Oral health after head and neck cancer: Supportive care needs and quality of life implications

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Abstract

Background
Head and neck cancers (HNC) account for 3.5% of the overall Australian cancer incidence. Despite forming only a subset of the national incidence, these cancers often cause significant personal morbidity and may affect multiple domains of quality of life (QoL). The mouth is central to eating and communicating and treatment for cancers of the oral cavity or oropharynx may cause profound changes in function and comfort. Surgery, radiotherapy and chemotherapy independently cause side-effects that affect the oral cavity, and have a cumulative effect when combined. High intensity multi-modal treatments have improved survival outcomes; but also result in a greater burden of treatment-related toxicities including mucositis, pain, dysphagia, xerostomia and fatigue.

Despite the vital importance of a well-functioning mouth to maintaining nutritional, aesthetic and social wellbeing there is a paucity of literature describing oral health outcomes after HNC. A majority of prior research in this field has reported findings from structured questionnaires. This approach may assist in evaluating outcomes across the broader HNC population, however lacks the flexibility to capture nuanced treatment experiences, or to understand how an individual’s social, environmental or medical context influence QoL perceptions.

Aims
This thesis aimed to explore QoL and supportive care needs following HNC; with a focus on exploring how oral changes are experienced and managed post treatment. Thus, this thesis aimed to explore the conceptually distinct constructs of symptom experience, QoL and supportive care needs and how these are experienced and evaluated from the patient perspective.

Methods
A mixed-methodology was used to explore oral health quality of life and supportive care needs. Mixed methods in the context of this thesis refers to a series of studies that varied in methodological approach (i.e. quantitative and qualitative), but contributed its findings to the overall thesis aims and objectives. These constructs were evaluated at varying points of treatment recovery and survivorship by a series of discrete studies. Perceived supportive care needs and influence on QoL was explored, using qualitative methods, among people who had previously been treated for HNC. The role of cognitive appraisal,
coping and adjustment to chronic stressful outcomes were discussed, using the theory of stress, appraisal and coping as a framework. This framework was also applied to investigating how oral health was experienced and managed six months post treatment, in a separate study.

Quality of life over the first six months following the diagnosis and treatment of head and neck cancer was explored prospectively among a convenience sample of HNC patients. Changes in scores to the University of Washington Quality of Life Questionnaire, version 4 (UW-QoL v4) between pre-treatment, one month and six months post treatment were described, in addition to the influence of geographical location on QoL outcomes. Analysis of open-ended responses to the UW-QoL was conducted using automated content analysis, and the potential use of text data to identify QoL issues and opportunities for supportive care intervention was discussed.

Oral health, quality of life and supportive care needs were further extended by the final qualitative study, which explored the management of oral health from behavioural and access to care perspectives. Qualitative data was gathered from semi-structured interviews and analysis was performed by thematic analysis.

**Findings**

QoL in most UW-QoL domains decreased between baseline and one month post treatment and increased towards pre-treatment scores at the six month follow up (with the exception of anxiety and saliva). Pain at baseline was significantly worse in the regional-remote participants compared to metropolitan participants. The themes identified in free-text responses also changed at each follow up. At six months post treatment the most frequently identified difficulties concerned the mouth and eating.

The cognitive appraisal and coping process influenced the perceived impact of unmet needs on QoL, and the threat of acute, stressful outcomes of treatment changed as time since treatment progressed. The use of problem-focused coping, meaning-focused coping and accepting a ‘new normal’, contributed to downplaying the impact of these changes on overall quality of life. This was also observed in regard to permanent oral health outcomes. Oral health was perceived to have a new meaning following treatment, and the motivation to promote oral health was greater than before treatment. Factors that affected QoL and
the management of oral health included social support networks, ability to fund oral health care, and the experience of psychological distress.

Oral health-related supportive care needs stemmed from structural gaps in the organisation and provision of dental oncology services. Support needs relating to the continuity of care and quality and appropriateness of dental care were also identified. The need for ongoing psychosocial support emerged throughout the thesis findings.

Initiatives to address unmet supportive care needs include establishing peer support networks to facilitate the cognitive appraisal and adjustment process, ongoing psychological support services, and greater integration between medical and dental oncology services.
Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

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**Publications during candidature**

**Declaration of surname change**
Over the course of this thesis, my surname changed from Moore to Pateman. Some of the early work is published under my maiden name. This is clearly marked in the publications during candidature section.

- **Peer reviewed papers**

  **Pateman, KA,** Ford PJ, Farah CS, Batstone MD. Coping with an altered mouth and perceived supportive care needs following head and neck cancer treatment. Supportive Care in Cancer. 23(8):2365-73, August 2015. doi:10.1007/s00520-015-2607-y. Epub 2015 Jan 16


- **Conference abstracts**


• Poster presentations


• Other presentations


Publications included in this thesis

Incorporated as **Chapter 1**.

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Contributions by others to the thesis

In addition to the contributions listed above, I wish to acknowledge the contribution made by the following people to this thesis:

- Chapter 3, Ms Nicole Cockburn conducted the statistical analysis component of this work. Ms Cockburn’s overall contribution to the Chapter is 20%
- Chapter 6, Dr Arosha Weerakoon assisted with data analysis by performing coding of the data transcripts. Dr Weerakoon’s contribution to the Chapter is 10%

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Statement of parts of the thesis submitted to qualify for the award of another degree

None.
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Head and neck cancer, oral cancer, mouth neoplasm, quality of life, support needs, oral health, access to care.

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**List of Abbreviations**

EPHPP - Effective Public Health Practice Project
HNC – Head and neck cancer
QoL – Quality of Life
HRQoL – Health-related quality of life
HNCSG – Head and neck cancer support group
PEG – Percutaneous Endoscopic Gastrostomy tube
PROM – Patient reported outcome measure
ASGC-RA – Australian Standard Geographic Classification-Remoteness Index
CAE – Centre for Adult Education
TAFE – Technical and Further Education
Tis – Tumour in situ

*Abbreviations used in Table 1-3*

P= Prospective
PCI = Patient Concerns Inventory
PEG = Percutaneous Endoscopic Gastrostomy
PSS = Head and Neck Performance Status Scale
R= Retrospective
RAND-36 = Dutch Version of Short Form-36
R-C = Retrospective Correlational
SDI = Social Difficulties Inventory
SSQ-6 = Short Form Social Support Questionnaire
UW-QoL v4 = University of Washington Quality of Life Scale version 4
WHOQoL-BREF = World Health Organisation Quality of Life abbreviated version
WOC-CA = Ways of Coping – Cancer Version
BDI = Beck Depression Inventory
BIS = Body Image Scale
CAGE = Alcohol Screening Tool
C-C = Case control
CES-D = Centre for Epidemiologic Studies Depression Scale
CRT = Chemoradiation Therapy
CS= Cross sectional
DAS = Dyadic Adjustment Scale
DIC-2 = Distress Inventory for Cancer, Version 2
EORTC QLQ-C30 and EORTC QLQ-H&N35 – European Organisation for Research and Treatment of Cancer Quality of Life- Core 30 and Head & Neck 35
EPHPP = Effective Public Health Practice Project
FACT = Functional Assessment of Cancer Therapy; FACT-H&N = Head and Neck
FOR = Fear of Recurrence
GHQ-20 = General Health Questionnaire
HADS = Hospital Anxiety and Depression Scale
KPS = Karnofsky Performance Status
L=Longitudinal
MAC-Q = Mental Adjustment to Cancer Questionnaire
MAST = Michigan Alcohol Screening Test
MSPSS = Multidimensional Scale of Perceived Social Support
OC = Oral Cancer
OSCC = Oral Squamous Cell Carcinoma
Preliminary material
**Preliminary material**

i. **Context**

Head and neck cancers account for approximately 3.5% of the national Australian cancer incidence\(^1\). The term head and neck cancer (HNC) collectively refers to site-specific cancers that arise from the oral cavity, pharynx, larynx, paranasal sinuses and nasal cavity\(^2\). Incidence rates vary by sub-type, country and gender\(^3\). Globally, an estimated 300,400 new cases and 145,000 deaths from lip, oral and oropharyngeal cancers occurred in 2012\(^4\). In Australia, 4,243 new cases were diagnosed in 2012\(^1\).

Most HN/oral cancers are squamous cell carcinomas (SCC) and share the major risk factors of tobacco (including smokeless tobacco products) and alcohol use\(^4\). Infection with the Human Papilloma Virus (HPV) is a further risk factor for oropharyngeal carcinoma. A rise in HPV-linked oropharyngeal cancers has caused a shift in the demographic and risk profile of the disease\(^5\). The incidence of HPV-linked oropharyngeal cancer has risen among younger males (aged 40-55 years) with a limited history of alcohol and tobacco exposure\(^5\). This has occurred alongside a decline in the incidence of oral cancers in developed nations\(^3\), including Australia\(^6\).

Curative treatment approaches for HNC are often multi-modal and vary based on tumour site and staging. Multidisciplinary management is the recommended standard of care to enable accurate diagnosis, disease staging and treatment planning. An inter-professional team additionally provide supportive care, and typically includes speech and language pathologists, dieticians, physiotherapists, psychologists and oral health professionals.

Oral cavity, lip & salivary gland tumours are predominantly treated by surgery followed by post-operative radiotherapy, whereas oropharyngeal cancers tend to be treated by a non-surgical approach, involving radiotherapy or chemoradiotherapy\(^7\). Early stage laryngeal cancers are managed with a surgical organ-preservation approach, however locally advanced cases may require laryngectomy and
subsequently are associated with significant supportive care and rehabilitation needs.8.

The treatment for HNC affects multiple domains of quality of life (QoL) and physical functioning. Surgery is often complex and may involve composite resection of oral soft tissues and supporting structures. Free-flap reconstruction is often required for extensive defects, which adds to the complexity of procedures and increases rehabilitation needs.9. Oral rehabilitation may also involve the fabrication of a specialty prosthesis to retain function and replace teeth. Consequently, surgery is associated with functional deficits to swallowing, speech and chewing and may affect facial appearance.10,11 Neck dissection involving the removal of lymph nodes with metastasis or at high risk of metastasis may also be required and may cause shoulder dysfunction and pain that adversely affects QoL.12,13.

Radiotherapy to the oral cavity and oropharynx causes considerable acute toxicity including oral pain, dysphagia, mucositis, unintended weight loss and fatigue.14 The oral complications of radiotherapy may be explained by the high cellular turnover rates of the oral mucosa, a diverse oral microflora and trauma to the oral tissues as a part of normal function.15 Radiation doses above 30 Gray cause irreversible damage to salivary glands, resulting in an increased risk of caries for all teeth, not only those included in the field of radiation.16 Most of the acute toxicities associated with radiotherapy reduce over the first year following treatment, however permanent dysfunction may remain in regard to swallowing, loss of teeth and worse dental health, mouth opening, xerostomia and sticky saliva.17,18.

Across HNC sites, concomitant chemotherapy may be delivered to improve the response to radiotherapy in locally advanced cases.7 While this may improve prognosis, it also results in greater systemic toxicities, such as fatigue and nausea, and may increase the severity of oropharyngeal mucositis and pain caused by radiotherapy.14.

There are many definitions of oral health available from leading health organisations worldwide. The World Dental Federation has recently reviewed their definition of
oral health, and is now recognised as being “multifaceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort, and disease of the craniofacial complex.” With this definition in mind, the treatments for HNC may adversely impact on several oral health domains. Salivary hypofunction as a result of radiotherapy increases the risk of carious and non-caries tooth loss, the risk of opportunistic infections and means that life-long preventive dental care is essential. Changes to oral health may affect facial aesthetics due to missing teeth, soft tissue contour and muscular changes and also social functioning, nutrition and general wellbeing due to the changes to speech, eating and swallowing function. Not surprisingly, these changes can have a profound impact on QoL, encompassing psychosocial wellbeing and social functioning.

Poor oral health is attributed to the avoidance of health promoting behaviours such as use of fluoride toothpaste, regular mechanical plaque removal, the consumption of a low-cariogenic diet, and frequent access to professional dental care. Poor oral health is experienced as dental disease, and this includes periodontal disease, dental caries and odontogenic infections that may ultimately result in tooth loss. Both oral diseases and oral cancer incidence occur along a social gradient, where a higher incidence is observed among low-socio-economic groups. This is likely due to increased engagement in the common risk factors of tobacco, alcohol consumption and poor nutritional intake. A complicating factor in the management of oral health among people treated for oral and HNC is a commonly reported history of infrequent dental attendance and dental neglect, especially among those individuals most at risk. Despite this, and the increased threat to maintaining a functioning dentition caused by the treatment for HNC, supportive oral health care is comparatively under-researched.
ii. **Problem statement**
There is a lack of evidence describing the QoL and supportive care needs relating to oral health after the treatment for HNC. Existing literature has predominantly described oral health outcomes based on quantified scores of symptom experience measured on QoL and health-related QoL questionnaires (i.e. xerostomia, dysgeusia, speech). This has resulted in a lack of understanding of the individual experience; how symptoms are judged to influence QoL and how this may potentially be addressed by supportive care.

Recognising that oral health is closely integrated with general health, this thesis aims to address this lack of information about oral health, quality of life and supportive care needs following HNC treatment in a holistic sense. There are potentially many factors that may influence oral health after HNC treatment: ranging from how an individual copes with side effects (and what support is available and drawn on), to the behavioural management of oral health and dental care, to accessing dental care. Within the Australian context, the latter is complicated by the dissociation between the dental and medical health systems.

iii. **Thesis aims, objectives and methods**
The objective of this thesis is to explore the changes to oral health (as perceived by the individual) that occur as a result of HNC treatment and identify associated quality of life implications and supportive care needs.

Specifically, the following aims are addressed:

1. To explore the relationship between quality of life and perceived supportive care needs by investigating the intermediary role of cognitive appraisal, coping and adjustment to chronic outcomes of treatment.

2. To investigate quality of life by conducting a prospective study of a cohort of newly diagnosed HNC patients and to explore the influence of area of residence (metropolitan versus regional or remote area) on quality of life scores.

3. To discuss the use of a widely used structured questionnaire in quality of life assessment and highlight the potential use of open-ended text in identifying supportive care needs.
4. To further investigate the influence of the cognitive appraisal and coping response to describe how oral health outcomes are adjusted to six months after treatment.

5. To explore how oral health is maintained after treatment by exploring factors related to individual oral health behaviours and access to care.

The overall objective of this research is to contribute to an evidence base for approaches to care that better meet the needs of HNC patients.

A mixed-methodology was used to perform the aims and objectives described above. In the context of this thesis, mixed methods describes a series of studies with varied in methodological approach (i.e. quantitative and qualitative), that contribute findings to the overall thesis aims and objectives. The link that each experimental chapter has to the overall research aims and objectives is conceptualised in Figure A (page 26).

Rather than being positioned within a single theoretical approach or paradigm, this thesis is informed by several theoretical frameworks. There are elements of this thesis that are aligned with positivism, which are extended by subjectivist approaches to exploring the individual experience. The approaches to qualitative data collection draw from phenomenological methods (involving interviews exploring the lived-experience of oral health symptoms and quality of life), however health behaviour and psychological theories are used as an interpretive framework for data analysis and discussion of findings.

The methodology selection was partly a pragmatic decision and also necessary to address the broad research question, dealing with quality of life and supportive care, with a focus on oral health. A majority of this research occurred within the clinical setting and involved participants who had recently completed treatment for cancer. These factors required an applied qualitative approach to be used and adapted to the research environment. There was also a need to position the work in light of the previous literature evaluating QoL; to enable a contextual basis for discussion around this approach and its potential to assess oral health and supportive care needs. Positioning oral health needs within this methodological framework was intended to
enhance the collection of evidence in a manner that was both clinically relevant and be an extension of the existing literature in this area.

i. Scope of thesis

The research contained in this thesis refers to supportive care needs and QoL implications from an oral health perspective. As a result, this thesis does not intend to address all support needs that may influence quality of life during and after HNC treatment.

The constructs of interest (QoL, supportive care needs and oral health experiences) are described at varying time points in the cancer trajectory. As each study involved the recruitment of a discrete sample of participants, these changes are not longitudinal. The time frame of reference is clearly described in each Chapter.

Throughout the academic literature and colloquially, there is a blurring of definitions describing head and neck and oral/oropharyngeal cancers. The close proximity of the structures of the head and neck region means that treatments targeted at a particular site, for instance the tonsil, may overlap and affect other areas such as the oral cavity or neck depending on the modality used. The thesis aims encompass understanding a whole person experience and how physical outcomes of treatment, as well as the interaction with the social and environmental context, shape quality of life and supportive care perceptions. Therefore, this thesis uses a broad definition of HNC and includes participants treated for cancers of the oral cavity and oropharynx as well as other sites, but excludes the brain.
Figure A: Overview of thesis chapters and links to thesis aims and objectives

QoL; supportive care needs (inclusive of oral health related and non-oral health related issues/outcomes)

Management of oral health: appraisal and coping; oral health behaviours; access to care

Chapter 1: Systematic review of published literature

Chapter 2: Influence of supportive care needs on QoL

Chapter 3: QoL over the first 6 months after diagnosis & treatment for HNC

Chapter 4: Open-ended data to assess QoL & identify supportive care needs

Chapter 5: Coping with changes to OH six months post treatment

Chapter 6: Managing OH and accessing dental care

Experimental chapter outline & methodology
Chapter 1

Support needs and quality of life implications in oral cancer: a systematic review
Chapter 1: Support needs and quality of life implications in oral cancer: a systematic review

1.1 Introduction

Oral and oropharyngeal cancer is the sixth most common cancer world-wide, with the annual incidence of oral cancer estimated to be 275,000\textsuperscript{23}, with developing nations sharing a disproportionate burden of disease\textsuperscript{24}. Oral cancer is associated with significant mortality, with global five year survival rates estimated to be 50\%\textsuperscript{23}. Treatment for oral cancer is particularly disabling and disfiguring and disrupts the core aspects of daily life\textsuperscript{25}. The mouth is central to an individual's ability to eat, speak and interact with others, and as such the treatment of oral cancer is associated with a significant physical and psychological burden.

