2013) in the context of pharmaceutical treatments for Alzheimer’s disease.
7.1.3 TEMPORALITY

The temporality of a status passage concerns its scheduling, rate and pace. For many of the participants in the present study, the status passage into having periodontitis was non-scheduled, because its onset was unanticipated. The diagnosis came as a shock for those who had not experienced any symptoms. The shock was also linked to social stigma; some had preconceived ideas about the ‘type of person’ who suffered from periodontitis. For those who had not previously considered themselves to fit within this group, the perceived change in their social status was confronting. While the initial diagnosis was non-scheduled for most of the participants, the passage became more scheduled as they sought professional care and entered the treatment phase. Similar findings were reported by Gibson et al. (2017), whereby participants’ passages into edentulism gradually became scheduled as they underwent extractions and denture fabrication.

Passagees’ knowledge of the rate and pace of their passage reduces their uncertainty and may increase their acceptance (Kristiansen and Antoft 2016). In the present study, this point was illustrated in the participants’ concerns upon diagnosis about the potential for tooth loss. Initially, they were unfamiliar with the probable course and outcomes of periodontitis. However, as their understanding of the disease increased, they perceived a greater degree of control, which reduced these concerns. Their greater awareness of the potential disease course largely came about through interactions with their treating clinicians. At completion of treatment, the participants had an improved outlook on periodontitis and were less concerned by its potential for negative outcomes, such as tooth loss.

7.1.4 SHAPE

The shape of a status passage denotes its direction over time, and considers those who may influence or control it (Glaser and Strauss 1971). Shape is affected by personal, social and contextual factors which can be highly individualistic. Accordingly, the shapes of the passages differed among the participants in the present study. The underlying theme ‘progression to a more positive outlook’ described how most had a more optimistic view of their passage at the completion of non-surgical therapy. However, the participants’ pathways towards this point (which were discussed in the results section)
were unique and complex. They involved both positive and negative progress, which Glaser and Strauss noted may feature in the shape of a passage. Negative aspects were generally related to the theme ‘patient comfort as paramount’, because this theme encompassed the emotional and physical discomfort of the participants during the study period. The shape of each individual’s passage was thus dependent on their experiences, personality, and coping mechanisms.

The passages were shaped by the clinicians and the passagees themselves. The status passage into being diagnosed and treated for periodontitis was, for the most part, prescribed by the clinicians, because they followed a conventional sequence of periodontal treatment. There was, however, a balance of control and responsibility between the two parties which was recognised by the participants, particularly as they began to understand the importance of their own behaviours on the treatment outcomes. On occasion, some participants perceived alterations in the balance of power, which impacted on their experiences. Some also described the influence of third parties (such as family and friends) on the shape of their passage. Most commonly, this was beneficial, because discussing their condition and/or emotions helped them to come to terms with them. Similar findings were reported in another study, where interactions with others suffering from the same condition during patient support meetings helped to shape the passages of those who were newly diagnosed (Kristiansen and Antoft 2016).

7.1.5 DESIRABILITY

Glaser and Strauss (1971) emphasised that the desirability of a status passage was closely linked to social factors. The participants in the present study considered diagnosis with periodontitis to be undesirable, because of the social stigma attached to the condition. The negative emotions experienced by most upon diagnosis reflected their displeasure. While the passage was undesirable as a whole, the participants identified parts of the diagnosis and treatment phases which were desirable. Such examples included the resolution of troublesome symptoms (such as halitosis and gingival bleeding), and the positive effects of the treatment upon their social wellbeing. As the participants progressed through treatment and developed a more positive outlook, their perceptions of the desirability also evolved. At the completion of treatment, many reflected positively
on the experience. This may have related to their increased feelings of control, as the relationship between a lack of control and the undesirability of a passage has been described elsewhere (Tolhurst and Kingston 2013).

7.1.6 CIRCUMSTANTIALITY

The circumstantiality of a status passage concerns its social context; that is, whether the passagee undergoes the passage solo, or as part of an aggregate or collective (Glaser and Strauss 1971). A majority of the participants entered their passage into having periodontal disease solo, usually because of the perceived stigma. The theme ‘concealment’ depicted the extent of their attempts to prevent others from becoming aware of their condition, which indirectly contributed to their solo passages. The theme ‘progression to a more positive outlook’, however, documented the participants’ increasing confidence to openly discuss their condition after they had commenced treatment. Some described the positive impact of sharing their experiences, especially with others who had been through similar treatment. This allowed them to form informal aggregates with others who were undergoing similar passages.

7.1.7 MULTIPLICITY

The status passage into having periodontitis also impacted on the participants’ concurrent status passages, because of conflicts with their social and occupational roles. For example, for several participants, the diagnosis represented a ‘crisis’, which preoccupied their thoughts for a time afterwards. The passage therefore took precedence over others, such as those related to their family lives. The symptoms of periodontitis had a profound social impact on many of the participants, which included the avoidance of social interactions, functions, and intimacy with others. The resulting changes in their social behaviour likely impeded other status passages, such as entering into friendships or relationships. Other participants considered the status passage into periodontitis as a threat to their identity in the professional realm, and this may have impacted upon work-related passages such as promotions. Conversely, the participants’ other passages may also have impacted on their adherence to their periodontal treatment, including maintaining their oral hygiene routines and/or attending clinic appointments.
7.1.8 AWARENESS CONTEXTS

Some participants were more cognisant of their status passages into having periodontal disease than others. According to Glaser and Strauss (1964), a passagee who is unaware of their status passage designates a closed awareness context. A closed awareness context may also occur when passageees attempt to keep the passage confidential. This was regularly seen in the present study; the theme ‘concealment’ described the participants’ extensive efforts to keep their passage hidden from others. Many of the participants chose to conceal aspects of their passage into periodontitis from those close to them, such as family and friends, as well as those less familiar to them, because of their concerns about being judged or stigmatised.