Oral cancer describes malignancies of the oral cavity, including structures such as the gingiva, buccal mucosa, hard palate, floor of mouth, salivary glands and anterior two thirds of the tongue\textsuperscript{26}. Cancers of the oropharynx and oral cavity share several risk factors and the term head and neck cancer is commonly used to define cancers of the oral cavity and oropharynx\textsuperscript{2}. This review focuses on oral cancer but makes reference to the findings of studies incorporating mixed head and neck cancer samples that are inclusive of oral cancer patients.

Quality of life (QoL) is greatly affected by oral cancer diagnosis and treatment. QoL is a measure of an individual’s subjective wellbeing, in the context of the culture and value system where they live\textsuperscript{27}. Health related quality of life (HRQoL) is a subset of QoL that encompasses four domains: physical functioning, psychological functioning, social interaction and disease and treatment related symptoms\textsuperscript{28}. HRQoL is an important indicator in patients undergoing treatment for head and neck cancer, as it is a measure of disease experience and is a predictor of disease survival\textsuperscript{28}.

The assessment of QoL as a treatment outcome has become an important aspect of oral cancer research and has allowed the evaluation of the impacts of treatment from the patient’s perspective\textsuperscript{17}. Validated questionnaires form the mainstay of QoL assessment, and have provided an indication of patient-related factors associated
with worse QoL after treatment. There is little evidence however as to how the QoL deficits reported by patients may be improved, especially after treatment, by offering practical and appropriate support for patients.

In this sense, support needs assessment may be used to complement QoL evaluations in oral cancer patients. In contrast to QoL assessment, needs assessment aims to directly investigate and identify issues and their perceived importance to patients. In practical terms, “needs” can be defined as the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being. Needs relating to cancer and its treatment are broad; and may include physical, psychosocial and practical needs.

There are several long term side effects associated with the treatment of oral cancer. Surgical removal of the cancer may result in physical disruption to the anatomy and neuromuscular control structures of the oral cavity. Post-treatment radiotherapy may further compound the functional deficits caused by surgery. Patients who have received radiotherapy to the oral cavity report ongoing issues with dysphagia and xerostomia several years after treatment.

The diagnosis and treatment of oral cancer has a significant burden on the psychological wellbeing of patients. Suicide rates are higher among head and neck cancer patients than the general population, and the general cancer population and oral cancer patients report significantly worse QoL across physical and psychosocial domains when compared to people with other cancers. Additionally, oral cancer patients perceive higher support needs than patients with other cancers, particularly related to physical and daily living needs, patient care and support needs and health system and information needs.

Oral cancer patients require professional support in coping with the consequences of treatment, including adjusting to changes in swallowing, nutritional intervention and psychological support. The symptom specific scales of commonly used QoL questionnaires measure several of these treatment outcomes. Although not a direct measure of support need, the issues identified on symptom specific QoL
scales associated with poor QoL may provide evidence as to the type of support needs perceived by oral cancer patients across the oral cancer trajectory. There have been a number of reviews published previously evaluating QoL outcomes in oral cancer, however there are few that discuss support needs or a supportive care approach. This review aimed to use the literature describing QoL outcomes in oral cancer patients to create an evidence base for the support needs perceived by this patient group and describe their impact on QoL.

1.2 Methods

Literature search
The search aimed to answer the following question: “what support needs are identified by oral cancer patients during cancer diagnosis, treatment and post-treatment and how do they affect quality of life?” Electronic databases Cochrane, Embase, Pubmed, CINAHL, Scopus, Web of Science and PsycINFO were searched using a combination of keyword, Medical Subject Heading (MeSH) or equivalent database thesaurus subject headings. See below for a description of the search strategy used for Pubmed. This search strategy was adjusted for each of the databases used.

Figure 1-1: Search strategy

1. Exp Nutritional support/ OR Exp Social support/ OR Exp Financial support/
2. Support need* or social support
3. #1 OR #2
4. Exp mouth neoplasms/ OR “oral cancer”
5. (Mouth OR oral) AND (cancer* OR malignan* OR carcinoma* OR tumor* OR tumour* OR neoplasm*)
6. #4 OR #5
7. Exp Quality of life/
8. “Health related quality of life” OR “quality of life” OR “lived experience” OR QoL OR HRQOL
9. #7 OR #8
10. #3 AND #6 AND #9
One researcher (KP) screened the abstracts of the complete data set, while another researcher (PF) independently screened a subset and the selections were then compared. Disagreements were resolved by discussion among the researchers until a consensus decision was reached. The full-text versions of the potentially relevant articles were then obtained and assessed for eligibility by the first researcher (KP).

**Eligibility criteria**

Articles were included if they described patient-reported QoL outcomes that were translatable to support needs in oral cancer patients, were in English, and were original studies. Studies reporting QoL findings from heterogeneous head and neck cancer samples were also included if they were inclusive of oral cancer patients. Articles that described findings only in participants with cancers outside the oral cavity, did not describe QoL outcomes translatable to support needs, and were published in languages other than English were excluded. Studies reporting findings from heterogeneous head and neck cancer samples in which oral cancer patients were unable to be identified were also excluded, as were qualitative and case-report studies. The literature search methodology is outlined in Figure 1-2, below.
Quality assessment

The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies was used to assess the methodological quality of the included studies. This tool classifies the strength of a study as strong, moderate or weak based on assessment of several components of the methodology and results. This tool was selected based on the ability to convey a numerical rating of a study’s relative strength or weakness. The EPHPP tool is validated, has been widely used in the public health field and is suitable for the assessment of quality in cohort studies.
Data synthesis
Fundamental differences in study design, study population, outcome measures and methodology presented a challenge in synthesising the key findings of the included studies. Support needs were interpreted by the authors and were formed based on the outcomes reported from symptom specific QoL questionnaires used in the included studies. For data synthesis, “support needs” were defined as a QoL issue that had the potential to be improved by the provision of an action or resource \(^{30}\). Support needs were extracted from the studies by one researcher (KP), and were then discussed with a second researcher (PF) to ensure clinical relevance.

For each study, the relative impact on QoL for the reported support need along with its prevalence were categorised and reported in table-form. The relative impact of each support need on QoL and its prevalence was described as low, moderate or high. The cut off for each category was determined by the authors, and is described in Table 1-1. To ensure reliability and trustworthiness of data extraction, categories of support needs directly related to the quality of life symptoms or domains reported by the included studies.
### Table 1-1: Description of support need classification

<table>
<thead>
<tr>
<th>Relative impact on quality of life (QoL)</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>High</strong></td>
<td>Support need perceived by more than 65% of population</td>
</tr>
<tr>
<td><strong>Moderate</strong></td>
<td>Support need perceived by 45% to 65% of population</td>
</tr>
<tr>
<td><strong>Low</strong></td>
<td>Support need perceived by less than 45% of population</td>
</tr>
<tr>
<td>Strongly significant clinically relevant change reported by authors*</td>
<td></td>
</tr>
<tr>
<td>Clinically relevant change reported by authors*</td>
<td></td>
</tr>
<tr>
<td>No clinically relevant change reported by authors*</td>
<td></td>
</tr>
</tbody>
</table>

*Classification based on authors' conclusions about significance of impact on QoL.
1.3 Results

The initial database search yielded 1124 potentially eligible articles. Thirty-one articles met the inclusion criteria. The selection process is described in Figure 1-2. A range of methodological approaches and a variety of outcome measures were used to measure QoL and support needs in the studies included in this review. A majority of the included studies were of cross-sectional design (n=21), followed by smaller proportion of longitudinal or prospective designs (n=7). Two studies were of case-control design and one study used a retrospective chart review methodology. Qualitative studies were excluded from the analysis. A summary of study characteristics and the support needs identified is provided in Table 1-3.

The use of cross-sectional design by several of the studies contributed to a high number of ‘weak’ appraisals in the results. Studies that used longitudinal or prospective methods were generally awarded a stronger EPHPP rating. Most studies that used a non-validated outcome measure also included previously validated measures in their study designs to strengthen and validate the results of the self-designed measures. One of the included studies used a non-validated self-designed outcome measure, and therefore was awarded a weak rating.
### Table 1-2: Summary of study characteristics and support needs identified

<table>
<thead>
<tr>
<th>Author/ Year (country)</th>
<th>Study type</th>
<th>Study population</th>
<th>Outcome measure(s)</th>
<th>Timeframe of QoL assessment</th>
<th>Support need(s) identified</th>
<th>Relative impact on QoL</th>
<th>Prevalence among patients*</th>
<th>EPHPP Global rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdenstein 2005 (Norway)</td>
<td>P</td>
<td>N=167 HNC</td>
<td>EORTC QLQ-C30; EORTC QLQ-H&amp;N35</td>
<td>Diagnosis, 1yr and 5yrs after treatment</td>
<td>Sticky saliva, Sexuality</td>
<td>High, Moderate</td>
<td>n/a</td>
<td>Moderate</td>
</tr>
<tr>
<td>Al Newas 2006 (Germany)</td>
<td>C-C</td>
<td>N=42 OC</td>
<td>EORTC QLQ-C30; EORTC-H&amp;N35 &amp; objective measures of salivary flow</td>
<td>After treatment. Mean time from irradiation 46 months</td>
<td>Xerostomia</td>
<td>High</td>
<td>Low</td>
<td>Weak</td>
</tr>
<tr>
<td>Bekiroglu 2011 (UK)</td>
<td>CS</td>
<td>N=641 OC</td>
<td>UW-QoL</td>
<td>1-2 years after treatment</td>
<td>Adjuvant RT group: Xerostomia, Swallowing, Chewing, Speech</td>
<td>High, High, High, High</td>
<td>High, High, High, High</td>
<td>Strong</td>
</tr>
<tr>
<td>Bjordal 1994 (Norway)</td>
<td>L</td>
<td>N=213 HNC</td>
<td>EORTC QLQ-C30 and EORTC-H&amp;N35; GHQ-20; measures of general satisfaction with life and strength and fitness</td>
<td>7-11 years after RT</td>
<td>Xerostomia</td>
<td>High</td>
<td>Low</td>
<td>Weak</td>
</tr>
<tr>
<td>Duke 2005 (USA)</td>
<td>CS</td>
<td>N=86 HNC</td>
<td>UW-QOL; PSS-HN; FACT; dental evaluation</td>
<td>5 years post treatment</td>
<td>Tooth loss, Compromised dentition (DMF &gt;14), Denture use</td>
<td>Moderate, High</td>
<td>Moderate, High</td>
<td>Weak</td>
</tr>
<tr>
<td>Epstein 1999 (Canada)</td>
<td>CS</td>
<td>N=65 HNC</td>
<td>EORTC QLQ-C30 plus addendum sheet to assess oral symptoms and function*</td>
<td>6 - 12 months after completion of treatment</td>
<td>Xerostomia, Dysphagia, Taste, Tooth decay</td>
<td>High, High, High, High</td>
<td>High, High, High, High</td>
<td>Weak</td>
</tr>
<tr>
<td>Epstein 2001 (Canada)</td>
<td>P</td>
<td>N=20 HNC</td>
<td>EORTC QLQ-C30 Oral symptoms and function scale</td>
<td>Pre-treatment, 1 month &amp; 6 months post-treatment</td>
<td>Chronic pain, Xerostomia, Taste, Speech difficulties, Eating difficulties</td>
<td>High, High, High, High, High</td>
<td>High, High, High, High, High</td>
<td>Weak</td>
</tr>
<tr>
<td>Fang 2004 (Taiwan)</td>
<td>L</td>
<td>N=77 HNC</td>
<td>EORTC QLQ-C30 &amp; H&amp;N 35</td>
<td>Pre RT and 2 years post RT</td>
<td>Teeth, Xerostomia, Sticky saliva, Social eating</td>
<td>High, High, High</td>
<td>Moderate, Moderate, Moderate</td>
<td>Strong</td>
</tr>
<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
<td>Sample Size</td>
<td>Diagnosis</td>
<td>Instruments</td>
<td>Timing</td>
<td>Domains</td>
<td>Level of Evidence</td>
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<tr>
<td>Fingeret 2012 (USA)</td>
<td>2012</td>
<td>USA</td>
<td>N=280</td>
<td>HNC</td>
<td>BIS; FACT-HN; survey designed for study*</td>
<td>Pre treatment &amp; post treatment</td>
<td>Body image concerns; Dissatisfaction with information received</td>
<td>High</td>
</tr>
<tr>
<td>Fingeret 2012 (USA)</td>
<td>2012</td>
<td>USA</td>
<td>N=280</td>
<td>HNC</td>
<td>BIS; FACT-G; survey designed for study*</td>
<td>&gt;1 month – 5 years post diagnosis</td>
<td>Speech/Eating concerns; Body image concerns</td>
<td>High</td>
</tr>
<tr>
<td>Handschel 2012 (Germany)</td>
<td>2012</td>
<td>Germany</td>
<td>N=1652</td>
<td>OC</td>
<td>Impairment scale*; depression and anxiety scales</td>
<td>&gt;6 months after treatment</td>
<td>Psychological support</td>
<td>High</td>
</tr>
<tr>
<td>Hassanein 2005 (UK)</td>
<td>2005</td>
<td>UK</td>
<td>N=68</td>
<td>OC</td>
<td>HADS; UW-QoL1; EORTC QLQ- C30; MAC-Q</td>
<td>Mean 23 months after treatment</td>
<td>Anxiety Depression</td>
<td>High</td>
</tr>
<tr>
<td>Hassanein 2001 (UK)</td>
<td>2001</td>
<td>UK</td>
<td>N=68</td>
<td>OC</td>
<td>UW-QoL; HADS; MAC-Q; SSQ-6</td>
<td>6 months to 6 years after treatment</td>
<td>Depression/ anxiety Coping</td>
<td>High</td>
</tr>
<tr>
<td>Jenewein 2008 (Switzerland)</td>
<td>2008</td>
<td>Switzerland</td>
<td>N=31</td>
<td>OC</td>
<td>WHOQOL-BREF; EORTC QLQ-C30 &amp; H&amp;N35; DAS</td>
<td>Post treatment</td>
<td>Marital satisfaction Anxiety</td>
<td>Low</td>
</tr>
<tr>
<td>List 1999 (USA)</td>
<td>1999</td>
<td>USA</td>
<td>N=46</td>
<td>HNC</td>
<td>KPS; PSS; McMaster University Head and Neck Radiotherapy Questionnaire; FACT-H&amp;N</td>
<td>3 months intervals during treatment; 6 monthly after treatment</td>
<td>Xerostomia Difficulty tasting</td>
<td>High</td>
</tr>
<tr>
<td>List 2002 (USA)</td>
<td>2002</td>
<td>USA</td>
<td>N=79</td>
<td>HNC</td>
<td>WOC-CA; FACT; PSS-HN; KPS; CAGE</td>
<td>Pre-treatment</td>
<td>Emotion focused coping</td>
<td>High</td>
</tr>
<tr>
<td>Low 2009 (UK)</td>
<td>2009</td>
<td>UK</td>
<td>N=350</td>
<td>HNC</td>
<td>EORTC QLQ-H&amp;N35 sexuality scale; UW-QoL and self designed intimacy questions*</td>
<td>Post treatment</td>
<td>Sexuality and intimacy dysfunction</td>
<td>Moderate</td>
</tr>
<tr>
<td>Millsop 2006 (UK)</td>
<td>2006</td>
<td>UK</td>
<td>N=278</td>
<td>HNC</td>
<td>UW-QoL</td>
<td>Pre-treatment or 6 or 12 months after treatment</td>
<td>Appearance</td>
<td>N/a</td>
</tr>
<tr>
<td>Pandey 2009 (India)</td>
<td>2009</td>
<td>India</td>
<td>N=123</td>
<td>HNC</td>
<td>DIC2; FACT-HN</td>
<td>During treatment</td>
<td>Psychological distress</td>
<td>High</td>
</tr>
<tr>
<td>Potash 2010 (USA)</td>
<td>2010</td>
<td>USA</td>
<td>N=283</td>
<td>HNC</td>
<td>HNCI; BDI; MAST</td>
<td>1 year post treatment</td>
<td>Alcohol use Alcohol abuse</td>
<td>Moderate</td>
</tr>
</tbody>
</table>
### Chapter 1: Systematic review