Some participants also attempted to conceal their passage into periodontitis from themselves. Prior to diagnosis, some had symptoms which they knew indicated a problem but chose to ignore or deny them. While the nature of this awareness context was not strictly closed, it may not be considered to be open either. Gibson et al. (2017) introduced ‘compound awareness contexts’, which might be applicable here, because they consider the interface between open and closed awareness contexts. A suspicion awareness context was discussed by Gibson et al. in relation to the participants’ understanding of the reasons for their complete tooth loss. Similarly, some participants in the present study suspected a problem, but delayed addressing it because they did not wish to face the reality of the passage.

After the participants sought treatment and received a diagnosis of periodontitis, the awareness context became open. The clinician communicated the diagnostic information to the participants, who subsequently developed an increased awareness and understanding of the passage they were traversing. While this was confronting for some at first, the participants began over time to recognise the benefits of the open awareness context. This led to them becoming more open about the passage with other individuals, and this further assisted with their processing and acceptance of the diagnosis.
7.1.9 CONCLUSION

The study’s findings have been preliminarily considered in the context of status passage, a sociological theory. The applicability of the key components of this theory to the findings suggests that it may be relevant to the experience of periodontitis diagnosis and treatment. Future studies are required to further investigate the extent to which status passage theory is applicable to periodontal patients. These studies might consider the status passages of the pre-treatment and treatment phases separately, in order to distinguish the status passage into ‘having periodontitis’ from that of ‘being treated for periodontitis’. If further studies confirm that status passage is relevant to the periodontitis experience, it may be used in future qualitative research as a framework for data analysis.
Chapter Eight – Overview

It is now generally accepted that traditional biomedical measures of disease offer limited perspectives on the comprehensive concept of health. Thus, the biopsychosocial approach to health and disease has necessitated the adoption of a more holistic view. This extends beyond clinical disease indicators and considers the impact on psychological, social, and emotional health, function, and general wellbeing. PROs such as OHRQoL have become an important evaluation tool for clinical outcomes, and qualitative research methods allow examination of patients’ perspectives in further detail. This is particularly relevant for periodontitis, whereby the biomedical outcome measures favoured by clinicians (such as PPD and CAL) are largely intangible to patients. Since periodontitis is highly prevalent both in New Zealand and worldwide, this study was developed to gain insight into its impact on individuals.

The study examined participants’ experiences of periodontitis during the pre-treatment, treatment, and post-treatment phases, using a mixed-methods approach. Qualitative data were collected from patient diaries and semi-structured interviews, while the quantitative data comprised self-reported measures of OHRQoL and periodontal status. Thematic analysis identified the three key themes of ‘concealment’, ‘having a guilty conscience’ and ‘patient comfort as paramount’, which were underpinned by a central theme termed ‘progression to a more positive outlook’. The themes and their respective sub-themes were arranged into a conceptual framework which depicted the participants’ experiences through their diagnosis and treatment for periodontitis.

The theme ‘concealment’ incorporated the sub-theme ‘stigma’, in which the participants acknowledged periodontitis as a condition which was stigmatised by society. They were ashamed of their periodontal symptoms and the fact that they required periodontal treatment. Thus, the participants gave powerful accounts of the behavioural adaptations they made in order to conceal their periodontitis from those around them and preserve their social standing. These concealment behaviours often had a marked impact on the participants’ social and psychological wellbeing. Fortunately, as they progressed through periodontal treatment, the participants’ perceived improvement in their symptoms and
confidence allowed them to abandon many of these behaviours. This was closely related to the core theme ‘progression to a more positive outlook’.

‘Having a guilty conscience’ was a common finding amongst the participants in the pre-treatment phase. They harboured guilt about past behaviours which they believed to have contributed to their periodontitis, such as smoking, inadequate oral hygiene and avoiding dental care. The reasons for the latter were explored, and included financial concerns, fear of dental work, and lack of a perceived need. While the participants’ guilty consciences about these behaviours reduced somewhat as they sought periodontal treatment, a different type of guilt was identified in the treatment and post-treatment phases. This was linked to their failures to adhere to the treatment recommendations.

The theme ‘patient comfort as paramount’ comprised the participants’ experiences of physical and emotional discomfort throughout the pre-treatment, treatment, and post-treatment phases. While pre-treatment physical discomfort was not a common finding, a majority of the participants found non-surgical periodontal therapy difficult and unpleasant. Experiences of physical discomfort during treatment were multifactorial and varied among the participants in a reflection of their differing personalities, coping mechanisms, mindsets and pain thresholds. In the post-treatment phase, physical discomfort was generally due to post-operative dentine hypersensitivity, which reduced with time after the non-surgical therapy.