<table>
<thead>
<tr>
<th>Study (Year)</th>
<th>Design</th>
<th>Country</th>
<th>Questionnaires/Endpoints</th>
<th>Time After Treatment</th>
<th>Modality/Scales</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rogers 2009 (UK)</td>
<td>CS</td>
<td>N=123 HNC</td>
<td>UW-QOL v4; List of PCI issues</td>
<td>&lt;6 weeks after completion of treatment</td>
<td>Depression</td>
<td>High</td>
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<td></td>
<td>Anxiety</td>
<td>High</td>
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<td></td>
<td>Fear of recurrence</td>
<td>High</td>
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<td>Dental health/teeth</td>
<td>High</td>
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<td></td>
<td>Mouth opening</td>
<td>High</td>
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<td></td>
<td>Swallowing</td>
<td>High</td>
</tr>
<tr>
<td>Rogers 2010 (UK)</td>
<td>C-C</td>
<td>N=68 HNC</td>
<td>UW-QoLv4; PCI; FOR questionnaire</td>
<td>Post treatment</td>
<td>Fear of recurrence</td>
<td>High</td>
</tr>
<tr>
<td>Rogers 2007 (UK)</td>
<td>CS</td>
<td>N=243 HNC</td>
<td>UW-Qol v4 and self designed PEG questionnaire</td>
<td>Post treatment</td>
<td>Chewing dysfunction</td>
<td>High</td>
</tr>
<tr>
<td>Rogers 2009 (USA)</td>
<td>CS</td>
<td>N=65 HNC</td>
<td>BMI; CES-D; FACT-H&amp;N</td>
<td>&gt;6 months post treatment</td>
<td>Depression</td>
<td>High</td>
</tr>
<tr>
<td>Rogers 2012 (UK)</td>
<td>CS</td>
<td>N=447 HNC</td>
<td>SDI; EORTC QLQ-C30; UWQOL; self designed questions about financial burden</td>
<td>Post-treatment</td>
<td>Financial burden</td>
<td>High</td>
</tr>
<tr>
<td>Van Cann et al. 2005 (Netherlands)</td>
<td>CS</td>
<td>N=105 HNC</td>
<td>EORTC QLQ-C30 and EORTC QLQ-H&amp;N35</td>
<td>2-7 years after treatment</td>
<td>Post op RT:</td>
<td>High</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Swallowing</td>
<td>High</td>
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<td></td>
<td>Social eating</td>
<td>High</td>
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<td></td>
<td>Xerostomia</td>
<td>High</td>
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<td></td>
<td></td>
<td>Trismus</td>
<td>High</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>Nutritional supplements</td>
<td>High</td>
</tr>
<tr>
<td>Van den Berg 2008 (Netherlands)</td>
<td>P</td>
<td>N=47 HNC</td>
<td>EORTC QLQC-30 and EORTC H&amp;N35</td>
<td>Pre-treatment, end of treatment and 6 months after treatment</td>
<td>Weight loss</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Malnutrition</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Nutritional support (gastrostomy)</td>
<td>High</td>
</tr>
<tr>
<td>Van Wilgen 2004 (Netherlands)</td>
<td>CS</td>
<td>N=154 HNC</td>
<td>CES-D; RAND-36</td>
<td>&gt;1 year post treatment</td>
<td>Shoulder and neck pain/morbidity</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression</td>
<td>High</td>
</tr>
<tr>
<td>Vartanian 2006 (Brazil)</td>
<td>CS</td>
<td>N=301 HNC</td>
<td>UW-QoL</td>
<td>&gt; 2 years after treatment</td>
<td>Decreased income</td>
<td>Moderate</td>
</tr>
<tr>
<td>Verdnock-de Leeuw 2010 (Netherlands)</td>
<td>CS</td>
<td>N=85 HNC</td>
<td>EORTC QLQ-C30 &amp; H&amp;N35; HADS; Study specific questionnaire re employment</td>
<td>2 Years post treatment</td>
<td>Difficulty returning to work</td>
<td>Moderate</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>Social eating</td>
<td>High</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Social contact</td>
<td>High</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>Study</th>
<th>N</th>
<th>Setting</th>
<th>Outcome measures</th>
<th>Timepoint</th>
<th>Trismus</th>
<th>Sticky saliva</th>
<th>Emotional distress</th>
<th>Trismus</th>
<th>Sticky saliva</th>
<th>Emotional distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verdock-de Leeuw 2009</td>
<td>P</td>
<td>HNC</td>
<td>EORTC QLQ-C30 &amp; H&amp;N35; HADS;</td>
<td>Pre-treatment and follow up (median time since diagnosis = 4.2 months)</td>
<td>High</td>
<td>Low</td>
<td>High</td>
<td>Low</td>
<td>Moderate</td>
<td>Moderate</td>
</tr>
</tbody>
</table>

*Low = no clinically relevant change in QoL. Moderate/high = clinically relevant change, subjective classification based on authors conclusions*

*Percentage of participants who reported support need. Low = <45%; Moderate = 65%-40%; High = >65%

*Non- validated outcome measure

n/a = Prevalence figures not available
A range of physical, psychosocial and practical support needs were identified in the included studies and varied according to treatment modality and time points relative to treatment.

1.3.1 Physical support needs

Physical support needs extracted from the studies were the symptoms and physiological functioning difficulties expressed by patients that could be improved by access to tailored professional support, for example, to allied health disciplines for issues related to oral health and rehabilitation, nutrition, dysphagia, difficulties in speech, or shoulder morbidity.

Oral health related support needs

Several of the included studies described a high prevalence of oral health and functional support needs, particularly related to the side effects of radiotherapy and chemoradiotherapy. Issues relating to pain, mucositis, xerostomia and eating difficulties were identified in several of the included studies describing QoL issues in the acute treatment period of radiotherapy and chemoradiotherapy. Both treatment modalities were associated with significant oral morbidity in the respective cohorts. Epstein et al. described significant issues with speech and oral pain among patients at the end of treatment. Six months post-treatment patients reported continued issues with chronic pain, xerostomia, taste and speech. A lack of clinical or statistical improvement for the symptoms of xerostomia and taste dysfunction 12 months following treatment with chemoradiotherapy for advanced stage disease was reported in 58% of patients, despite a gradual improvement in other functional and physical scales. A clinically significant deterioration in sticky saliva between one and five years post treatment was reported in patients who had received radiotherapy as their primary treatment or as an adjunct to surgery.

Cross-sectional studies described long term support needs related to symptoms of xerostomia, chewing, trismus and sticky saliva one-to-two years post treatment, and significant issues with xerostomia 7-11 years post treatment.
Duke et al.\textsuperscript{51} reported a lack of teeth, or no teeth secondary to cancer was associated with worse QoL compared to non-edentulous patients. A lack of denture use was also associated with worse QoL. The same study reported an association between a compromised dentition (measured as number of decayed/missing or filled teeth) and worse QoL and weight loss five years after treatment. Rogers\textsuperscript{57} found that dental health/teeth, chewing and eating and pain in the head and neck were among the most frequent concerns identified by head and neck cancer patients (inclusive of oral cancer patients n= 89/123) for discussion during a follow up appointment at an outpatient clinic.

\textbf{Dysphagia}

Dysphagia following radiotherapy was a significant issue identified in the included studies\textsuperscript{46,58,59}. All participants of a small cohort study (n=20) experienced dysphagia at the end of treatment, however the small sample size limited the generalisability of results\textsuperscript{52}. The impact of dysphagia over time was reported to be most severe immediately following treatment, with gradual improvement up to 12 months after treatment\textsuperscript{55}. Rogers\textsuperscript{57} reported “swallowing” ranked among the most frequently selected concerns (ranked sixth out of a total 45 concerns) that patients wished to discuss with a consultant at an outpatient clinic.

\textbf{Nutrition and weight loss}

Van den Berg\textsuperscript{60} identified 32\% (n=15/47) of participants were malnourished (defined as ≥10\% weight loss) following treatment with surgery, radiotherapy or chemotherapy. Malnutrition was recorded in 13/15 patients who had radiotherapy included in their treatment regimen\textsuperscript{60}. A small number of patients who received nutritional support from a dietician (6.3\% or 3/47) did not report malnutrition during treatment\textsuperscript{60}. Rogers and colleagues\textsuperscript{61} reported lower Body Mass Index (BMI) was significantly associated with depression and poor physical wellbeing in a cohort of 65 patients at least six months post treatment, however a majority of the sample (n=50/65) had advanced stage disease (stage III or IV).

Long-term nutritional support via percutaneous endoscopic gastrostomy (PEG) feeding was associated with limited chewing, swallowing, taste and worse overall
QoL in 8% (n=20/243) of respondents to a mail based survey\(^48\). Respondents also described difficulties with the PEG and interference with family life, intimate relationships, social activities and hobbies\(^48\).

**Neck and shoulder morbidity**

One study described the impact of shoulder morbidity on QoL following surgical treatment with neck dissection\(^13\). Shoulder morbidity was associated with poorer physical and social functioning one year post treatment and was also associated with depression\(^13\).

**1.3.2 Psychosocial support needs**

The psychosocial support needs extracted from the studies referred to wider social or emotional issues that affected quality of life and had the potential to be improved by appropriate professional support, for example counselling.

**Depression, anxiety and emotional distress**

The prevalence of depression reported by the studies that used the Hospital Anxiety and Depression Scale (HADS) varied between 18% and 25% following treatment\(^62\)-\(^64\). There was great variability among the studies in the prevalence and outcome measures used to report anxiety and depression. However, depression was identified as a significant issue in several studies and was associated with lower physical wellbeing\(^61\) functional impairment and issues regarding pain, disfigurement and worse overall QoL\(^62\).

A majority of studies used cross-sectional methodology to describe depression and anxiety, which limited the conclusions able to be drawn about the impact of anxiety and depression over time. Verdonck-de Leeuw et al.,\(^64\) reported 18% (n=10/55) of participants had high levels of distress at the time of diagnoses compared to 25% (n=14/55) at follow up (median 4.2 months since diagnosis), however only 21% (n=3/14) of patients with distress were referred for psychosocial care at follow-up. The authors suggested that a belief among health practitioners that emotional distress was an expected consequence of cancer diagnosis and treatment may have influenced referral patterns\(^64\). Handschel et al.,\(^49\) reported worse QoL in patients who
wished to have a psychological interview but did not receive one (17% or 280/1652). The results of this study were limited by the use of a non-validated “impairment scale” to assess QoL.

**Appearance and body image**

Oral cancer patients formed the majority of patients who reported concern or embarrassment with speech or eating (53% or 46/86) in a mixed head and neck cancer population following treatment\(^\text{11}\). Speech and eating concerns were associated with a higher frequency of body image related concerns and more interest in psychosocial intervention to address appearance related difficulties. Thirty-four percent of the entire sample (n=96/280) indicated a need for psychosocial intervention at the time of the survey or previously\(^\text{11}\).

A retrospective chart review found 41% (n=114/278) of participants reported appearance related concerns on the University of Washington Quality of Life Scale (UW-QoL), however only seven participants had these appearance concerns noted in their charts. The influence of appearance related concerns on QoL was not discussed in the study\(^\text{65}\).

**Sexuality, intimacy and relationships**

Low et al.,\(^\text{47}\) found one third (116/350) of respondents to a postal survey reported substantial issues with sexuality and intimacy after cancer treatment. However a further third of respondents (n=116/350) refused to answer the intimacy or sexuality questions. Abendstein\(^\text{17}\) reported that patients aged over 65 had more problems with sexuality five years post treatment than younger patients.

The stability of marital relationships after cancer treatment and its effect on QoL was examined by one study\(^\text{66}\). In this sample, overall QoL was associated with high levels of marital satisfaction. However the study sample was not representative of the wider oral cancer population as only patients and their spouses in a stable relationship were included\(^\text{66}\).
Chapter 1: Systematic review

Coping
A wide range of coping strategies were used by patients; behavioural escape-avoidance and cognitive escape-avoidance comprised 20% and 14% of the total coping strategies, respectively. Hassenein described an association between poor coping style and functional impairment after treatment, although lacked statistical significance. List reported the preference for the emotion focused coping strategies of behavioural escape-avoidance and cognitive escape-avoidance was associated with worse QoL before treatment.

Alcohol use
Alcohol abuse twelve months after head and neck cancer treatment was associated with depressive symptoms in a cross-sectional study. Twenty-two percent of participants (n=63/283) were classified as problem drinkers and reported worse overall QoL and more depressive symptoms than others reporting alcohol use one year after diagnosis.

1.3.3 Practical support needs

Financial support
Cancer treatment resulted in a restricted ability to work and significant decrease in household income for 41.9% (n=126/301) of Brazilian patients. One-third (n=138/447) of patients responding to a postal questionnaire reported cancer had affected their working status. Poorer social and emotional functioning was associated with increased financial burden and greater loss in income due to their condition in the previous week.

Verdonck-de Leew et al. reported a high rate of return to work within six months of treatment among their study population (71% n=60/85). However for those participants that did not return to work (n=9/85), or changed jobs (n=16/85), employment difficulties were associated with significantly worse QoL relating to loss of appetite, social contacts, social eating, a high level of anxiety and oral dysfunction.
1.4 Discussion

Oral cancer diagnosis and treatment is associated with considerable functional and psychosocial deficits for those with the disease. Multiple QoL domains are affected, as patients must cope with the physical and psychological changes as a result of their illness and its wider social implications. Treatment often results in permanent changes to communication, appearance, eating and oral function that have marked effects on individual's self-confidence and relationships with loved ones\textsuperscript{72,73}.

Access to individualised support from a multidisciplinary professional team that reflects the perceived support needs of oral cancer patients may enhance QoL outcomes in this group. The members of the multidisciplinary team should reflect the broad support needs expressed by oral cancer patients. The range of support needs described in this review indicate, that in addition to specialists and oncology nurses, speech pathologists, dentists and oral health therapists, psychologists, physiotherapists, dieticians and social workers may play an important role in the supportive care of oral cancer patients\textsuperscript{74}.

The results of prospective and longitudinal studies were impacted by loss of follow up from participants due to death or withdrawal due to the physical or psychological burden of cancer treatment\textsuperscript{33,51}. Participants with an advanced stage of disease (stage III or IV) were more commonly lost to follow up and also received more extensive treatment\textsuperscript{17,33}. This suggests that patients with poor prognosis, or advanced tumour staging may have higher support needs, and that the QoL issues reported in the literature may be under-represented.

Several of the included studies described findings from small sample sizes, and a lack of statistical power limited the conclusions able to be drawn from some studies\textsuperscript{46,51}. The heterogeneity of outcome measures and study populations limited the comparability of findings, a limitation reported by other reviews reporting on QoL in oral cancer patients\textsuperscript{75}. It is possible that the choice the EPHPP as the assessment tool may have influenced the number of ‘weak’ ratings based on its development to evaluate large-scale population health studies. In this field, assessing selection bias, generalisability, confounding factors and blinding are essential components in
evaluating the research evidence. When evaluating the studies included in this review, a common reason for a weak rating was the study design (cross-sectional) and the influence of attrition in longitudinal studies. As identified by the review findings, studies reporting on QoL issues in HN/oral cancer are frequently limited by sample size, cross-sectional or retrospective designs and are prone to selection bias and high attrition rates due to non-response or the mortality associated with the disease. This presents as a separate issue, however, when needing to assess the quality of the study for the purposes of a systematic review. To our knowledge, there are no literature assessment tools, including the EPHPP tool, with the capacity to weight responses based on subjective limitations of the field. This indicates a need for the development of critical appraisal criteria that account for these population-specific limitations.

Among the included studies, support needs varied throughout the cancer journey and according to treatment modality. Oral and functional deficits were significantly associated with radiotherapy and chemoradiotherapy, whereas surgical treatment was associated with appearance related concerns. The highest prevalence of symptoms from the side effects of radiotherapy and chemotherapy were reported at the completion of treatment. The post treatment period has been described by oral cancer patients as the most difficult in coping with no saliva, no taste, less teeth and a mouth that does not function normally. The need for emotional and physical support may be greatest at this time point.

Despite improvements in treatment toxicity and overall QoL in the first 12 months following oral cancer treatment, continued concerns with chronic xerostomia, sticky saliva and taste issues were reported in a number of studies evaluating long-term QoL. Long-term oral functional impairment and, dental morbidity, especially among patients who have received radiotherapy, indicates a need for long-term supportive care in managing permanent changes to oral health and function.

Dysphagia was a commonly described issue in the post-treatment period for oral cancer patients, and is regarded as the most common nutrition related problem arising from treatment for head and neck cancer. A common sequelae of
dysphagia is nutritional compromise that has an impact on overall wellbeing and QoL. Adverse effects of treatment that cause disruption to physiological functions of taste, smell, dysphagia and xerostomia may contribute to long-term nutritional outcome and changes in social interaction and willingness to socialise\textsuperscript{32,41,73}. Malnutrition and changes in social functioning have significant psychological implications and have been linked to depression and emotional distress\textsuperscript{41}.

Depression and anxiety were reported to have a significant influence on QoL in the included studies\textsuperscript{54,62}. The relationship between depression, QoL and functional deficits remains poorly defined in the included studies and the literature\textsuperscript{75}. In the included studies, cross-sectional methodology limited the conclusions able to be drawn about the relationships between poor function and depressive symptoms\textsuperscript{54,62,63}. Depression has significant implications for the oral cancer patient as depressed patients are less likely to complete the prescribed treatment plan, more likely to have longer hospital stays and less ability for self-care after treatment, influencing mortality and morbidity\textsuperscript{40}.

Evidence for the classification of alcohol misuse and sexuality and intimacy concerns as high-impact support needs were less well supported than other physical and psychological support needs described in this review. While there is evidence that continued tobacco use post treatment, in addition to being a risk factor for developing a second primary malignancy, is associated with depression and poor QoL\textsuperscript{77}, the influence of continued alcohol consumption on QoL is less clear\textsuperscript{75}. Nevertheless, smoking and alcohol cessation are important support needs among this group of patients. Problems with sexuality and intimacy were largely unreported in the included studies, despite the inclusion of a sexuality question on the European Organisation for the Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30)\textsuperscript{78}. It is suggested that a lack of experience of clinicians is a barrier to approaching this sensitive topic with patients\textsuperscript{47}. Sexuality and intimacy should be considered as an issue affecting QoL in future research in light of the relationship of intimacy issues to depression, mood and body image\textsuperscript{40}.
Limitations of review

There are a number of limitations that are important to consider in light of the findings of this review. Firstly, the findings include results from studies with heterogeneous head and neck cancer samples, which may affect the validity of the support needs identified as it assumes that the broader head and neck cancer population, and the oral cancer population both share the same support needs and QoL issues. Head and neck cancer is a broad term referring to cancers of the oral cavity, oropharynx, hypopharynx and larynx. Ambiguity exists in the literature relating to the definition of head and neck cancer and oral cancer, with the term ‘head and neck cancer’ often being used to refer to cancers of the oral cavity and oropharynx. While a sincere attempt was made to describe the support needs and QoL outcomes related to only patients with oral cancer, some studies did not provide enough description of the findings to allow this. Therefore, the results included support needs identified from heterogeneous head and neck cancer populations that met the inclusion criteria and included patients with oral cancer in the study sample. An effort was made to control this by only including studies with head and neck cancer populations that included patients with oral cancer.

Additionally, the results comprised a large number of studies that described changes to QoL and function associated with radiotherapy and chemotherapy. Surgery is also associated with adverse effects and its importance in terms of support needs may be underrepresented in the results.