In addition to physical discomfort, the reported emotional discomfort arising from periodontal diagnosis and treatment was substantial. Anxiety was commonly reported in the pre-treatment and treatment phases, since participants felt anxious about their diagnosis, the prospect of treatment, and the potential for tooth loss. Their concerns were predominantly related to a fear of the unknown, but they were mostly alleviated as they became increasingly familiar with the clinicians and treatment process. While anxiety was common, the emotional reactions to diagnosis differed among participants and included embarrassment, confusion, disappointment, anger and shock. By the end of the study period, however, the participants had mostly overcome their physical and emotional discomfort and were highly appreciative of the treatment.
The core underlying theme ‘progression to a more positive outlook’ described a contrast between the participants’ pre-treatment and post-treatment attitudes. This core theme also encompassed aspects of the other themes referred to above; as they progressed through treatment, they displayed fewer concealment behaviours, their guilty consciences eased, and their physical and emotional discomfort resolved.

At the outset of periodontal treatment, many participants presented feeling resigned, anxious and generally negative, but they became increasingly empowered and optimistic. Their more positive outlooks were linked to their recognition of the benefits of treatment and a tangible reduction in symptoms, which translated to improved psychosocial wellbeing. While some participants took a more complicated pathway towards this more optimistic state, they all reflected positively on their treatment and had a better future outlook at completion. The participants identified that this progression was shaped by their relationships with their treating clinicians, giving positive and negative examples of communication and power relationships between them. Ultimately, the participants’ improved outlooks were related to greater feelings of control of their periodontitis, and they mostly appreciated their own responsibilities in maintaining this control.

Interestingly, the core underlying theme ‘progression to a more positive outlook’ was not reflected in the quantitative findings, since the participants’ OHRQoL was slightly worse at follow-up than baseline. Nevertheless, some positive changes in self-rated oral health and accuracy of self-reported periodontal status were noted. Comparison of periodontal charts taken at baseline and follow-up for each participant suggested that the non-surgical periodontal therapy had beneficial effects on clinical outcome measures such as CAL, PPD and BOP.

This study was the first to consider periodontitis in the context of status passage, a sociological theory which has been applied to some other chronic diseases. The findings were considered relevant to the six key properties of a status passage, which suggested that status passage may represent an appropriate framework for future studies of patients’ experiences of periodontitis.
In summary, the study findings highlighted the profound psychosocial impact that periodontitis may have on patients. They gave insights into the broad impact of untreated periodontitis in the pre-treatment phase, and into patients’ emotional fragility as they underwent diagnosis and treatment. While non-surgical therapy did improve traditional biomedical outcome measures, these improvements were surpassed by an impressive array of psychosocial benefits, including improved self-esteem, mood, attitudes and social wellbeing. This suggests that non-surgical periodontal therapy is beneficial from a patient-centred perspective. Moreover, the findings may be used to improve the delivery of clinical periodontal care. Clinicians should value the participants’ personal reflections and consider them a reminder to treat all patients as individuals, with empathy and respect. The role of the clinician extends beyond the provision of periodontal care, to support patients in expression and acceptance of the emotions that inevitably arise during diagnosis and treatment for periodontitis. The underlying theme of this study (‘progression to a more positive outlook’) confirms that periodontal therapy has a multitude of benefits which may be used to reassure those at the outset of their treatment.
References


Higgins JPT, Green S. 2008. Cochrane handbook for systematic reviews of interventions. West Sussex: John Wiley & Sons Ltd.


Appendix I. Periodontal self-report questions (Foster Page et al. 2016)

1. Do you think you have gum disease?
   - YES
   - NO
   - DO NOT KNOW

2. Has a dental professional ever told you that you have lost bone around your teeth?
   - YES
   - NO
   - DO NOT KNOW

3. Have you ever had scaling, root planing, or surgery for gum disease?
   - YES
   - NO
   - DO NOT KNOW

4. Have you ever had teeth that have come loose by themselves without some injury (not baby teeth)?
   - YES
   - NO
   - DO NOT KNOW
Appendix II. Locker’s global oral health item (Locker 2001)

<table>
<thead>
<tr>
<th>How would you describe the health of your teeth or mouth?</th>
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<tr>
<td>EXCELLENT</td>
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</table>
Appendix III. OHIP-14 questionnaire (Slade 1997a)

**WITHIN THE PAST FOUR WEEKS, HOW OFTEN:**

Please choose ONLY ONE answer for each question.

<table>
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<tr>
<th></th>
<th>VERY OFTEN</th>
<th>FAIRLY OFTEN</th>
<th>OCCASIONALLY</th>
<th>HARDLY EVER</th>
<th>NEVER</th>
<th>DON’T KNOW</th>
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<tr>
<td>1. Have you had trouble <em>pronouncing any words</em> because of problems with your teeth, mouth or dentures?</td>
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<td>2. Have you felt that your <em>sense of taste</em> has worsened because of problems with your teeth, mouth or dentures?</td>
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<td>3. Have you had <em>painful aching</em> in your mouth?</td>
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<td>4. Have you found it <em>uncomfortable to eat any foods</em> because of problems with your teeth, mouth or dentures?</td>
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<td>5. Have you been <em>self-conscious</em> because of your teeth, mouth or dentures?</td>
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<td>6. Have you <em>felt tense</em> because of problems with your teeth, mouth or dentures?</td>
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WITHIN THE PAST FOUR WEEKS, HOW OFTEN:

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<td>7. Has your <em>diet been unsatisfactory</em> because of problems with your teeth, mouth or dentures?</td>
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<td>8. Have you had to <em>interrupt meals</em> because of problems with your teeth, mouth or dentures?</td>
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<td>NEVER</td>
<td>DON’T KNOW</td>
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<td>9. Have you found it <em>difficult to relax</em> because of problems with your teeth, mouth or dentures?</td>
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<td>VERY OFTEN</td>
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<td>DON’T KNOW</td>
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<td>10. Have you been a bit <em>embarrassed</em> because of problems with your teeth, mouth or dentures?</td>
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<td>VERY OFTEN</td>
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<td>11. Have you been a bit <em>irritable with other people</em> because of problems with your teeth, mouth or dentures?</td>
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<td>VERY OFTEN</td>
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<td>DON’T KNOW</td>
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<td>12. Have you had <em>difficulty doing your usual jobs</em> because of problems with your teeth, mouth or dentures?</td>
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<td>VERY OFTEN</td>
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WITHIN THE PAST FOUR WEEKS, HOW OFTEN:

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<thead>
<tr>
<th>Question</th>
<th>Description</th>
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<tr>
<td>13.</td>
<td>Have you felt that life in general was <em>less satisfying</em> because of problems with your teeth, mouth or dentures?</td>
</tr>
<tr>
<td>14.</td>
<td>Have you been <em>totally unable to function</em> because of problems with your teeth, mouth or dentures?</td>
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<tr>
<th></th>
<th>Very Often</th>
<th>Fairly Often</th>
<th>Occasionally</th>
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Appendix IV. Māori consultation

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

Tuesday, 07 June 2016.

Associate Professor Lyndie Foster Page,
Faculty of Dentistry - Department of Oral Science,
DUNEDIN.

Tēnā Koe Associate Professor Lyndie Foster Page,

Psychosocial Aspects of Periodontal Disease Diagnosis and Treatment

The Ngāi Tahu Research Consultation Committee (the committee) met on Tuesday, 07 June 2016 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee suggests including in the research team a researcher with expertise in analysing and interpreting data by ethnicity.

The Committee suggests dissemination of the findings to relevant Māori health organisations, for example the National Māori Organisation for Dental Health, Oranga Nīho and to Professor John Broughton and Malcolm Daker, who are involved in Māori Dental Health, University of Otago.

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Puketeteraki
Te Rūnanga o Moeraki

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Puketeteraki
Te Rūnanga o Moeraki
Ngāi Tahu Research Consultation Committee
Te Komiti Rakahau ki Kāi Tahu

We wish you every success in your research and the committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 07 June 2016 to 7 December 2017.

Nāhaku noa, nā

[Signature]

Mark Brunton
Kaiwhakahaere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Ītāgo
Ph: +64 3 479 8738
Email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Paketareiki
Te Rūnanga o Moeraki

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Dear Assoc. Prof. Foster Page,

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled “Psychosocial aspects of Periodontal Disease Diagnosis and Treatment”.

As a result of that consideration, the current status of your proposal is: Conditional Approval

For your future reference, the Ethics Committee’s reference code for this project is: H16/072.

The comments and views expressed by the Ethics Committee concerning your proposal are as follows:-

Please address the following comments before proceeding with the research:

Recruitment

The Committee would be grateful if you could confirm whether the clinician is recruiting their own patients for this research, and, if so, how this will be managed in order to avoid patients’ perception of feeling pressured.

Peer Review

The Committee did not consider the indication of Peer Review provided at item 6.2 was acceptable. Please arrange for a Scientific Peer Review of the study protocol and provide the evidence of the review and any response to the issues raised to the Committee for review.
Before approval of the research to proceed can be granted, a response must be received addressing the issues raised above. The Committee expects that these comments will be addressed before recruitment of participants begins. Please note that the Committee is always willing to enter into dialogue with applicants over the points made. There may be information that has not been made available to the Committee, or aspects of the research may not have been fully understood. Please provide the Committee with copies of the updated documents, if changes have been necessary.

Yours sincerely,

Mr Gary Witte  
Manager, Academic Committees  
Tel: 479 8256  
Email: gary.witte@otago.ac.nz

c.c. Professor W M Thomson  
Department of Oral Sciences
Appendix VI. Ethical Approval

Dear Assoc. Prof. Foster Page,

I am again writing to you concerning your proposal entitled "Psychosocial aspects of Periodontal Disease Diagnosis and Treatment", Ethics Committee reference number H16/072.

Thank you for your letter of 13th July 2016, with attached documentation, addressing the issues raised by the Committee.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

http://www.otago.ac.nz/healthandsafety/index.html

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:
Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

The Human Ethics Committee (Health) asks for a Final Report to be provided upon completion of the study. The Final Report template can be found on the Human Ethics Web Page http://www.otago.ac.nz/council/committees/committees/HumanEthicsCommittees.html

Yours sincerely,

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Professor W M Thomson Department of Oral Sciences
ADVICE OF RESEARCH FUNDING GRANT APPLICATION AS ASSESSED BY THE BOARD
OF THE NEW ZEALAND DENTAL RESEARCH FOUNDATION
NZDA HOUSE, 19 JULY 2017