The support needs described in this review are largely derived from the findings of QoL questionnaires, and as such are not a conclusive list of the support needs of oral cancer patients, rather a suggestion of areas that may be relevant for patients. This method of analysis also may underreport the true clinical impact of anxiety and depression as these issues typically have low prevalence, but marked impact on QoL.

The literature included in the search referred only to published material and did not include grey literature or unpublished works. This may have influenced the scope of support needs identified by this review. Additionally, there may be other relevant
support needs beyond the scope of this review, for example the role of familial and professional support networks in coping with oral cancer diagnosis and treatment\textsuperscript{72,73}.

1.5 Conclusion
The support needs expressed by patients with oral cancer are varied and highly subjective, reflecting the complex nature of the disease and its treatment. This review has provided evidence for areas of support need relating to oral health and functional impairment, swallowing issues, nutritional issues and psychological issues that affect overall QoL. However specific gaps were identified in regard to understanding how changes to oral health may influence quality of life and supportive care needs, and how this may vary based on an individual's social or environmental context.
Chapter 2

“I have quality of life...but...”: Exploring support needs important to quality of life in head and neck cancer: An application of the stress, appraisal and coping model
Chapter 2: Exploring support needs important to QoL from a stress, appraisal & coping perspective

Chapter 2: “I have quality of life…but...”: Exploring support needs important to quality of life in head and neck cancer: An application of the stress, appraisal and coping model

2.1 Introduction
Treatment for head and neck cancer (HNC) causes considerable interruption to the core aspects of daily life\(^\text{25}\). This is due to the close proximity of the tumour to structures essential to eating, speaking and communication. Additionally, the treatment for HNC may result in alterations to appearance, and permanently compromise senses, swallowing function, salivary flow and speech\(^\text{53,79}\). Coping with the functional and symptomatic outcomes of treatment, in addition to facing a potentially life threatening diagnosis, means that HNC diagnosis and treatment is associated with a significant physical and psychological burden for those with the disease\(^\text{28}\).

The treatment for HNC is complex and involves a specialist multidisciplinary oncology team including head and neck surgeons, medical oncologists, radiation oncologists, radiologists, plastic surgeons and dentists\(^\text{2}\). A network of allied health disciplines including nurses, speech pathologists, dieticians and physiotherapists also provide supportive care for patients during and post treatment\(^\text{74}\).

Treatment advances have improved tumour control and survival outcomes, however increased treatment intensity causes more symptom and functional toxicities during and post treatment, which affect quality of life\(^\text{14,80}\).

Patients who receive treatment for HNC report a range of supportive care needs, caused by the disruption to normal functioning and the emotional and psychological challenges of treatment\(^\text{79}\). Higher support needs are perceived by oral cancer patients regarding physical and daily living needs, patient care and support needs, and health and system information needs than patients with other cancers\(^\text{81}\). Support needs are defined as the requirement of some action or resource that is necessary,
desirable, or useful to attain optimal well-being. Needs relating to cancer and its treatment are broad; and may include physical, psychosocial and practical needs.

HNC treatment is associated with poorer QoL outcomes across general QoL and symptom specific domains. The existing literature in this field is primarily quantitative with validated questionnaires forming the mainstay of QoL assessment. A recent study reported a relationship between unmet support needs and poorer QoL in the general cancer setting. This finding is also supported among HNC populations. Oskam et al., reported that a higher need for supportive care in the active phase of treatment was associated with a reduction in QoL among patients with advanced stage oropharyngeal cancer.

Despite recent literature investigating an association between perceived supportive care needs and QoL outcomes, understanding the consequences of unmet support needs for individuals with HNC, throughout the cancer trajectory, is poorly understood. Therefore, this study aimed to explore the experiences of patients who have received treatment for HNC and describe support needs that had an influence on QoL during treatment and post treatment. The study also aimed to describe patient experiences in managing their unmet support needs.

2.1.1 Conceptual framework

The Lazarus and Folkman stress, appraisal and coping model guided the study. This model is a framework for evaluating processes of coping with stressful events and has been applied to a range of health disciplines, including patient coping responses to cancer, adjusting to chronic illness, and caregiver stress.

According to the Lazaurus and Folkman model, coping as an outcome of the dynamic and constantly changing relationship between a person and their environment. As an encounter changes, the coping response and how an individual appraises the situation also changes. Appraisal is a process whereby an individual classifies a stressful encounter as harm or loss, threat or a challenge (primary appraisal). Appraisals are made based on what is at stake for an individual and its potential ability to affect wellbeing. Harm or loss appraisals are made when an
individual believes that the stressor has already caused him or her damage. Threat appraisals focus on a risk of future damage, and challenge appraisals are made when an individual sees a stressful encounter as an opportunity for growth or development\textsuperscript{87}. Secondary appraisals occur when an individual evaluates what can be done about the stressor, taking into account the coping options available to them.

The cognitive appraisal process triggers an emotional response. Harm or loss appraisals are usually associated with anger or sadness; threat appraisals with anxiety and fear, and challenge appraisals anxiety mixed with excitement\textsuperscript{88}.

Coping describes the thoughts and behaviours individuals use to manage stressful events. Coping responses are classified as emotion focussed, problem focussed or meaning focussed. Problem focussed coping refers to strategies such as planful problem solving, to address the problem causing distress. Emotion focussed coping regulates negative emotions and includes strategies such as escape-avoidance (e.g. wishing situation would go away) and distancing (e.g. going on as if nothing happened)\textsuperscript{88,89}.

The appraisal and coping process is influenced by person and situational factors\textsuperscript{83,90}. Person factors are the deeply held beliefs and commitments that determine what is at stake for a person in the encounter, and are conceptualised as personal traits or characteristics. Situational factors are characteristics of the situation or environment that affect how an individual appraises a stressful encounter\textsuperscript{90}. Situational factors include the characteristics of an individual's cancer and external influences such as social support, professional support and financial resources\textsuperscript{83}. External influences are important factors that are potentially modifiable and may be targeted by intervention.

The constructs of the stress, appraisal and coping model have been refined since the model's initial development in the late 1980's\textsuperscript{83,91}. As part of this process, the appraisal process was extended beyond harm, loss and challenge and additional components were introduced to explain the relationship between constructs\textsuperscript{91}. Other coping theories have been developed that extend on the core constructs of the
Chapter 2: Exploring support needs important to QoL from a stress, appraisal & coping perspective

stress, appraisal and coping model with the aim to more accurately reflect the processes of cancer adaptation and survivorship\textsuperscript{92}. There has been a particular focus on how positive psychological states may facilitate resilience and adaptation in the face of significant stress\textsuperscript{93}.

A criticism of recent theoretical developments is that the extended coping theories have yet to establish an empirical base\textsuperscript{92}. The wide use of the original constructs of the stress, appraisal and coping model supports its prominence in the psycho-oncology literature. Support for the core constructs of the model (as originally described) have been established, including the relationship between appraisal type and coping style\textsuperscript{84,94}. Thus, the original version of the model was selected to guide data analysis for this study.

2.2 Methods

Study design

An exploratory, descriptive design involving qualitative methods was used to answer two research questions:

a) What support needs influence the QoL of people who have experienced head and neck cancer?

b) How do individuals appraise and cope with unmet support needs (stressors) during and post treatment?

Participants

Convenience and snowball sampling methods were used to identify potentially eligible participants from attendees of a community based Head and Neck Cancer Support Group (HNCSG). The group meets monthly and each meeting addresses a theme that is relevant to life after HNC treatment and survivorship. The numbers of attendees at meetings vary, and may range from 10 to 20 people. Professional staff who are involved in HNC treatment and support are also members of the group. Two authors (KP, CSF) attended a HNCSG meeting and gave an informal presentation about the study and extended an invitation to participate in the study. Attendance at group meetings is often transient; therefore information about the study and an
invitation to take part was also circulated by the HNCSG facilitator, on the researchers’ behalf, to all members on the HNCSG email contact list.

Participants were eligible for inclusion if they had previously undergone treatment for HNC and were able to provide informed consent. Nine interested participants contacted the research team and expressed interest in participation; however one person later chose not to go ahead as they felt it would be too much of an emotional burden. The final sample was comprised of eight participants.

**Ethical considerations**
The study was approved by the University of Queensland School of Dentistry Human Research Ethics Committee (project no: 1208). All participants provided informed consent prior to participation.

**Setting**
The HNCSG is based in a metropolitan area of Australia, and is in close proximity to a tertiary hospital that provides multidisciplinary treatment for cancers of the head and neck. Membership is open to all people who are undergoing, or who have previously received treatment for cancers of the head and neck.

**Procedures**
The interview followed a semi-structured format and the duration of the interviews ranged from 50 to 70 minutes. Informed consent was provided prior to the interview and all interviews were audio recorded with the permission of the participants. The interviews were conducted by the first author (KP), an Oral Health Therapist. The interview questions were developed and refined based on feedback from HNCSG members. The final interview guided is included as Appendix 1.

**Data collection**
Qualitative data was gathered from a single face to face interview. Interviews were guided by a semi-structured instrument that was comprised of open ended questions about quality of life, physical and psychological support needs and coping with unmet support needs. Questions elicited descriptive responses, for example “How would you describe your overall quality of life currently?” and “How would you
describe your support needs post treatment?" Probing questions were used as necessary to prompt more detailed responses from participants. The interview guide underwent evaluation and was refined as necessary throughout the data collection process to ensure it reflected emerging themes described by participants.

Background information on age, gender, cancer, and treatment received was recorded for each participant.

**Data analysis**

Interviews were recorded with a tablet device (iPad, Apple Inc, USA) and transcribed verbatim and imported into Nvivo 10 © QSR International for data management and coding. Field notes were recorded on the tablet device after each interview. Data collection and analysis was ongoing, and began during the transcription process. Memos, in the form of written notes, were used to document the initial thoughts and ideas that emerged during interview transcription (performed by author KP).

Interview data were analysed using both inductive and deductive methods. Firstly, support needs were described through a process of open coding. Codes were then grouped and classified into categories reflecting patterns in the text. Codes and categories of support needs were constantly compared and appraised in the analysis process to ensure meaningfulness and accuracy.

Following inductive analysis, the interview data was further analysed by directed content analysis, guided by the Lazarus and Folkman stress, appraisal and coping model. This model was selected over other potential health behaviour and psychological theories based on the emerging themes from participants. During interviews, participants described how support from others assisted them in coping with the acute stress (both in physical and psychological) terms of their illness. Therefore, perceived support needs referred to the availability of adequate social support from health professionals, close family members and peers.

Directed content analysis is more structured than conventional content analysis and is applied to validate or extend conceptually a theoretical framework or theory.
Chapter 2: Exploring support needs important to QoL from a stress, appraisal & coping perspective

concepts of the stress, appraisal and coping model served as a coding framework to describe the coping response of participants to the stressful situation of cancer. As this framework has not yet been explored in the context of head and neck cancer, data that did not fit within the themes of the framework were further analysed to determine if they were subcategories of existing themes, or new themes. During data analysis it was found that the model was unable to categorise the responses describing the reappraisal of chronic stressors over time. As such, the model was adapted to reflect the emergent themes arising from interviews. Stressors in the model were conceptualised as the support needs described by participants that affected QoL. For data analysis, the model was modified to form a cycle whereby outcomes of treatment that were appraised as harmful became chronic stressors that triggered continual cognitive reappraisal and coping efforts (see Figure 2-1 below).
Accuracy in data analysis was ensured by triangulation and respondent validation\textsuperscript{95,97}. Analyst triangulation was applied in both the inductive and deductive phases of data analysis through the independent co-coding of interview transcripts by authors KP and PF. The authors collectively discussed the analysis and results and differences in interpretation were settled by referring to the stress, appraisal and coping model. The Lazarus and Folkman model was used as a form of theoretical triangulation to enhance rigor in interpretation. Respondent validation was sought from participants who were provided with a copy of the data analysis and invited to
comment on the accurateness of the analysis. Five of the eight participants responded, and indicated that the analysis was an accurate representation of the issues discussed during the interview. Procedural rigor and trustworthiness of the study was ensured through clear description of how the research was conducted and the methods of participant sampling, data collection and analysis.

2.3 Results

2.3.1 Participants
Seven men and one woman took part in the interviews. The details of tumour location and treatment received by each participant are outlined in Table 2-1 (below). Time since treatment ranged from 1-8 years, with a mean of 4.25 years since treatment. The age of participants ranged from 51-60 years, with a mean age of 60 years.

Table 2-1: Participant characteristics

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Tumour location</th>
<th>Treatment received</th>
</tr>
</thead>
<tbody>
<tr>
<td>P01</td>
<td>Base of tongue</td>
<td>Chemoradiotherapy</td>
</tr>
<tr>
<td>P02</td>
<td>Parotid gland</td>
<td>Surgery &amp; radiotherapy</td>
</tr>
<tr>
<td>P03</td>
<td>Submandibular gland</td>
<td>Surgery, radiotherapy &amp; chemotherapy</td>
</tr>
<tr>
<td>P04</td>
<td>Base of tongue</td>
<td>Chemoradiotherapy</td>
</tr>
<tr>
<td>P05</td>
<td>Metastatic SCC; Occult primary</td>
<td>Surgery, Radiotherapy &amp; chemotherapy</td>
</tr>
<tr>
<td>P06</td>
<td>Oropharyngeal</td>
<td>Chemoradiotherapy</td>
</tr>
<tr>
<td>P07</td>
<td>Parotid gland</td>
<td>Surgery, radiotherapy &amp; chemotherapy</td>
</tr>
<tr>
<td>P08</td>
<td>Tongue</td>
<td>Surgery &amp; radiotherapy</td>
</tr>
</tbody>
</table>
2.3.2 Stress, appraisal and coping model

Support needs during treatment (acute stressors)
Support needs during treatment were categorised into three key themes: managing the side effects treatment; everyday demands while undergoing treatment; and coordination of the multidisciplinary team.

Managing the side effects of treatment
The intensity of radiotherapy side effects escalated towards the end of treatment. Nutritional support was most important at the end of treatment, as the taste and smell of nutritional supplements became unbearable as toxicity from cumulative fractions of radiotherapy increased. Mouth ulcers and a painful sore throat, and a lack of taste provided little motivation to eat. Confusion about correct nutritional management at home during radiotherapy caused stress for participants.

P05...I went back one day and the nurse [at the hospital] said “if you don’t eat you will die” and I said, “yes I know that, I’m eating [nutritional supplement] Ensure” and she said, “well how much are you having?” and I said” three a day, one for breakfast, one for lunch & one for dinner”...you’re supposed to have 7!

Participants described difficulties with sleep deprivation, fatigue and in some cases coping with a feeding tube at home in the weeks following treatment. Participants reached out to allied health and nursing staff for support in managing the acute side effects of treatment, and were essential in meeting the supportive care needs.

P06...She [a nurse] became my angel and I would bug her every time there was an ulcer, and she would say what time are you on, ok when you’ve finished radiation come see me and we’ll do something to alleviate the pain and treat it.

Aspects of treatment caused anxiety for participants, especially the moulding of the stabilisation mask used for radiotherapy. Participants struggled with the lack of communication about the processes involved in moulding the mask, which was described as claustrophobic and traumatic.

P04... Suddenly they brought this, looked like very heavy weave silicone, and they just plonked it over your face and there’s all these fingers going all over and molding it and that sort of stuff. And you can’t see anything, you can hardly breathe.
Chapter 2: Exploring support needs important to QoL from a stress, appraisal & coping perspective

Being fixed in one place by the mask during radiotherapy was a continued cause of anxiety and stress for participants during treatment, particularly as the side effects of dysphagia and xerostomia worsened and swallowing became painful and difficult.

Everyday demands while undergoing treatment
Participants relied on family support networks to attend appointments, as fatigue from daily radiotherapy and chemotherapy appointments worsened as treatment progressed. For those without family support, the hospital became a surrogate support network for the duration of treatment.

P02…I put my hand up to the radiation oncologist and said “I am very much afraid I will become involuntarily non-compliant and I need help”. So to their very great credit they [the hospital] covered that situation. I love the hospital; they had to almost get security to throw me out of there.

The grueling nature of treatment meant that it was impossible for participants to focus on other aspects of their home environment and life. Help was needed in the practical aspects of running a household, for example paying bills and home maintenance. Out of pocket medical expenses became an unforeseen burden that added to the financial impact of being unable to work while undergoing treatment and immediately post treatment.

Coordination of the multidisciplinary team
Inadequate communication between members of the multidisciplinary oncology team caused stress and confusion about treatment. Although the quality of treatment was appreciated, participants described issues with finding consistent information in the early stages of diagnosis and treatment. This confusion culminated after attending the multidisciplinary head and neck clinic for assessment and treatment planning.

P05…There was no overall communication, there was no one saying “this is what’s going to happen”. It was like the plastic surgeon was going to do his bit, the medical oncologist was going to do her bit, the ear nose and throat person was going to do their bit, the maxillofacial person was going to do their bit and so I was just going from specialist to specialist and there was no one telling me what was going to happen. So that was a bit confusing and also a bit unsettling.
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Insensitive remarks and conflicting information from doctors about treatment contributed to pre-treatment anxiety. Participants were left to bridge the communication gap between the different disciplines involved in treatment.

P01…He said, “oh, no the tongue will have to come out.” And that was all he said and then he just walked out.

P01…I’d go and see the ear nose and throat [doctor] and he’d be very surprised at what one of the other people had said or done, you know, there just wasn’t any communication between specialists.

**Support needs post treatment (chronic stressors)**

Support needs post treatment were categorised into the themes: Managing the “hangovers” of treatment and returning to a normal life.

*Managing “hangovers” of treatment*

In the first six to twelve months following treatment, participants struggled with a lack of organized supportive care. Participants felt isolated after discharge and did not know what to expect in terms of treatment recovery.

P01…They just say “well everyone’s different”. I’d say, “what can I expect, is this normal? Is what I’m experiencing normal?” and invariably the answer would come back, “oh well I can’t tell you whether it’s normal or not because everyone’s different”.

Navigating a large hospital system to access support post treatment proved difficult. In the absence of a dedicated contact person, participants struggled to find help in managing problems related to diet, appearance and wound healing post treatment. Participants struggled to find professional support and information about support therapies to help mitigate the side effects of radiotherapy.

P08…It’s like the surgeons and the radiation oncologists, once the surgery’s done or the radiations done, that’s it, and too bad sort of thing…if it’s not related to the surgery or the radiation it’s like getting blood from a stone to find out about other things that could help you.

P01… It was difficult to find consistent medical advice, you’d find it in patches when you go to see the specialists you know, once every month or once every two months, but in between it was just terrible. And emotionally and it was just a void in that six months.

The true impact of treatment “hangovers” was realised in the months following treatment. Prolonged issues with muscle stiffness and atrophy, diminished function of swallowing and speech, xerostomia, and appearance affected QoL. Participants
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described a gap between services offered through the hospital and the level of support needed.

P03…We went to [the hospital] a few times to talk with dieticians…they started to give us a bit of an idea of what was going to happen but even those discussions weren’t in depth… I didn’t have any long term guidance. Now I’ve just learnt.

Participants described a lack of preparation for the damaging effects of radiotherapy to their oral health. There was a lack explanation prior to treatment about the life-long changes to oral health and importance of meticulous oral hygiene in preventing future complications.

P07…They didn’t tell me that the radiation was going to kill my mouth…They tell me I can’t have my teeth taken out now by a normal dentist… it’ll take a long time for it to close, to heal. I didn’t know any of that was going to happen until after this radiation.

A lack of formal guidance about managing oral health and changed eating abilities post treatment forced many participants, in the words of one participant, to “learn through the school of hard knocks.” Living with a permanently dry mouth affected several aspects of participants QoL, related to chewing and eating, sleeping and motivation for social eating.

P01…Dry mouth at night time, it really affects your sleep because you wake up every two hours…so you never get a good quality sleep.

P03…So I’ve got to think now about every process, everything that I eat…either I’ve got to have water with it, or it’s got to have some constituent part that’s got to have some water in it… I can’t drink everything, and that which I do drink is largely affected, and not affected in a pleasant way. So that’s a big thing.

Returning to a normal life
Ongoing fatigue, difficulty eating and the ability to return to full time employment affected participant’s goals to return to a normal life post treatment. Reduced work capacity due to diminished speech and physical functioning affected the post treatment employment of some participants, while ongoing fatigue and cognitive deficit caused by chemotherapy meant returning to work was a struggle.

P05…I had problems with concentrating…forgetting things, not being able to associate words with particular
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objects or things.

A reduced income after treatment caused stress due to higher healthcare bills necessary to manage the side effects of treatment. For one participant without private health insurance, the ongoing cost of dental care was a large concern.

P07... I am worried about after my pension runs out next year... I can't afford to go to the dentist, not on the money I earn. So I feel that if this is not there when my pension runs out my teeth could go backwards, cos I haven't got that support anymore.

Changed eating function also reduced motivation to eat out in public or in situations where participants could not control what food was served. This resulted in changed eating habits, with some participants preferring to eat alone to avoid embarrassment when eating with others.

P01...When I swallow you probably hear this, I make a bit of a noise, sort of thing and everything is a bit unsociable, so I feel very self-conscious about that. So I deliberately try to avoid situations where I'm eating with people, so I'm eating alone most of the time.

Cognitive appraisal

Cancer diagnosis and treatment were highly stressful events and appraised as a threat by most participants, with the exception of one participant who appraised cancer diagnosis as a challenge. New stages in treatment were appraised as threatening, due to a fear of the unknown as the experience of cancer was not comparable to past sicknesses or illnesses.

P 07...Back then it didn't take much to upset me. I was crying a lot because I didn't know what was going to happen...Each step I was going on I didn't know what was ahead of me.

P03...When used to having a cold and getting better, or having a broken leg then getting better, with this you have a big, big, big operation, then it's a very long time before you start to get anywhere near the functionality that you used to.

As treatment progressed, familiarity with treatment procedures lead to reappraisal and resulted in increased coping potential. The stress caused by radiotherapy was reappraised as treatment progressed.

P06...The gradual feeling of being trapped and being stuck in one location improved because as I was losing weight I could wriggle a little bit underneath [the mask]...I'd count the number of beeps and the machine would go, like the sun rising over the other side and so I'd start to count 17 and the next were 12 and so on.
Medical professionals influenced the appraisal process. Support and approachability lead to an increased coping potential for managing unexpected complications from treatment, where as an insensitive manner caused added stress. The importance of the oncology team in the appraisal process stemmed from the life-threatening nature of cancer diagnosis.

P01... It amazes me how much empathy some of them have and understand. It was quite wonderful. Others were just terrible; they treat you like a piece of meat. You’re just a process that they go through. All these things become magnified when you’re going through treatment and post treatment because that’s your life....you know your life is very dependent on these people.

Diminished chewing, salivary and swallowing function post treatment were appraised as harm or loss by four of the eight participants. As the acute side effects of treatment subsided, and participants learnt ways of managing chronic side effects, the impact of diminished function was reappraised to be less threatening. However, social eating caused additional stress for participants due to a reduced ability to control the food environment.

P08...In a social situation for example, work morning teas...I end up most of the time not eating because it's really hard for me to eat standing around I can’t just open up my mouth and shove food in. I really need to be relaxed and preferably have a fork so I can control the size.

Harm or loss appraisals were associated with treatment side effects that prevented participants regaining full physical function post treatment. Two participants described a reduced capacity to return to full time employment post treatment, which was described as a very stressful outcome of treatment.

P02...I'm effectively suffering and will suffer for the rest of my life from the impacts of treatment. Forget about the cancer, hopefully the cancer is done and dusted, but I have a terrible dry mouth and I have very bad radiation damage to my left maxillary sinus that discharges all the time. And so I can’t stand in front of a class and do the work for which I am trained.
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**Emotional response**

Situations where participants felt ‘different’ from others triggered feeling of embarrassment and self-consciousness related to the side effects of treatment.

*P07*… I feel sorry for my wife, she goes up town with me and you always want to look good for your partner and I just, I don’t have the confidence now in looking nice. I just hate my photo being taken now.

Peer support provided participants with hope for recovery after treatment. Other members of the support group who were further ahead in the treatment and recovery journey provided hope about the recovery process.

*P01*… When I met [another support group member] he said to me, “it gets better”. And that was probably one of the best things that ever happened to me because at that stage I didn’t think it was ever going to get better.

**Coping response**

While undergoing treatment, participants described a number of coping strategies. During and immediately post treatment emotion focussed coping was used as participants narrowed their focus on survival and attempted to block out thoughts of an uncertain future.

*P06*… At the time when you get diagnosed, you have so much coming towards you that you just focus on survival from your cancer, but you don’t dwell too much on what’s going to be after because you’re grateful if you have an after.

Participants used the experiences of others undergoing treatment at the same time to positively reappraise their own situations. This method of coping was also used in managing the chronic side effects of treatment, however for some this was a forced and conscious effort.

*P01*… You have to be careful not to become a victim, or have a victim mentality. You have to really work hard to say, “Ok, I’ve got these things, I’ve to live with them now, let’s get on with it.” But that’s something you have to, almost on a daily basis; I find I’ve got to remind myself.

Coping responses to changed social eating varied. Avoidance coping measures were used in cases where participants were embarrassed or self-conscious about changed eating habits, whereas problem focussed coping, by carrying moisturising foods or preferring to eat at home, was used in situations with greater perceived coping potential.
Coping by seeking social support was used in several contexts. Participants sought peer support in response to isolation post treatment by joining the support group. Using social and professional networks to find information about alternative treatments including humidifiers and vaporizers, meditation courses and cognitive training were also described in coping with the outcomes of treatment.

Coping by self-control was used to manage anxiety about cancer recurrence. Participants described changes to diet and lifestyle that stemmed from motivation not to return to previous behaviours that may have contributed to cancer development.

There was a reduced desire to return to high stress jobs, or jobs that participants believed contributed to their cancer.

Outcomes
Outcomes of the appraisal and coping process were appraised as positive if the stressor no longer posed a threat to wellbeing, or stressful if the outcome was negative, and therefore affected wellbeing. Stressful outcomes were then reappraised and triggered a subsequent emotional and coping response, thus continuing the appraisal and coping cycle.

Somatic outcomes of treatment including dry mouth, swallowing dysfunction, and difficulty feeding through a percutaneous endoscopic gastrostomy (PEG) tube at
home were reappraised as stressors post treatment. Outcomes that impacted on the psychosocial wellbeing of participants were appraised as chronic stressors, and included eating, swallowing and appearance related changes.

P02…Eating food is a real chore. It’s something that I don’t look forward to, and so many social activities are centred around eating. And I’ve got a crisis going on now where what’s remaining of my saliva has actually suddenly diminished dramatically in the last few weeks …so my quality of life has actually dropped even more significantly than what it was six weeks ago.

Psychological outcomes of depression and anxiety in the first six to twelve months after treatment were described by four of the eight participants. Feelings of isolation caused by lost connections to the previously supportive hospital network influenced depression and anxiety in this time period. A lack of accessible professional counselling within the hospital framework negatively affected QoL. Several participants sought their own counselling support; however for most this was only sought post treatment.

P08…I was convinced I was going to die, and if I went back to work I was going to die. It was a bad time. So probably, yeah…I was probably in dire need of some sort of therapy or counseling.

P01…You’re still mentally in a very bad place, and physically in a bad place….it took me a long time to come out of that bad place… I went through depression and all sorts of terrible things in that six months after treatment.

Positive outcomes of the HNC journey stemmed from self-control focussed coping measures and meaning focussed coping. Participants who preferred these coping strategies described a new appreciation of life after surviving cancer treatment and reduced stress levels associated with work.

P03…a great change in my stress levels associated with work, so that’s a good thing. I think that I have more time for people.
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2.4 Discussion
The findings of this study highlight several areas of support need during, and post treatment that negatively affected QoL. Support needs during treatment were related to managing anxiety about unknown treatment processes, and coping with the toxicities of treatment. Radiotherapy was associated with progressively increasing nutritional and oral health related support needs, as the effects of mucositis, dysphagia, xerostomia and sensory dysfunction worsened. Participants drew support from specialists and allied health professionals within the hospital framework whilst undergoing treatment. For some this met their level of need; however for others it fell short. Participants also relied heavily on family support networks to meet the practical and financial supportive care needs associated with treatment.

There was a gap in the provision of routine emotional support from counsellors or psychologists in the hospital setting. This negatively affected QoL for individuals who perceived a need for psychological support following diagnosis and in the early phases of treatment. The prevalence of depression among HNC patients has been reported to be as high as 46%, with oropharyngeal cancer reporting the highest rate of depressive disorders. Appropriate management of psychological distress (anxiety and depression) is essential in HNC because of its influence on QoL and potential to predict survival. Recommendations have been made for the routine inclusion of professional psychologists in the multidisciplinary team as the evidence of the impact of psychological issues on the experience of HNC patients grows.

The radiotherapy mask and particularly a lack of communication about the processes involved in its fabrication caused anxiety prior to treatment. The stabilisation mask is reported to have a marked emotional impact on patients as it causes distress and panic. Our findings confirm issues with anxiety brought on by the claustrophobic nature of the mask and highlight the need for provision of adequate support for patients during this challenging process.

Support needs regarding the oral health impacts of radiotherapy and supportive care in managing changes to oral health post treatment were reported by several participants. Dental assessment prior to radiotherapy is essential, especially as
many patients have poor oral health before starting treatment and radiotherapy has a detrimental effect on oral health\textsuperscript{104}. In the Australian context, a pre-treatment dental assessment is standard at many treatment institutions, however there are less defined guidelines for long-term oral health support\textsuperscript{22,105}. Access to tailored oral health care is essential to providing supportive care, especially as many HNC patients report a history of poor dental attendance prior to treatment that contributes to a greater risk for dental morbidity post treatment\textsuperscript{22}. Oskam et al.,\textsuperscript{42} reported care from a dental hygienist ranked among the highest level of perceived support needs during treatment and 8-11 years after treatment in patients treated for HNC.

The first six to twelve months following HNC treatment is associated with considerable difficulty for patients in adjusting to the outcomes of treatment and managing acute side effects at home\textsuperscript{72,106}. For patients who received radiotherapy, residual fatigue and weakness, xerostomia, mouth ulcers and pain, dysguesia and sore throat are debilitating outcomes of treatment\textsuperscript{103,106}. These outcomes compromise nutrition and may result in weight loss and malnutrition\textsuperscript{107,108}. The side effects of radiotherapy are compounded by the consequences of surgical treatment for HNC. The degree of functional deficit and impact on QoL caused by surgery depends on the surgical site, amount of tissue removed and the type of reconstruction performed\textsuperscript{29,38}.

Surgery causes a physical disruption to the to the anatomy and neuromuscular control structures of the oropharynx that results in impaired swallowing, speech and chewing function post treatment\textsuperscript{10}. Neck dissection involving the surgical removal of lymph nodes at highest risk of metastases may cause shoulder dysfunction and chronic pain, which affect acute and long term QoL\textsuperscript{12,26}. Physical disfigurement, impaired function and communication are associated with psychological distress following HNC treatment\textsuperscript{29,79}. Our findings support the conclusions of previous studies, that the first six to twelve months are critical time to provide supportive care. The results of the present study suggest there may be other important issues in returning to a normal life post treatment, including the influence of cognitive deficit and changed priorities in returning to previous employment, and the psychosocial
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ramifications of perceived isolation from medical help post treatment. These topics should be the focus of future research.

To our knowledge, this is the first study to apply the Lazarus and Folkman stress, appraisal and coping model to describe the experiences of HNC patients. The framework for analysis highlights the influence of environmental factors on the appraisal and coping process. During data analysis it was found that the model was unable to categorise the responses describing the reappraisal of chronic stressors over time. As such, the model was adapted to reflect the emergent themes arising from interviews. Townsley et al.\textsuperscript{92}, found that attitudes, sense of self, disease and treatment, intervening factors, and coping strategies constructed the coping process in a study of older adult survivors of cancer. The findings of this study support the suggestion that linear coping models do not fully account for the complex nature of cancer survivorship, encompassing both the disease and the person\textsuperscript{92}. The findings of this study must be approached with caution due to the limited sampling frame and lack of data saturation. The influence of reappraisal stressors over time warrant investigation by future studies, particularly to identify whether adaptation to illness may be influenced by the provision of supportive care.

Structured environmental support from medical professionals increased the coping potential of participants while undergoing treatment. A less supportive post treatment environment meant that previously used coping strategies were less effective for participants. Bigatti et al.\textsuperscript{,87} reported that higher harm or loss appraisals and greater use of escape-avoidance coping predicted higher depressive symptoms among patients with breast cancer. While measuring depressive symptoms is beyond the scope of the present study, it suggests that examining the appraisal process may important for future studies when attempting to understand psychosocial impacts of HNC treatment.

Peer support received from the HNCSG was an important aspect in the appraisal and coping process, as it was a source of information and also emotional support for participants. Vakharia et al.\textsuperscript{,109} reported participation in a support group post HNC treatment was associated with improved QoL, compared to non-participation. It
should be noted that all participants of the present study were recruited from a head and neck cancer support group, which limits the conclusions able to be drawn from this study about the importance of peer support in the wider HNC context. None-the-less, the findings provide a base for further investigation about the social and environmental factors that influence coping by HNC patients, particularly in the post treatment phase.

**Limitations**

Although qualitative research focuses on information rich cases rather than relying on statistical significance, the findings of this study are limited due to the small sample size and method of sampling. A limitation of convenience sampling is that our results are not generalisable to the wider HNC population, as we were unable to purposively sample based on clinical and patient characteristics that may influence support needs, for example treatment modality, tumour location, geographical location and level of social support. A further limitation of this sampling method is that it did not facilitate the recruitment of additional cases to confirm that a point of data saturation was reached in the analysis.

Participants in the study were recruited from a peer support group. This may have predisposed participants to preferring seeking social support as a coping strategy. As participants used the support group to access information post treatment, the influence of information related support needs are likely to be under represented in the findings. As all participants lived within a close proximity to the hospital where treatment was received, our results cannot account for support needs that may be related to location and travelling to receive treatment.

The small number of participants of this study limits the conclusions able to be drawn about the characteristics of patients who may require more targeted support prior to treatment. The findings provide an evidence base for future research aimed at the development of interventions to support coping.
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2.5 Conclusion
The support needs of head and neck cancer patients while undergoing treatment were largely met by medical professionals and family support networks. Post treatment, patients described greater difficulties in coping with the side effects of treatment and accessing supportive care when away from the hospital setting. Our findings suggest the first six to twelve months post treatment are a critical time in providing supportive care, especially related to coping with the side effects of radiotherapy. The stress, appraisal and coping model is useful in understanding the psychosocial outcomes of head and neck cancer.
Chapter 3

Changes in quality of life over the first six months following head and neck cancer diagnosis and treatment
Chapter 3: Changes in quality of life over the first six months following head and neck cancer diagnosis and treatment

3.1 Introduction

The number of head and neck cancers (HNC) diagnosed in Australia has increased in recent years. Although cancers occurring in the head and neck region make up a relatively small proportion of the overall cancer incidence (3.5% of all cancers) they are associated with significant treatment related morbidity. Treatment advances have resulted in improved survival rates both in Australia and in other economically advanced countries. The Australian relative five-year survival rate for all HNC is now 68.2%. As survival outcomes continue to improve there is increased emphasis on survivorship and the impact of treatment on quality of life (QoL).

QoL involves multiple broad constructs relating to an individual’s perception of their physical and mental health, social relationships and environment, in the context of their culture, value system and expectations. Health-related quality of life (HRQoL) is a subset of QoL and is conceptually distinct from overall QoL. HRQoL specifically addresses the impact of a disease and its treatment on wellbeing. Both QoL and HRQoL are affected by the diagnosis and treatment of HNC.