<table>
<thead>
<tr>
<th>Date of Advice</th>
<th>3 August 2017</th>
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<tbody>
<tr>
<td>Name of Applicant/s</td>
<td>Poppy HORNE, L Foster Page, J Leichter, M Thomson, E Knight</td>
</tr>
<tr>
<td>Award Reference</td>
<td>RF 8.07 2017</td>
</tr>
<tr>
<td>Title of Research</td>
<td>Psychosocial aspects of periodontal disease diagnosis and treatment</td>
</tr>
<tr>
<td>Amount Awarded</td>
<td>$4,100 International College of Dentists Award Note: The request for $3000 publication costs were not supported by the NZDRF Board</td>
</tr>
<tr>
<td>Condition/s of Award</td>
<td>Funding of this project is conditional on the applicants providing assurance that the project can be completed with this level of funding and in accordance with the reporting conditions below. A payment of $4,100 will be made on receipt of a copy of the ethics approval for this study and on the receipt of an invoice for such. Progress Reports, a Final Report and abstract are due on the dates shown below. A separated annual report is required for the ICD. Please provide copies of any publications arising from the research with your reports.</td>
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<tr>
<td>Project Start Date</td>
<td>01/11/2017</td>
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<tr>
<td>Project End date</td>
<td>31/10/2018</td>
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**1st Progress Report due** 15/05/18 Please email your report (template here [http://www.otago.ac.nz/otago409403.html](http://www.otago.ac.nz/otago409403.html)) to – research@otago.ac.nz

**Final report and Abstract due** 31/10/18 Please email your report (template here [http://www.otago.ac.nz/otago409403.html](http://www.otago.ac.nz/otago409403.html)) to – research@otago.ac.nz

**General Comments**
The project ranked sufficiently for the Board to agree to award $4,100 subject to the payment conditions. Publications should acknowledge funding support from the NZ Dental Research Foundation and International College of Dentists, and include the award reference number.

**Signed:** Richard Jefferies (Chair, New Zealand Dental Research Foundation Board)

The Principal Researcher should sign and date this advice notice in the panel below and then return a COPY to research@otago.ac.nz to acknowledge the conditions and enable payment of the Award. If the Principal Researcher is a post-graduate student, then the student’s supervisor should sign and return this form. Thank you.

<table>
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<th>Name: ___________________</th>
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<tr>
<td>Principal Researcher OR</td>
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<tr>
<td>Student Supervisor</td>
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1 Abstract should be suitable for publication in the NZDA News
Appendix VIII. Participant information sheet

PARTICIPANT INFORMATION SHEET

<table>
<thead>
<tr>
<th>Study title:</th>
<th>Psychosocial aspects of periodontal disease diagnosis and treatment</th>
</tr>
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</table>
| Principal investigator: | Poppy Horne  
Doctoral Candidate- Periodontics  
Department of Oral Sciences |  
Contact email:  
poppy.horne@postgrad.otago.ac.nz  
Phone: 027 364 5298 |

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with whanau, relatives or friends, before deciding whether or not to take part.

If you decide to take part, we thank you. If you decide not to take part, there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

Most of what we know about gum disease treatment is about what is important to dentists, rather than patients.

This study will examine patients’ experiences as they journey through diagnosis and treatment for periodontal (gum) disease. Using diaries and interviews, we hope to find out more about what patients think and feel when they are diagnosed and treated for gum disease (periodontitis).

Once we understand our patients’ point of view, we can improve the ways we provide care to patients with gum disease.

This project is being undertaken as part of the Doctorate of Clinical Dentistry in Periodontics.

Who is funding this project?

This study is funded by the Fuller Scholarship.
Who are we seeking to participate in the project?

We are looking for people who have been recently diagnosed with gum disease (periodontitis) and have been referred to the specialist periodontal clinic at the Faculty of Dentistry, University of Otago for treatment. You must be able to speak English to a reasonable standard.

If you have previously been diagnosed or treated for gum disease (periodontitis), apart from routine scaling/polishing of teeth, you will not be eligible for this study. You must be able to commit to the requirements of the study, (as explained below).

If you participate, what will you be asked to do?

When you first come to the Periodontal Specialist Clinic at the School of Dentistry, a post-graduate student in Periodontics will see you for an examination. At this time, they will explain to you the nature of your gum disease, the proposed treatment, and any costs.

The treatment provided to you will not be different in any way because of your participation in this study.

Should you agree to take part in this project, you will be asked to keep a diary of your experiences as you are diagnosed and treated for your gum disease. This will take about 4-6 weeks, depending on the treatment you need. The format of this diary will be your choice from a video diary, audio diary, or written diary. The amount of time you spend on this diary is entirely up to you. We are interested in your thoughts and feelings about having gum disease, the ways that gum disease affects your life, and your experiences of gum treatment at our clinic.

Throughout the diary period, the interviewer will contact you by email or phone to answer any questions you may have, and discuss your diary entries. Afterwards, you will be invited to take part in an interview where we will discuss the main points from your diary entries. This will take about one hour, and will take place in a private location at the School of Dentistry.

Any additional travel or parking costs to you as a result of this project will be reimbursed. You will also receive a $50 voucher as a token of our appreciation for your participation.

Please be aware that you may decide not to take part in the project, without any disadvantage to yourself.

Is there any risk of discomfort or harm from participation?

As mentioned earlier, the treatment you receive will be identical to what you would receive if you were not involved with the study. There are no additional risks to you as a result of participation in this study. Any risks of discomfort involved with treatment procedures will be discussed with you before you commence treatment.
What data or information will be collected, and how will it be used?

Information from the diaries and interviews will be audio-taped, transcribed and analysed for themes. Analysing the themes brought up by you and other participants will allow us to understand how gum disease and its treatment affects our patients.

In the follow-up interview, we will discuss your diary entries and check if we have understood what you said in your diary properly. You will have the chance to change anything at this time.

These interviews will use open-ended questions. The types of questions asked will include how your gum disease affects your daily life, including eating, social relationships, appearance, and pain. We will also ask questions about how it felt to be diagnosed with gum disease and have treatment. The precise questions that may be asked cannot be determined in advance, as they will depend on the way the interview develops. Although the University of Otago Human Ethics Committee is aware of the general line of questioning in the interview, the committee cannot review the precise questions that will be used. Therefore, if the questioning makes you feel uncomfortable, you have every right to decline to answer any questions, and you may withdraw from the project at any stage, without any disadvantage to yourself of any kind.

What about anonymity and confidentiality?

Every attempt will be made to preserve your anonymity. Your real name will not be used throughout data handling and analysis, or in any reports produced with the information. The anonymous data will be only accessible by researchers, supervisors, transcribers and examiners of the thesis. It will be stored in a secure way such that nobody, other than those people mentioned above, can access it.

Any data from this study will be retained for at least five years in secure storage. Any personal information, such as contact details, or video/audio recordings (once transcribed), will be destroyed at the completion of the study. However, the anonymous data derived from the research will be kept for an indefinite period of time. The results of the study will be published and will be available in the University of Otago Library in Dunedin. We will make every attempt to ensure that your anonymity is maintained.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project at any time and without any disadvantage to yourself.
Any questions?

If you have any questions now or in the future, please feel free to contact either:

<table>
<thead>
<tr>
<th>Name:</th>
<th>Email address:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poppy Horne</td>
<td><a href="mailto:poppy.horne@postgrad.otago.ac.nz">poppy.horne@postgrad.otago.ac.nz</a> Ph. 027 364 5298</td>
</tr>
<tr>
<td>Position: Post-graduate student, Periodontics Department: Department of Oral Sciences, Faculty of Dentistry</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name:</th>
<th>Contact phone number: Email address:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lyndie Foster Page</td>
<td>03 479 5853 <a href="mailto:lyndie.fosterpage@otago.ac.nz">lyndie.fosterpage@otago.ac.nz</a></td>
</tr>
<tr>
<td>Position: Associate Professor Department: Department of Oral Sciences, Faculty of Dentistry</td>
<td></td>
</tr>
</tbody>
</table>

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.
Appendix IX. Participant consent form

Psychosocial Aspects of Periodontal Disease Diagnosis and Treatment

Principal Investigator: Poppy Horne
poppy.horne@postgrad.otago.ac.nz  ph. 027 364 5298

CONSENT FORM FOR PARTICIPANTS
Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant: ..............................................................

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage.
6. I know that when the project is completed all personal identifying information will be removed from the paper records, recordings and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least five years.
7. I know that the follow-up interview questions will explore the effect of gum disease on my daily life, and my diagnosis and treatment experiences, using open questions. If the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and/or may withdraw from the project without disadvantage of any kind.
8. I understand that the results of the project may be published and be available in the University of Otago Library, but I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study.
9. I know that as a participant I will attend appointments, complete questionnaires and meet the diary entry requirements to the best of my ability. I understand that the purpose of this study is to collect honest information about my experiences. I will attempt to be as open with this information as I feel comfortable
with, regardless of whether it is positive or negative. I understand that there will be no repercussions to me as a result of sharing this information.

10. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.

11. I understand that I will be reimbursed for my travel expenses for this study, and will be reimbursed for my participation with a $50 New World voucher.

Signature of participant: ____________________________ Date: ____________

Name of person taking consent: ____________________________ Date: ____________
Appendix X. Diary entry guidelines

**DIARY GUIDELINES**

Thank you for taking part in this study.

**WHAT TO USE THE DIARY FOR:**

Please use this diary to record anything you think will help me understand what it is like to have gum disease, and have treatment for gum disease.

This could include things like:

- How you found out that you have gum disease, and how this felt
- How gum disease affects your life, such as when you are eating, working, smiling, talking, going out and interacting with other people
- Any symptoms you notice (such as pain, bad breath, red gums or wiggly teeth)
- If you talked about your gum disease with any other people, and how they reacted
- Your interactions with dental professionals
- Your experiences of treatment in the clinic
- How you think your treatment is going
- Any side effects of your treatment
- Both positive and negative entries are welcomed

**WHEN TO USE THE DIARY:**

I would appreciate it if you make a diary entry:

- After each time you visit the Dental School for an appointment, AND;
- Whenever you think about something to do with your gums or your treatment: please note it down.

Otherwise, it is up to you how often you would like to make a diary entry. **One every few days would be excellent**, but you do not need to make an entry just for the sake of doing so.

The diary entries can be made in any way you like: please feel free to express yourself using pictures, photographs, or words. **Please date your entries**. If you would like to use a computer for your diary, you can email your entries to: poppy.horne@postgrad.otago.ac.nz.

Please remember that these diary entries are confidential and the information will not be shared with anyone, including the people providing your treatment at the Dental School. Please be as open and honest as you feel comfortable with.

I will be in touch with you regularly over this time to discuss your diary and answer any questions.

Thank you once again.