There are disparities in survival outcomes, quality of life and perceived supportive care needs for cancer patients living in urban and regional/remote areas. This is due to factors such as delayed diagnosis, reduced access to services and the economic, emotional and relationship strains caused by needing to travel to receive cancer treatment if living outside metropolitan areas. An Australian study found that poorer swallowing outcomes post HNC treatment were associated with living in a rural area and former heavy alcohol consumption, in addition to tumour characteristics and the type and intensity of radiotherapy received.

There is a lack of research comparing quality of life outcomes between metropolitan and regional head and neck cancer patients and to our knowledge, no data from an Australian perspective. This study aimed to describe the QoL of a cohort of patients...
treated for head and neck cancer and to observe variations in QoL by area of residence.

### 3.2 Materials and methods

#### Study design and participants

A prospective, observational study design was used to evaluate QoL. Patients were consecutively sampled from the maxillofacial clinic or the multidisciplinary head and neck clinic of a large tertiary hospital in Queensland, Australia. Recruitment occurred between February and July 2013. Patients were first assessed for eligibility by a specialist surgeon (author MB) and then approached by author KP. The study eligibility criteria included a recent diagnosis, or suspected diagnosis, of a malignant tumour in the head and neck region, an ability to provide informed consent and being aged over 18 years. Patients who were referred for a recurrence of a previously treated malignancy were not eligible for inclusion, nor were patients who had already started treatment.

QoL was recorded at recruitment (prior to treatment), one month and six months post treatment. The pre-treatment survey was completed in person at the time of recruitment and the post treatment follow up surveys were either conducted at a review appointment (if attending the maxillofacial clinic) or via post.

#### Ethical considerations

This study was reviewed and approved by the Royal Brisbane and Women’s Hospital Human Research Ethics Committee (ref: HREC/12/QRBW/220) and the University of Queensland Human Research Ethics Committee (Project no. 1208). All participants provided informed consent prior to participation in the study.

#### Outcome measure

There are multiple patient reported outcome measures (PROM) available to researchers for the collection of data around symptom experience, psychological outcomes, health related QoL and general QoL. Measures may be HNC specific, or be applied to cancers more generally. Selection of a PROM is complicated by the lack of a ‘gold standard’ measure meaning that no one instrument is suitable for all.
purposes\textsuperscript{117,118}. As a result, many studies use a combination of outcome measures to enhance comparison of outcomes between existing HNC and cancer literature. However, this may have implications for participant burden, especially if completed during or close to the completion of treatment when experiencing significant treatment side-effects\textsuperscript{117}.

The University of Washington Quality of Life Survey version 4 (UW-QoL v4)\textsuperscript{119} was selected to measure QoL. This measure is one of the most frequently used throughout the HNC literature. It is a HNC specific tool that includes 12 questions about symptom experience; 3 general QoL and HRQoL ratings; symptom domain importance ratings and a free text section, where respondents have space to list additional issues not sufficiently covered by the questionnaire. Responses are scored on a Likert scale ranging from 0-100, whereby 0 equals the worst score and 100 equals the best, with the exception of the importance question, in which participants select the three most important domains affecting their overall QoL\textsuperscript{119}. This measure is unique in that it includes a free-text area, that prompts the respondents to provide further information about issues affecting QoL that were not adequately addressed by the questionnaire\textsuperscript{120}. This instrument was selected for the present study as it is patient centred, brief to complete, includes mood and anxiety domains in addition to physical symptoms and collects data in the form of scored and open-ended data, reflecting the overarching methods of the thesis. A copy of the UW-QoL v4 is included as Appendix 2.

Demographic information, including age, gender, postcode, marital status, education, smoking history and identification as Aboriginal or Torres Strait Islander were collected at baseline. Postcodes were categorised using the Australian Standard Geographic Classification-Remoteness Area (ASGC-RA) system\textsuperscript{121}. This was used to explore differences in UW-QoL responses by urban or regional/remote status.

\textbf{Statistical analysis}

Responses to the UW-QoL v4 were scored according to the author guidelines\textsuperscript{122}. This involved the computation of a summary score created from the sum of individual
items (i.e. scored from 0-100, with 100 indicating best QoL or functioning and 0 indicating the worst).

The UW-QoL domain scores were analysed descriptively. Repeated measures ANOVA was used to compare UW-QoL scores over time. Differences in UW-QoL score based on geographical location (ASGC RA1 (metropolitan) and ASGC RA2-5 (inner regional, outer regional, remote and very remote)) were tested using independent sample t-tests.

Differences in demographic and clinical variables and dropout at one and six months post treatment were assessed using Pearson’s chi-square or Fishers exact test. Statistical analysis was performed using SPSS version 23.0 (IBM Corp, Armon, United States of America) and the level of statistical significance was considered to be $P=0.05$.

**Participant follow up**

Out of 111 patients approached, 98 participants were recruited and completed the baseline questionnaires. Three participants were later excluded (due to recurrent disease $n=1$ or benign tumour $n=2$). The final sample consisted of 95 participants. Over the course of the study, 54 participants (56.8%) were lost to follow up. The largest attrition occurred at the one month post treatment time point ($n=46/95$). Dropout was due to non-response to postal follow up ($n=21$), but also due to missing treatment information ($n=8$), treatment at another facility ($n=11$) or completion of treatment outside of the study period ($n=1$). A detailed description of sample recruitment and follow up is presented as Figure 3-1.
Chapter 3: Quality of life among urban and regional HNC patients

Figure 3-1: Sample drop out and retention

111 participants approached

Pre-treatment sample (baseline)  
n=95

No information, treatment elsewhere or treatment outside of study period  
n=18

1 month post treatment follow up  
Completed n=49

Dropout n=28  
Withdrew from study (4)  
Withdrew from treatment (2)  
Passed away (1)  
No response to postal follow up (21)

6 months post treatment follow up  
Completed n=41

Dropout n=10  
Passed away (3)  
Non-response to postal follow up (7)
3.3 Results

Participants
Data describing participant characteristics at baseline is presented as Table 3-1. The sample consisted of 71 males and 24 females, oral cavity and oropharyngeal cancers accounted for 33.7% and 29.5% of tumour sites respectively and over half (52.7%, n=49/95) of tumours were diagnosed as stage IV.

Approximately half of all participants lived in a major city (n=48/95) and nearly one quarter of participants lived in an inner regional area (n=25/95). Nineteen percent (n=18/95), of participants lived in an outer regional area, 3% (n=3/95) lived in a remote area and 1% (n=1/95) of participants lived in a very remote area.

3.3.1 Quality of life and domain scores over time
The changes in responses to UW-QoL domain scores and overall quality of life scores over time are presented in Table 3-2. Overall, most domain scores decreased from pre-treatment to one-month post treatment, indicating more issues with symptom experience and reduced QoL. This was with the exception of responses to the anxiety domain, which tended to improve over time and saliva, which decreased over time (not statistically significant).

Statistically significant improvements between the one and six month scores were observed in the pain, activity, recreation, chewing, speech, taste, and mood domains and the rating of health-related QoL over the previous seven day period.

Participants who failed to complete the one month follow up reported significantly worse baseline scores in the pain, appearance, shoulder and anxiety domains compared to retained participants (see Table 3-3). There were no statistically significant differences in baseline UW-QoL scores for participants who failed to complete the six-month post treatment interval.
3.3.2 Quality of life scores and remoteness

Differences in UW-QoL domain and overall quality of life scores between metropolitan and regional/remote participants are presented as Table 3-4. At baseline, the regional/remote group scored significantly worse in the pain domain compared with the metropolitan group (p=0.031). There was a trend towards lower scores in the global QoL question among the regional/remote group at all three time points, however this association did not reach statistical significance. Post-hoc analysis revealed no statistically significant differences based on tumour stage or treatment between metropolitan and regional/remote groups.
Table 3-1: Participant characteristics at baseline by remoteness (n=95)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total n (%)</th>
<th>Metropolitan (ASGC RA1) n (%)</th>
<th>Regional/remote (ASGC RA2-5) n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>71 (74.7)</td>
<td>39 (81.3)</td>
<td>32 (68.1)</td>
</tr>
<tr>
<td>Female</td>
<td>24 (25.3)</td>
<td>9 (18.8)</td>
<td>15 (31.9)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
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<tr>
<td>&lt;45 years</td>
<td>11 (11.6)</td>
<td>7 (14.6)</td>
<td>4 (8.5)</td>
</tr>
<tr>
<td>45-65 years</td>
<td>44 (46.3)</td>
<td>23 (47.9)</td>
<td>21 (44.7)</td>
</tr>
<tr>
<td>&gt;65 years</td>
<td>40 (42.1)</td>
<td>18 (37.5)</td>
<td>22 (46.8)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>59 (62.1)</td>
<td>35 (72.9)</td>
<td>24 (51.1)</td>
</tr>
<tr>
<td>De facto</td>
<td>6 (6.3)</td>
<td>2 (4.2)</td>
<td>4 (8.5)</td>
</tr>
<tr>
<td>Never married</td>
<td>14 (14.7)</td>
<td>6 (12.5)</td>
<td>8 (17.0)</td>
</tr>
<tr>
<td>Divorced</td>
<td>10 (10.5)</td>
<td>3 (6.3)</td>
<td>7 (14.9)</td>
</tr>
<tr>
<td>Widowed</td>
<td>6 (6.3)</td>
<td>2 (4.2)</td>
<td>4 (8.5)</td>
</tr>
<tr>
<td>Aboriginal or Torres Strait Islander</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>94 (98.9)</td>
<td>48 (100.0)</td>
<td>46 (97.9)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>1 (1.1)</td>
<td>0 (0.0)</td>
<td>1 (2.1)</td>
</tr>
<tr>
<td>Highest level of school completed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>4 (4.3)</td>
<td>0 (0.0)</td>
<td>4 (8.5)</td>
</tr>
<tr>
<td>Years 8-10</td>
<td>48 (51.6)</td>
<td>19 (41.3)</td>
<td>29 (61.7)</td>
</tr>
<tr>
<td>Years 11-12</td>
<td>41 (44.1)</td>
<td>27 (58.7)</td>
<td>14 (29.8)</td>
</tr>
<tr>
<td>Other qualifications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>37 (38.9)</td>
<td>13 (27.1)</td>
<td>24 (51.1)</td>
</tr>
<tr>
<td>University</td>
<td>11 (11.6)</td>
<td>6 (12.5)</td>
<td>5 (10.6)</td>
</tr>
<tr>
<td>CAE/TAFE</td>
<td>37 (38.9)</td>
<td>25 (52.1)</td>
<td>12 (25.5)</td>
</tr>
<tr>
<td>Other</td>
<td>10 (10.5)</td>
<td>4 (8.3)</td>
<td>6 (12.8)</td>
</tr>
<tr>
<td>Smoking status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>17 (18.1)</td>
<td>8 (16.7)</td>
<td>9 (19.6)</td>
</tr>
<tr>
<td>Never</td>
<td>24 (25.5)</td>
<td>13 (27.1)</td>
<td>11 (23.9)</td>
</tr>
<tr>
<td>Former</td>
<td>53 (56.4)</td>
<td>27 (56.3)</td>
<td>26 (56.5)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC</td>
<td>79 (83.2)</td>
<td>39 (81.3)</td>
<td>40 (85.1)</td>
</tr>
<tr>
<td>Other</td>
<td>16 (16.8)</td>
<td>9 (18.8)</td>
<td>7 (14.9)</td>
</tr>
<tr>
<td>Site</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral cavity</td>
<td>32 (33.7)</td>
<td>16 (33.3)</td>
<td>16 (34.0)</td>
</tr>
<tr>
<td>Oropharynx</td>
<td>28 (29.5)</td>
<td>12 (25.0)</td>
<td>16 (34.0)</td>
</tr>
<tr>
<td>Nasopharynx, nasal cavity &amp; sinuses</td>
<td>4 (4.2)</td>
<td>3 (6.3)</td>
<td>1 (2.1)</td>
</tr>
<tr>
<td>Salivary gland</td>
<td>12 (12.6)</td>
<td>6 (12.5)</td>
<td>6 (12.8)</td>
</tr>
<tr>
<td>Larynx</td>
<td>8 (8.4)</td>
<td>5 (10.4)</td>
<td>3 (6.4)</td>
</tr>
<tr>
<td>Other (Skin, lip, thyroid, lymphnode, unknown primary)</td>
<td>11 (11.6)</td>
<td>6 (12.5)</td>
<td>5 (10.6)</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0 (Tis) &amp; Stage I</td>
<td>14 (15.1)</td>
<td>5 (10.6)</td>
<td>9 (19.6)</td>
</tr>
<tr>
<td>Stage II</td>
<td>16 (17.2)</td>
<td>8 (17.0)</td>
<td>8 (17.4)</td>
</tr>
<tr>
<td>Stage III</td>
<td>14 (15.1)</td>
<td>7 (14.9)</td>
<td>7 (15.2)</td>
</tr>
<tr>
<td>Stage IV</td>
<td>49 (52.7)</td>
<td>27 (57.4)</td>
<td>22 (47.8)</td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>20 (21.1)</td>
<td>9 (18.8)</td>
<td>11 (23.4)</td>
</tr>
<tr>
<td>Surgery &amp; (chemo)radiotherapy</td>
<td>32 (33.7)</td>
<td>20 (41.7)</td>
<td>12 (25.5)</td>
</tr>
<tr>
<td>(Chemo)radiotherapy</td>
<td>38 (40.0)</td>
<td>17 (35.4)</td>
<td>21 (44.7)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>1 (1.1)</td>
<td>0 (0.0)</td>
<td>1 (2.1)</td>
</tr>
<tr>
<td>Laser</td>
<td>2 (2.1)</td>
<td>1 (2.1)</td>
<td>1 (2.1)</td>
</tr>
</tbody>
</table>
Laser & XRT | 1 (1.1) | 1 (2.1) | 0 (0.0)
Declined treatment | 1 (1.1) | 0 (0.0) | 1 (2.1)

### Table 3-2: UW-QoL scores over time

<table>
<thead>
<tr>
<th>UW-QoL domain</th>
<th>Baseline Mean (SE)</th>
<th>1 month Mean (SE)</th>
<th>6 months Mean (SE)</th>
<th>P*</th>
<th>P§</th>
<th>P¤</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>79.0 (4.0)</td>
<td>67.7 (3.9)</td>
<td>87.9 (2.8)</td>
<td>&lt;0.001</td>
<td>0.085</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Appearance</td>
<td>89.5 (2.8)</td>
<td>77.4 (2.4)</td>
<td>83.1 (2.4)</td>
<td>0.004</td>
<td>0.002</td>
<td>0.097</td>
</tr>
<tr>
<td>Activity</td>
<td>83.1 (3.6)</td>
<td>59.7 (3.6)</td>
<td>73.4 (3.1)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.007</td>
</tr>
<tr>
<td>Recreation</td>
<td>87.9 (2.8)</td>
<td>64.5 (4.5)</td>
<td>76.6 (2.6)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.033</td>
</tr>
<tr>
<td>Swallowing</td>
<td>94.2 (2.2)</td>
<td>71.9 (4.9)</td>
<td>84.8 (4.2)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.084</td>
</tr>
<tr>
<td>Chewing</td>
<td>90.3 (3.6)</td>
<td>50.0 (6.6)</td>
<td>80.6 (5.5)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Speech</td>
<td>96.1 (1.8)</td>
<td>85.2 (3.2)</td>
<td>91.3 (2.5)</td>
<td>0.003</td>
<td>0.010</td>
<td>0.037</td>
</tr>
<tr>
<td>Shoulder</td>
<td>98.1 (1.3)</td>
<td>85.5 (4.6)</td>
<td>91.6 (3.5)</td>
<td>0.005</td>
<td>0.006</td>
<td>0.402</td>
</tr>
<tr>
<td>Taste</td>
<td>95.5 (3.1)</td>
<td>52.3 (7.2)</td>
<td>75.2 (4.9)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.002</td>
</tr>
<tr>
<td>Saliva</td>
<td>99.0 (1.0)</td>
<td>64.5 (6.0)</td>
<td>64.8 (5.3)</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>0.999</td>
</tr>
<tr>
<td>Mood</td>
<td>79.8 (4.8)</td>
<td>73.4 (3.7)</td>
<td>85.5 (3.2)</td>
<td>0.013</td>
<td>0.174</td>
<td>0.007</td>
</tr>
<tr>
<td>Anxiety</td>
<td>69.4 (4.8)</td>
<td>78.4 (3.0)</td>
<td>86.1 (3.2)</td>
<td>0.002</td>
<td>0.184</td>
<td>0.224</td>
</tr>
<tr>
<td>HRQOL before cancer</td>
<td>49.2 (2.5)</td>
<td>43.5 (5.8)</td>
<td>56.5 (4.9)</td>
<td>0.075</td>
<td>0.976</td>
<td>0.120</td>
</tr>
<tr>
<td>HRQOL over past 7 days</td>
<td>58.7 (3.2)</td>
<td>49.7 (3.2)</td>
<td>63.2 (2.5)</td>
<td>0.006</td>
<td>0.166</td>
<td>0.006</td>
</tr>
<tr>
<td>Global QOL</td>
<td>65.2 (4.0)</td>
<td>55.5 (3.7)</td>
<td>65.8 (3.0)</td>
<td>0.062</td>
<td>0.288</td>
<td>0.063</td>
</tr>
</tbody>
</table>

*Across all months.
§baseline to 1 month comparison only
¤1 month to 6 month comparison only
### Table 3-3 Baseline mean UW-QoL scores for participants who dropped out or completed follow up