Poppy Horne
Email: poppy.horne@postgrad.otago.ac.nz; Phone or Txt: 027 364 5298
Appendix XI. Participants’ clinical periodontal information

PARTICIPANT 1001: BASELINE CHART

<table>
<thead>
<tr>
<th>Initial Exam</th>
<th>Reevaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td></td>
</tr>
<tr>
<td>Gingival Margin</td>
<td></td>
</tr>
<tr>
<td>Probing Depth</td>
<td></td>
</tr>
<tr>
<td>Plaque</td>
<td></td>
</tr>
<tr>
<td>Bleeding on Probing</td>
<td></td>
</tr>
<tr>
<td>Function</td>
<td></td>
</tr>
<tr>
<td>Note</td>
<td></td>
</tr>
</tbody>
</table>

### Buccal

<table>
<thead>
<tr>
<th>18</th>
<th>19</th>
<th>20</th>
<th>21</th>
<th>22</th>
<th>23</th>
<th>24</th>
<th>25</th>
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</tbody>
</table>

### Lingual

<table>
<thead>
<tr>
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<th>24</th>
<th>25</th>
<th>26</th>
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<td>0</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

---

Date: 11.04.2017
PARTICIPANT 1001: FOLLOW-UP CHART

**PERIODONTAL CHART**

**Patient Last Name:** 1001  
**First Name:**  
**Date Of Birth:**

<table>
<thead>
<tr>
<th>Mobility</th>
<th>Implant</th>
<th>Bleeding on Probing</th>
<th>Plaque</th>
<th>Gingival Margin</th>
<th>Probing Depth</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>17</td>
<td>16</td>
<td>15</td>
<td>14</td>
<td>13</td>
</tr>
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<td>0</td>
<td>0</td>
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<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**Initial Exam**  

**Reevaluation**

**Clinician:**

---

**Buccal**

**Lingual**

Note: Mean Probing Depth = 3.1 mm  
Mean Attachment Level = -3.2 mm  
60% Plaque  
19% Bleeding on Probing

---

**Buccal**

**Lingual**

---

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PARTICIPANT 1002: BASELINE CHART

Department Of Periodontology

PERIODONTAL CHART

Date: 20.03.2017

Patient Last Name: 1002  First Name:  

Clinician:  

龈缘    探诊深度    牙周袋

Buccal

Lingual
PARTICIPANT 1003: FOLLOW-UP CHART

znk bern
Zahnmedizinische Kliniken
der Universität Bern

Department Of Periodontology
PERIODONTAL CHART

Date 24.10.2017

Patient Last Name 1003 First Name Date Of Birth

Initial Exam Reevaluation Clinician

Mobility
Implant
Bleeding on Probing
Plaque
Gingival Margin
Probing Depth

Buccal

Lingual

Buccal

Gingival Margin
Probing Depth
Plaque
Bleeding on Probing
Furcation
Note

Mean Probing Depth = 3.1 mm
Mean Attachment Level = -5.1 mm
0% Plaque
25% Bleeding on Probing

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PARTICIPANT 1004: FOLLOW-UP CHART

zmk bern
Zahnmedizinische Kliniken
der Universität Bern

Department Of Periodontology

PERIODONTAL CHART

Date 10.10.2017

Patient Last Name 1004
First Name
Date Of Birth

Initial Exam Reevaluation

Clinician

Mean Probing Depth = 3 mm  Mean Attachment Level = 4.1 mm  8% Plaque  21% Bleeding on Probing

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NB. Participant 1005 did not return for a clinical follow-up appointment, so no follow-up periodontal chart is available.
### zmk bern
Zahnmedizinische Kliniken
der Universität Bern

**Department Of Periodontology**

**PERIODONTAL CHART**

**Patient Last Name**: 1006  
**First Name**:  
**Date Of Birth**:  
**Date**: 17.7.17

**Initial Exam**

<table>
<thead>
<tr>
<th>Mobility</th>
<th>Implant</th>
<th>Fissuration</th>
<th>Plaque</th>
<th>Bleeding on Probing</th>
<th>gingival Margin</th>
<th>Probing Depth</th>
</tr>
</thead>
<tbody>
<tr>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**Buccal**

- Mean Probing Depth = 2.7 mm
- Mean Attachment Level = -3 mm
- 8% Plaque
- 23% Bleeding on Probing

**Lingual**

**Buccal**

- Mobility
- Implant
- Fissuration
- Plaque
- Bleeding on Probing
- gingival Margin
- Probing Depth

**Lingual**

**Buccal**

- Mean Probing Depth = 2.7 mm
- Mean Attachment Level = -3 mm
- 8% Plaque
- 23% Bleeding on Probing

**Clinical Notes**

- Note
- Fissuration
- Bleeding on Probing
- Plaque
- gingival Margin
- Probing Depth

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PARTICIPANT 1006: FOLLOW-UP CHART
**Participant 1007: Baseline Chart**

---

**Periodontal Chart**

**Patient Last Name**: 1007  
**First Name**:  
**Date Of Birth**:  

**Date**: 25.07.17  

**Initial Exam**  

<table>
<thead>
<tr>
<th>Tooth</th>
<th>Mobility</th>
<th>Implant</th>
<th>Furcation</th>
<th>Bleeding on Probing</th>
<th>Plaque</th>
<th>Gingival Margin</th>
<th>Probing Depth</th>
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</thead>
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</tr>
</tbody>
</table>