<table>
<thead>
<tr>
<th>UW-QoL domain</th>
<th>1 month</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Completed Mean (SE)</td>
<td>Dropped out Mean (SE)</td>
</tr>
<tr>
<td>Pain</td>
<td>78.6 (3.2)</td>
<td>67.0 (4.8)</td>
</tr>
<tr>
<td>Appearance</td>
<td>91.3 (2.0)</td>
<td>80.4 (4.9)</td>
</tr>
<tr>
<td>Activity</td>
<td>83.2 (2.9)</td>
<td>76.8 (4.3)</td>
</tr>
<tr>
<td>Recreation</td>
<td>87.2 (2.2)</td>
<td>80.4 (3.7)</td>
</tr>
<tr>
<td>Swallowing</td>
<td>93.3 (1.8)</td>
<td>90.4 (2.7)</td>
</tr>
<tr>
<td>Chewing</td>
<td>87.8 (3.4)</td>
<td>85.7 (5.1)</td>
</tr>
<tr>
<td>Speech</td>
<td>93.5 (2.1)</td>
<td>96.7 (1.8)</td>
</tr>
<tr>
<td>Shoulder</td>
<td>97.4 (1.3)</td>
<td>84.1 (5.5)</td>
</tr>
<tr>
<td>Taste</td>
<td>93.5 (2.9)</td>
<td>91.8 (3.7)</td>
</tr>
<tr>
<td>Saliva</td>
<td>98.1 (1.1)</td>
<td>96.8 (1.8)</td>
</tr>
<tr>
<td>Mood</td>
<td>76.0 (4.0)</td>
<td>72.3 (4.9)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>65.5 (4.0)</td>
<td>48.6 (5.6)</td>
</tr>
<tr>
<td>HRQOL before cancer</td>
<td>52.0 (2.4)</td>
<td>53.6 (5.1)</td>
</tr>
<tr>
<td>HRQOL over past 7 days</td>
<td>59.2 (2.6)</td>
<td>55.0 (4.2)</td>
</tr>
<tr>
<td>Global QOL</td>
<td>65.3 (3.0)</td>
<td>58.6 (4.4)</td>
</tr>
</tbody>
</table>

*P <0.05

### Table 3-4: Mean UW-QoL scores for metropolitan and regional/remote groups

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>1 month</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Metro (SE)</td>
<td>R-R Mean (SE)</td>
<td>Metro (SE)</td>
</tr>
<tr>
<td>Pain</td>
<td>80.2 (3.0)</td>
<td>69.0 (4.1)</td>
<td>* 63.0 (3.9)</td>
</tr>
<tr>
<td>Appearance</td>
<td>89.6 (2.2)</td>
<td>86.2 (3.2)</td>
<td>75.0 (2.9)</td>
</tr>
<tr>
<td>Activity</td>
<td>80.7 (3.0)</td>
<td>80.9 (3.2)</td>
<td>61.0 (4.3)</td>
</tr>
<tr>
<td>Recreation</td>
<td>88.5 (2.5)</td>
<td>83.5 (2.8)</td>
<td>68.0 (5.1)</td>
</tr>
<tr>
<td>Swallowing</td>
<td>93.8 (1.8)</td>
<td>92.1 (2.3)</td>
<td>75.6 (5.6)</td>
</tr>
<tr>
<td>Chewing</td>
<td>88.5 (3.4)</td>
<td>87.2 (3.9)</td>
<td>54.0 (7.0)</td>
</tr>
<tr>
<td>Speech</td>
<td>94.7 (2.0)</td>
<td>94.6 (2.5)</td>
<td>86.3 (3.1)</td>
</tr>
<tr>
<td>Shoulder</td>
<td>93.6 (2.5)</td>
<td>93.7 (2.8)</td>
<td>82.9 (4.4)</td>
</tr>
<tr>
<td>Taste</td>
<td>91.7 (3.0)</td>
<td>94.8 (2.6)</td>
<td>48.8 (8.2)</td>
</tr>
<tr>
<td>Saliva</td>
<td>98.8 (0.9)</td>
<td>95.4 (1.6)</td>
<td>67.9 (6.7)</td>
</tr>
<tr>
<td>Mood</td>
<td>80.2 (3.8)</td>
<td>71.2 (3.8)</td>
<td>67.7 (4.6)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>62.3 (4.4)</td>
<td>56.0 (4.2)</td>
<td>75.4 (4.0)</td>
</tr>
<tr>
<td>HRQOL before cancer</td>
<td>53.1 (3.0)</td>
<td>52.7 (3.5)</td>
<td>37.0 (6.6)</td>
</tr>
<tr>
<td>HRQOL over past 7 days</td>
<td>59.6 (3.1)</td>
<td>57.4 (3.1)</td>
<td>43.2 (3.9)</td>
</tr>
<tr>
<td>Global QOL</td>
<td>64.6 (3.3)</td>
<td>61.7 (3.0)</td>
<td>57.6 (3.7)</td>
</tr>
</tbody>
</table>

*P <0.05

Metro= metropolitan
R-R = regional/remote
3.4 Discussion
The results indicated that QoL outcomes differed between some UW-QoL domains among metropolitan and regional HNC patients; however, most differences were not statistically significant. The sample size and rate of attrition are limitations that should be considered when interpreting the results. The findings do, however, suggest areas of potential importance for future investigation.

Pain was significantly worse at baseline among the regional/remote group compared to the urban group. Pain severity prior to HNC treatment has been associated with more advanced tumour staging and greater functional QoL impairment. Chaplin et al., reported 48% of patients reported pain at diagnosis of HNC, and 8% reported severe pain. Uncontrolled pain prior to cancer diagnosis may be due to barriers in communication and also the availability and usage of healthcare. In a general cancer setting, misconceptions about pain relief and a desire to be stoic and self-reliant prevent patients from raising pain relief concerns. Beliefs about pain relief may be further influenced among rural patients. Values of stoicism, optimism and machismo have been attributed to delays in rural men seeking medical attention for early cancer symptoms. Investigation of barriers to communicating pain warrants follow up by future research, especially considering the higher incidence of HNC among men. Our findings suggest there is a need for health-care providers to screen for pain that is affecting daily function and potentially affecting quality of life at diagnosis of HNC.

There was a trend towards poorer global QoL ratings among the regional/remote group at all three assessment intervals, compared to the metropolitan group. These findings are in contrast to the work of Thomas et al., who reported higher physical, emotional and HNC-specific QoL among HNC survivors living in rural Ireland. Australia, particularly Queensland, is unique in the population distribution and centralised nature of cancer services. This means that patients from regional or remote areas may need to travel daily to receive radiotherapy or stay in accommodation in a metropolitan centre. Travelling to receive cancer treatment is an additional source of stress and disruption for both patients and caregivers and is associated with financial and social disruption to daily life. There is growing
interest in telehealth as a model of service delivery in oncology. Telehealth has been used in HNC care to conduct remote diagnostic assessment\textsuperscript{130}, deliver rehabilitation support\textsuperscript{131}, and screening programmes\textsuperscript{132}. The benefits of receiving specialist support remotely include improved patient satisfaction with care, and a reduction in the economic, health and environmental impact of travelling for ongoing care\textsuperscript{130,131}. There is scope for future research to investigate the potential of integrated multidisciplinary care, delivered through a telehealth model, to improve QoL outcomes and enhance access to specialised care for HNC patients living in regional areas.

Additional factors, not measured by the UW-QoL, may have influenced QoL ratings for both metropolitan and regional/remote groups. Intrinsic traits such as personality, adaptation and coping styles influence how stressful experiences, such as cancer diagnosis and treatment, are appraised and managed\textsuperscript{133-135}. Future research should address QoL in a holistic context and include the individual, social and environmental factors that contribute to QoL.

\textbf{Limitations}

The study experienced a high rate of attrition: due to participant non-response but also due to a lack of information available to the researchers about treatment path and the location of treatment to enable follow up. It is possible that participants who were retained at the six-month follow up were the ones who fared better with cancer treatment and subsequently reported higher QoL scores. Participants who dropped out at one month reported worse scores in pain, appearance, shoulder and anxiety domains at baseline. This potentially led to an underrepresentation of these issues in the post treatment results. A high loss to follow up is common among longitudinal studies involving HNC patients, due to death but also due to the high physical and psychological burden of treatment\textsuperscript{136}. As such, the findings may not represent the experiences of the wider population of people treated for HNC.

The findings should be considered in light of potential limitations in how the data was transformed for analysis and also the implications of the high attrition rate on the final sample size, and subsequent data analysis.
Data analysis was informed by the author guidelines for the UW-QoL, and involved the transformation of Likert-type or categorical responses to a continuous format for analysis. Transformation of data in the manner can cause difficulty in determining whether intervals between scale values are equal, which may have implications for the validity of numerical calculations (such as means and further tests). This is a limitation of the results presented and also may reflect a limitation in the design and scoring of the UW-QoL.

Data analysis was limited due to the small sample size, which makes it difficult to determine the normality of the data distribution. This complicates the decision to apply parametric tests, or the non-parametric equivalent, and there are limitations of both parametric and non-parametric tests in the analysis of small samples. Parametric tests (t-tests, ANOVA) were used as they are robust even if the distribution is not completely normal. However, as a result of this, it is probable that the p-values are over estimated, therefore the results must be interpreted with this in mind. The sample size also restricted further sub-group analysis of QoL outcomes. The influence of potential confounders on differences in QoL outcomes between metropolitan and urban participants, such as gender, tumour stage and location may have influenced the QoL responses described, however were not able to be tested due to the small numbers in each sub-group.

3.5 Conclusion
The health of rural and regional Australians is a priority; due to the higher burden of chronic diseases, disparities in health outcomes and reduced access to services\textsuperscript{137}. This study has provided data to support the further investigation of QoL post HNC treatment in the Australian context. Pain management at diagnosis and additional individual, social and environmental factors affecting QoL should be investigated further.
Chapter 4

Joining the dots: Can UW-QoL free text data assist in understanding individual treatment experiences and quality of life outcomes in head and neck cancer?
Chapter 4: Joining the dots: Can UW-QoL free text data assist in understanding individual treatment experiences and quality of life outcomes in head and neck cancer?

4.1 Introduction

The diagnosis and treatment of head and neck cancer (HNC) may affect multiple domains of quality of life (QoL). The influence of a physical condition, such as HNC, on an individual’s physical, social, emotional and psychological wellbeing may be conceptualised as an interrelated network of factors, ranging from the biologic processes, to the expression of symptoms, to how changes are intrinsically appraised and coped with, to the availability and usage of external support. The range of outcomes that may be evaluated as part of QoL is mirrored in the large number of validated scales that exist that measure symptom burden and the impact of treatment on health-related quality of life (HRQoL) and general QoL. QoL and HRQoL are conceptually different outcomes. QoL involves multiple broad constructs relating to an individual’s perception of their physical and mental health, social relationships and environment, in the context of their culture, value system and expectations. HRQoL specifically addresses the impact of the disease and disease treatment on wellbeing.

Critical reviews of the HNC literature have identified heterogeneity in outcome measures, a lack of high-quality prospective studies evaluating QoL, and the broad conceptual definition of QoL as contributing to a confusion around the clinical relevance of QoL measurement. Additionally, the lack of a single ‘gold-standard’ instrument means that multiple measures are often combined and overlap the content measured. This has clear implications for participant burden, particularly in late treatment and early post-treatment timeframes, when patients are likely to be dealing with treatment-related fatigue and acute toxicities.

Despite the considerable disruption to daily life caused by HNC treatment, the relationship of symptom experience to overall QoL assessment is less clear. Patients may report clinically relevant problems with functional deficits or treatment related
toxicities, but simultaneously report little change to QoL, or conversely report improved QoL following HNC treatment\textsuperscript{140}.

The University of Washington Quality of Life Survey (UW-QoL) is a HNC specific patient reported outcome measure (PROM) that evaluates symptoms and HRQoL. The UW-QoL is among the most widely used HNC specific HRQoL measures in the literature\textsuperscript{43}. This tool was developed to measure HRQoL and symptom experience as a result of HNC and its treatment. Recent literature in this field has extended the use of PROMs, such as the UW-QoL, to provide insight into supportive care needs requiring intervention, with some authors proposing ‘cut-off’ scores to trigger a supportive care referral\textsuperscript{141,142}.

The UW-QoL is distinct from other HNC specific measures as it includes a free text question, whereby respondents are able to raise additional issues relating to QoL or symptom management\textsuperscript{143}. Despite its wide use in the literature, relatively few studies have reported findings from the free-text section of the UW-QoL. Instead, this data is primarily used for screening for additional problems and enhancing communication between the patient and treatment team\textsuperscript{24,120}.

A suggested reason for the lack of reporting of free-text outcomes is a methodological barrier to data analysis. Namely, issues with the transformation of qualitative open-ended responses into a format suitable for statistical analysis\textsuperscript{24}. The lack of reporting of qualitative data from this highly popular instrument\textsuperscript{118} is potentially a missed opportunity to gain further insight about QoL experiences and supportive care needs.

Qualitative research assists in making sense of the complex array of factors that may influence the QoL perceived by people treated for HNC, however, qualitative research is comparatively underrepresented in the HNC literature. Qualitative investigations of the impact of treatment on QoL offer many advantages and contribute a depth of understanding that complement population level quantitative reports of QoL outcomes. Qualitative research has assisted in the identification of “hidden” issues associated with treatment\textsuperscript{144} and may offer a therapeutic benefit for
participants by providing an opportunity to express comments and concerns not measured by standardised questionnaires\textsuperscript{120}.

Using a computer software program to perform an automated analysis of text data is one strategy to overcome the barriers to reporting findings from open ended-text. Software or machine-driven methods of text data analysis have been developed to facilitate the analysis of large text datasets and to overcome the time and resource intensive nature of manual content analysis (5). Machine-driven approaches include learning-based text mining (5) and unsupervised semantic mapping of language patterns (4). The text analytic software, \textit{Leximancer pro} uses pre-determined algorithms and machine learning to conduct an automated content analysis of text data. \textit{Leximancer} has been used in a range of fields, including health and communication research\textsuperscript{145}. It has been used to analyse interactions between nurses and cancer patients\textsuperscript{146} and to analyse free text case descriptions in an educational medical database\textsuperscript{147}, however has not previously been used in the HNC field.

This study aimed to explore the concepts and themes raised in free text responses to the UW-QoL from a prospective cohort of newly diagnosed HNC patients, and to highlight the additional information that can be gained from asking participants about their subjective experience. The use of open-ended data as an additional strategy to evaluate QoL outcomes following HNC treatment and to enhance the delivery of supportive care is discussed.

4.2 Methods
Open-ended responses included on the UW-QoL questionnaires used for QoL evaluation in the previous chapter formed the data for this study. The text data also included unsolicited written communication in the form of letters (n=2) returned with the completed questionnaires. The study design, participant eligibility criteria and setting are described in Chapter 3. Of the overall sample, open-ended responses were included on 9\% (n=95) of pre-treatment questionnaires, 33\% (n=16/49) of one-month post treatment questionnaires and 44\% (n=18/41) of six-month post treatment questionnaires.
Data analysis
Free-text responses were analysed using content analysis performed in Leximancer Pro (© Leximancer Pty Ltd). Responses to the pre-treatment, one-month post treatment and six-month post treatment questionnaires were analysed as separate data sets to enable comparison between follow up intervals.

Interpreting the Leximancer concept map
Leximancer uses pre-programmed algorithms to identify the commonly occurring concepts, themes and interconnectedness of a data set. The results of the Leximancer analysis are displayed on a concept map that enables visualisation of the underlying themes, concepts and the relationships that occur in a body of text. Themes are represented on the map as larger circles and include concepts (grey dots), which are words that occur in close proximity in the text. The grey network of pathways shows the most common connections between concepts, however other direct interconnections exist. Concepts cluster together on the map according to contextual similarity, for example, radiation and treatment are closely related, as responses refer to effects of ‘radiation treatment’.

Leximancer settings
Data analysis with Leximancer is automated; however users may also set key concepts to be searched within the data (termed ‘concept seeds’). For all data sets, under the ‘Text Processing Options’ command the prose test threshold was set to “0” and all tagging options were selected. The sentiment lens was applied using the ‘Concept Seed Editor’ command, to identify responses that conveyed favourable or unfavourable sentiments. The automated concept seeds were reviewed and judged to be sufficiently comprehensive; therefore no other user-defined settings were added.

4.3 Results
Twenty-nine participants made 43 open-ended comments over the course of the study. A summary of the baseline participant demographics and cancer related data is provided as Table 4-1.
Chapter 4: Using free-text data to understand quality of life

As prompted by the wording of the open-ended question, participants used the free text area to raise additional issues not listed in the UW-QoL. Responses also described the impact that a problem or side effect had on overall QoL and the strategies used to adjust to symptoms or side effects. Distinct differences were observed between the content displayed across the three concept maps. Table 4-2 describes the concepts identified within the three data sets. The concept map for each assessment interval is described in greater detail below and is supported by verbatim quotes extracted from the responses.