**Buccal**

**Lingual**

**Buccal**

---

**Mean Probing Depth**: 3.4 mm  
**Mean Attachment Level**: -2.7 mm  
**% Plaque**: 8%  
**% Bleeding on Probing**: 17%  

---

**Notes**

- Furcation
- Bleeding on Probing
- Plaque
- Gingival Margin
- Probing Depth

---

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PARTICIPANT 1007: FOLLOW-UP CHART

PERIODONTAL CHART

Date: 14.02.18

Patient Last Name: 1007
First Name: 
Date Of Birth: 

Initial Exam
Reevaluation

Mobility
Implant
Furcation
Bleeding on Probing
Plaque
Gingival Margin
Probing Depth

Buccal

Lingual

Gingival Margin
Probing Depth
Plaque
Bleeding on Probing
Furcation
Note

Mean Probing Depth = 1.9 mm
Mean Attachment Level = -0.8 mm
9% Plaque
14% Bleeding on Probing

Lingual

Buccal

Gingival Margin
Probing Depth
Plaque
Bleeding on Probing
Furcation
Implant
Mobility

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PARTICIPANT 1008: BASELINE CHART
PARTICIPANT 1008: FOLLOW-UP CHART

Department Of Periodontology
PERIODONTAL CHART

Patient Last Name 1008
First Name
Date Of Birth

Initial Exam
Reevaluation

Mobility
Implant
Furcation
Bleeding on Probing
Plaque
Gingival Margin
Probing Depth

Buccal

Lingual

Buccal

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PARTICIPANT 1009: FOLLOW-UP CHART
PARTICIPANT 1010: BASELINE CHART
PARTICIPANT 1011: BASELINE CHART

Department Of Periodontology

PERIODONTAL CHART

Date: 21.2.2017

Patient Last Name: 1011
First Name: 
Date Of Birth: 

Initial Exam
Reevaluation

Clinician: 

Mobility
Implant
Furcation
Plaque
Bleeding on Probing
Gingival Margin
Probing Depth

Buccal

Lingual

Gingival Margin
Probing Depth
Bleeding on Probing
Furcation

Note

Mean Probing Depth = 3.7 mm
Mean Attachment Level = 4 mm
0% Plaque
46% Bleeding on Probing

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### PERIODONTAL CHART

**PARTICIPANT 1011: FOLLOW-UP CHART**

**Patient Last Name**: 1011  
**First Name**:  
**Date Of Birth**:  

**Date**: 17.7.17  

<table>
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<tr>
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<th>17</th>
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<td>0</td>
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<td>3</td>
</tr>
</tbody>
</table>

**Buccal**

**Lingual**

**Gingival Margin**

**Probing Depth**

**Plaque**

**Bleeding on Probing**

**Furcation**

**Note**

**Mean Probing Depth**: 2.2 mm  
**Mean Attachment Level**: 3.2 mm  
**6% Plaque**:  
**14% Bleeding on Probing**:  

---

**Buccal**

**Lingual**

**Gingival Margin**

**Probing Depth**

**Plaque**

**Bleeding on Probing**

**Furcation**

**Implant**

**Mobility**

---

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PARTICIPANT 1012: BASELINE CHART
PARTICIPANT 1012: FOLLOW-UP CHART
PARTICIPANT 1013: BASELINE CHART

PERIODONTAL CHART

Date: 10.05.2017

Initial Exam

Buccal

Lingual

Buccal

Mean Probing Depth = 3.1 mm
Mean Attachment Level = -3.4 mm
8% Plaque
48% Bleeding on Probing

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PARTICIPANT 1013: FOLLOW-UP CHART
PARTICIPANT 1014: BASELINE CHART

PERIODONTAL CHART

Date: 10.10.2017

Initial Exam

Mobility
0

Implant

Furcation

Bleeding on Probing

Plaque

Gingival Margin
2 2 0

Probing Depth
2 2 3

Note

Buccal

Lingual

Mean Probing Depth = 3 mm
Mean Attachment Level = -4.6 mm
90% Plaque
36% Bleeding on Probing

Lingual

Buccal

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PARTICIPANT 1014: FOLLOW-UP CHART

PERIODONTAL CHART

Date: 14.3.2018

Patient Last Name: 1014
First Name: 
Date Of Birth: 

Initial Exam
Reevaluation

Mobility
0
0
0
0
0
0
0
0
0
0

Implant
Fissure
Bleeding on Probing
Plaque
Gingival Margin
1 0
3 2
0 0
0
0
0

Probing Depth
2 2
2 2
3 2
2 1
2 1
2 1
2 1
2 3
2 3
2 3
2 3

Buccal

Lingual

Gingival Margin
1 1
0 0
0 0
0 0
0 0
0 0
0 0
0 0
0 0
0 0
0 0
0 0

Probing Depth
2 2
3 2
3 2
2 2
2 2
2 1
2 1
2 2
2 2
2 2
2 2
2 2

Plaque

Bleeding on Probing
Furcation

Lingual

Buccal

Gingival Margin
2 2
1 1
2 1
2 1
3 2
3 2
3 2
3 2
3 2
3 2
3 2
3 2

Probing Depth
2 1
2 1
2 1
2 1
2 1
2 1
2 1
2 1
2 1
2 1
2 1
2 1

Plaque

Bleeding on Probing
Furcation

Note

Mean Probing Depth = 2.4 mm
Mean Attachment Level = -3.0 mm
6 % Plaque
21 % Bleeding on Probing

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