Table 4-1: Demographic and clinical characteristics of the participants who completed free text (n=26) and the total sample (n=95)

<table>
<thead>
<tr>
<th></th>
<th>Free-text n (%)</th>
<th>Total sample n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18 (62.1)</td>
<td>71 (74.7)</td>
</tr>
<tr>
<td>Female</td>
<td>11 (37.9)</td>
<td>24 (25.3)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;45 years</td>
<td>2 (6.9)</td>
<td>11 (11.6)</td>
</tr>
<tr>
<td>45-65 years</td>
<td>11 (37.9)</td>
<td>44 (46.3)</td>
</tr>
<tr>
<td>&gt;65 years</td>
<td>16 (55.2)</td>
<td>40 (42.1)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>18 (62.1)</td>
<td>59 (62.1)</td>
</tr>
<tr>
<td>De facto</td>
<td>1 (3.4)</td>
<td>6 (6.3)</td>
</tr>
<tr>
<td>Never married</td>
<td>2 (6.9)</td>
<td>14 (14.7)</td>
</tr>
<tr>
<td>Divorced</td>
<td>3 (10.3)</td>
<td>10 (10.5)</td>
</tr>
<tr>
<td>Widowed</td>
<td>5 (17.2)</td>
<td>6 (6.3)</td>
</tr>
<tr>
<td><strong>Remoteness (ASGC classification)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major city (RA1)</td>
<td>15 (51.7)</td>
<td>48 (50.5)</td>
</tr>
<tr>
<td>Regional &amp; remote (RA 2-5)</td>
<td>14 (48.3)</td>
<td>47 (49.4)</td>
</tr>
<tr>
<td><strong>Smoking status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>2 (6.9)</td>
<td>17 (18.1)</td>
</tr>
<tr>
<td>Never</td>
<td>10 (34.5)</td>
<td>24 (25.5)</td>
</tr>
<tr>
<td>Former</td>
<td>17 (58.6)</td>
<td>53 (56.4)</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC</td>
<td>27 (93.1)</td>
<td>79 (83.2)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (6.9)</td>
<td>16 (16.8)</td>
</tr>
<tr>
<td><strong>Site</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral cavity</td>
<td>9 (31.0)</td>
<td>32 (33.7)</td>
</tr>
<tr>
<td>Oropharynx</td>
<td>7 (24.1)</td>
<td>28 (29.5)</td>
</tr>
<tr>
<td>Nasopharynx, nasal cavity &amp; sinuses</td>
<td>1 (3.4)</td>
<td>4 (4.2)</td>
</tr>
<tr>
<td>Salivary gland</td>
<td>5 (17.2)</td>
<td>12 (12.6)</td>
</tr>
<tr>
<td>Larynx</td>
<td>3 (10.3)</td>
<td>8 (8.4)</td>
</tr>
<tr>
<td>Other (Skin, lip, thyroid, lymphnode, unknown primary)</td>
<td>4 (13.8)</td>
<td>11 (11.6)</td>
</tr>
<tr>
<td><strong>Stage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0 (Tis) &amp; Stage I</td>
<td>5 (17.2)</td>
<td>14 (15.1)</td>
</tr>
<tr>
<td>Stage II</td>
<td>5 (17.2)</td>
<td>16 (17.2)</td>
</tr>
<tr>
<td>Stage III</td>
<td>4 (13.8)</td>
<td>14 (15.1)</td>
</tr>
</tbody>
</table>
### Table 4-2: Overview of concepts identified from UW-QoL free-text responses

<table>
<thead>
<tr>
<th>Pre-treatment (n=9 responses)</th>
<th>One-month post treatment (n=16 responses)</th>
<th>Six-months post treatment (n=18 responses)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concept name</td>
<td>Count</td>
<td>Concept name</td>
</tr>
<tr>
<td>Favourable [sentiment]</td>
<td>5</td>
<td>Treatment</td>
</tr>
<tr>
<td>Life</td>
<td>4</td>
<td>Radiation</td>
</tr>
<tr>
<td>Writing</td>
<td>2</td>
<td>Unfavourable [sentiment]</td>
</tr>
<tr>
<td>Commitments</td>
<td>2</td>
<td>Cancer</td>
</tr>
<tr>
<td>Case</td>
<td>2</td>
<td>Tongue</td>
</tr>
<tr>
<td>Pain</td>
<td>2</td>
<td>Weeks</td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
<td>Mouth</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physical</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Effects</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problem</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Loss</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Favourable [sentiment]</td>
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<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 4.3.1 Pre-treatment responses

The pre-treatment concept map and list of concepts identified are provided as Figure 4-1. Seven concepts were identified and there were few connections between concepts. This was due to the small number of free text responses at this time-point. The pre-treatment responses were highly individualised and specific to individual
Chapter 4: Using free-text data to understand quality of life

circumstances. The concepts that cluster closely together are the responses from individual participants that offered the greatest level of explanation in responses.

‘Life’ and ‘writing’ referred to an explanation of the decision made by one participant to not progress with treatment in favour of an intention to enjoy the remaining life left. The concepts ‘case’ and ‘commitments’ were closely located on the concept map and described uncertainty around the ability to keep singing commitments post cancer treatment. ‘Pain’ referred to conditions (shingles and asbestosis), which caused pain that was not related to cancer.

“My decision is to go back [home] and enjoy what I have left with a smile and enjoy life.”

“Currently experiencing a lot of pain due to shingles which is affecting QoL +++”
4.3.2 **One-month post treatment**

The concepts identified from the one-month post treatment responses are presented as Figure 4-2. ‘Radiation’ and ‘treatment’ were the most common concepts identified, with the greatest connectivity. Nine concepts with an unfavourable sentiment were identified in the text, indicating problems or difficulties with treatment side effects. Conversely, one favourable sentiment was identified and this related to a statement about needing to be in a positive state of mind to achieve the best results.
Chapter 4: Using free-text data to understand quality of life

Problems associated with treatment related to physical side effects including dehydration requiring hospitalisation, pain when eating caused by ulceration to the mouth and throat, speech difficulty and recovery, lack of energy and loss of appetite. An increased build-up of mucous was an additional issue not identified on the questionnaire. Psychological and emotional difficulties as a result of treatment were also raised and included anxiety about whether the cancer was cured and a lack of knowledge of the side effects of radiotherapy. The ‘radiation’ concept was clustered closely with concepts related to support from friends and family, indicating a close proximity in the text. The importance of psychosocial support during treatment for head and neck cancer was highlighted in some responses:

*Mucus. Why is there no mention of incessant build-up of heavy mucus? It is one of the worst side effects. This factor alone can seriously affect one’s social life, sleeping habits, vomiting, eating and conversation.*

*Because I prepared myself as much as possible prior to the radiation treatment the after effects have been kept to a minimum. This preparation included all areas of my life physical, emotional and physical and involved a lot of support from family and friends. It is vital to undergo this treatment with a positive mind and attitude for the best results.*
Chapter 4: Using free-text data to understand quality of life

Figure 4-2: One month post treatment concept map (n=16 responses)
4.3.3 Six months post treatment

The concept map of responses to the six-month post treatment questionnaire is provided as Figure 4-3. At this follow-up, the map represents concepts relating to difficulty eating dry or sharp foods (i.e. ‘biscuits’, ‘crackers’, ‘careful’) and ‘dry mouth,’ as a result of salivary dysfunction. ‘Mouth’ was the most frequently ranked concept and referred to issues with xerostomia and the impact this had on sleep and energy levels, in addition to eating. Two responses identified the additional issue of ‘mouth opening’ that was not listed on the questionnaire.

As with the one-month post treatment questionnaire, there were a greater number of responses demonstrating an unfavourable sentiment indicating problems or difficulties with the outcomes of treatment. Emotional distress and psychological difficulties were identified from some responses, with concerns about mortality, inability to sleep, a lack of energy and inability to perform the same activities undertaken prior to cancer. One response, however, detailed how QoL had improved post treatment, due to weight loss and a new outlook on life:

_Cancer & treatment really have an emotional effect. I don't feel I have the energy physically...to do activities I was capable of pre-cancer._

_I'm now back at work and do shift work. I have been a little tired but listen to my body and rest. Walking 30kms a week. The saliva is my biggest issue but drink plenty of water. Overall I feel great & have lost 60kg & have a new lease on life._
Chapter 4: Using free-text data to understand quality of life

Figure 4-3: Six months post treatment concept map (n=18 responses)
4.4 Discussion

The analysis of free-text data enabled the identification of clinically relevant problems that were not otherwise recorded on the UW-QoL questionnaire, especially issues with adjusting to eating, psychological distress and symptoms of xerostomia, trismus and mucous build up. Additionally, responses offered greater detail as to the impact of treatment outcomes on psychological wellbeing and general health.

Longitudinal analysis of QoL outcomes in the literature describe a pattern of building treatment toxicities, lower QoL and increased support needs immediately following treatment, followed by a gradual recovery of function and improved QoL up to one year post treatment. Within the sample of free text data represented in this study, these changes were also observed in regard to the shifting issues identified at each follow-up.

Responses at six months post treatment centred around the mouth, eating and salivary dysfunction. These issues are separate, yet compounding outcomes that affect physical and psychosocial QoL post treatment. Trismus was an additional problem not listed on the questionnaire that was identified in two responses. Trismus is a common late-stage side effect of radiotherapy and chemoradiotherapy and is associated with poorer HRQoL and loss of function with regard to swallowing and eating as well as muscular tension and pain. Trismus additionally limits oral hygiene practices, which may increase the risk of dental disease post treatment.

Disruption to eating caused by head and neck cancer treatment has important physical implications, including malnutrition. The cumulative impact of xerostomia, trismus, dysphagia and disruption to the sensory and muscular functions of the oropharynx results in a “changed meaning of food” post treatment. This stems from an alteration to the type of food able to be consumed post treatment and disruption to the social, emotional and psychosocial eating experience. Thus, patients must develop a new way of eating and additionally learn to adjust and cope with the chronic changes to the mouth and swallowing. Adjustment to the chronic, functional outcomes of treatment that represent the “new normal” in eating is an essential aspect of recovery following treatment and the return to prior activities.
and social routines\textsuperscript{155}. This is an area that is under-researched and there is a lack of interventions that address the social and psychological aspects of eating that may negatively affect QoL\textsuperscript{156}.

QoL is an important outcome in evaluating HNC treatment; however there has been limited uptake of QoL data collection in routine clinical practice. A survey of Australian and New Zealand head and neck cancer clinicians reported 34\% of respondents had ever used a HRQoL questionnaire in clinical practice and 13\% were currently using one\textsuperscript{157}. Kanatas et al.,\textsuperscript{158} reported 53\% of British HNC clinicians had used HRQoL measures, and 42\% reported current use. The most common barriers to use were a perception that questionnaires were time consuming\textsuperscript{157,158} and offered little clinical benefit\textsuperscript{157}.

To enhance the clinical relevance of HRQoL measures, cut-off scores that identify unmet needs requiring intervention have been evaluated\textsuperscript{141,142}. This adds to a range of tools currently available to screen for supportive care needs in oncology, including a head and neck cancer patient concerns inventory\textsuperscript{57}, and a range of generic cancer needs assessment tools\textsuperscript{159}. Recent literature suggests that the method of supportive care needs screening is also important\textsuperscript{132}. An Australian study\textsuperscript{132} found greater sensitivity in the identification of symptom burden and mild to moderate distress in a patient-completed screening tool, compared to face-to-face assessment conducted by a health practitioner.

Given the large number of tools and outcome measures available for clinical use, an empirical evaluation of measures is required to assist clinicians in selecting a questionnaire to implement in clinical practice. Notably, the patient voice is missing in the development and evaluation of these measures. The findings of this study highlight the value of open-ended responses in allowing patients to express the issues most important to them and suggest that this approach may be complementary to structured needs assessment tools. However, if the goal of supportive care research is to improve patient outcomes and QoL, it is essential that the patient voice be represented in evaluating tools for routine clinical use.
This was the first study to use automated content analysis to evaluate open-ended responses to the UW-QoL. We found automated content analysis to be comparatively less time and resource intensive than manual content analysis. Our results suggest that automated data analysis may be a useful method to overcome some of the methodological barriers to free-text data analysis. However, there are caveats to note when performing software driven analysis. Data analysis may be ‘over-simplified’, causing inaccurate results and conclusions to be drawn from results. Familiarity with the data is required to make sense of the underlying meaning behind concepts and themes and would increase the time required for the analysis of large data sets.

**Limitations**

The results of this study describe the experience of a subset of participants within the overall study sample. As this work is primary exploratory in nature, the results are unlikely to be generalisable to the wider head and neck cancer population.

Many of the concepts identified had a frequency of one or two. This is an important consideration for interpreting the results, as it is possible that issues may have been over represented in the sample due to the size of the data set. Further investigation of these issues within a larger sample of responses is required. From a clinical perspective however, these issues were of high importance to the patients that reported them and therefore useful to identify areas requiring intervention or follow up from the treatment team.

There also appeared to be an over representation of the side effects of radiotherapy or chemoradiotherapy in the concept maps. This was due to a greater number of comments from participants that received radiotherapy as part of their treatment and reflected the treatment characteristics of the larger sample that the free text data was drawn from. As a result, the identification of problems following surgical treatment may have been underrepresented in the data. There are comparatively few studies that investigate the psychosocial outcomes associated with surgery only, as compared with radiotherapy or chemoradiotherapy. This is an area where future work is required to ensure that the needs of patients receiving surgery are identified and met.
4.5 Conclusion

The findings of the study are a base on which to build future empirical work examining the use of free text data in clinical needs assessment, patient outcomes reporting and health service evaluation. There is a need for consultation with patients, as well as clinicians, in the evaluation of tools for routine clinical use, so that information is collected in a meaningful and appropriate manner.

The mouth was the most frequently identified concept at six months post treatment. Future research is required to explore the influence of problems with the mouth and eating and the impact on general wellbeing and QoL.
Chapter 5
Coping with an altered mouth and perceived supportive care needs following head and neck cancer treatment
Chapter 5: Coping with an altered mouth and perceived supportive care needs following head and neck cancer treatment

5.1 Introduction

The treatment for cancers occurring in the head and neck region, especially those involving the oral cavity or oropharynx, often results in acute and chronic disruptions to oral health and functioning\textsuperscript{162}. The degree of oral morbidity and resulting impact on quality of life is influenced by tumour and treatment related factors, with a high burden of oral morbidity caused by toxicities of treatment involving radiotherapy and chemoradiotherapy\textsuperscript{10,53,163}.

Oral health describes a state in which an individual is free from facial pain, oral sores, periodontal disease, tooth decay, tooth loss and other diseases and disorders affecting the oral cavity\textsuperscript{164}. Oral health influences rehabilitation and recovery post head and neck cancer (HNC) treatment, as compromised oral function may impede dietary intake and affect nutritional status\textsuperscript{38}. Malnutrition following HNC treatment is also associated with poorer health related quality of life and higher psychological distress (anxiety and depression)\textsuperscript{165,166}.

Consequently, the supportive care needs perceived by people treated for HNC are complex and are linked to the physical disruption of structures essential to normal functioning in addition to the burden of coping with emotional and psychological challenges of treatment\textsuperscript{79}. People with HNC report greater support needs across a range of domains compared with other cancers\textsuperscript{37}.

Previous investigations of needs assessment in HNC have relied on questionnaires, with only a small number of studies reporting findings from HNC specific outcome measures\textsuperscript{37,149,167}. As established previously, this approach lacks flexibility to explore the wider social and environmental issues that may influence perceived supportive care needs. Qualitative methodology offers greater understanding of complex issues following cancer treatment. Previous qualitative studies have investigated the lived experience of oral cancer patients\textsuperscript{72,73} and spouses\textsuperscript{168}, experiences with treatment\textsuperscript{106,161,169}, the eating experience following radiotherapy\textsuperscript{154}, and communication between patients and clinicians\textsuperscript{170}. Most of this research has
employed interviews as the method of data collection\textsuperscript{72,73,106,154,169-171}, however focus group methods have also been used to explore rehabilitation needs\textsuperscript{172}.

In Chapter 4, problems with the mouth were the most frequently identified issue in free-text responses at six months post treatment and in Chapter 2, the unmet support care needs associated with oral health were greatest in the first 12 months following treatment. The objective of this chapter is to extend on previous work by exploring how the changes to oral health were perceived and coped with six months post treatment, and to identify the supportive care needs that underpinned oral health issues post treatment.

5.2 Methods

This study was qualitative in design and used a semi-structured instrument to explore changes to oral health and functioning and coping post treatment. This approach is flexible in that it allows the exploration of individual issues through the use of prompts, while being structured enough to enable the comparison of experiences across the study population. This approach was selected for the present study as it has an established record of use in the HNC field and enabled the exploration of both the experiences of oral health and the management of changes to the mouth (thus linking with Chapter 2).

Participants

The participants of this study were recruited from the prospective quality of life study described in Chapter 3. Potential participants were people who had completed the pre-treatment and one month treatment follow up UW-QOL questionnaires and who lived in the Brisbane area. Potential participants were sent an interview invitation alongside their six-month post-treatment questionnaire (n=14/51). The interview eligibility criteria are described below in Table 5-1 and participant recruitment from the overall study sample is described in Figure 5-1.
### Table 5-1: Interview eligibility criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥18 years of age</td>
<td>Diagnosed with recurrence</td>
</tr>
<tr>
<td>Diagnosed with primary malignancy in head &amp; neck region</td>
<td>Unable to provide informed consent</td>
</tr>
<tr>
<td>Completed baseline &amp; 1 month post treatment QoL follow up</td>
<td>Lived outside Brisbane area</td>
</tr>
<tr>
<td>Reside in Brisbane area</td>
<td>Non-consent for interview</td>
</tr>
</tbody>
</table>
Ethical approval was obtained from the Royal Brisbane and Women’s Hospital Human Research Ethics Committee (ref: HREC/12/QRBW/220) and the University of Queensland Human Research Ethics Committees (Project no. 1208). All participants provided informed consent prior to participating in the study.
Chapter 5: Coping with an altered mouth & perceived supportive care needs post HNC

**Procedures**
Data was collected from an individual, face-to-face interview conducted by author KP and guided by a semi-structured instrument. Follow up and probing questions were used as necessary to elicit further information from participants about the impact of oral health issues on overall wellbeing and supportive care needs. The interview guide is included as Appendix 3. Interviews ranged in duration from 25 to 80 minutes and were recorded with the permission of participants.

Nvivo 10 (© QSR International) was used for data management. The interview recordings were transcribed verbatim. Data analysis and transcription was ongoing throughout the data collection period.

**Data analysis**
The interview data was analysed by qualitative content analysis. Directed and inductive approaches to data analysis were used to ensure reflexivity and ‘best fit’ of the coding scheme to the data. Directed content analysis was performed by applying key components of the stress, appraisal and coping model to interpret the participant descriptions of coping post HNC treatment (Figure 5-2). This model was used to guide the data analysis in Chapter 2 and has previously been applied in the context of cancer to understand how patients appraise and cope with aspects of the disease. It views an individual’s response to a stressful situation as an outcome of the dynamic relationship between a person and their environment. A stressful situation may be appraised as a threat, loss, harm or challenge, based on its potential to affect wellbeing. How an individual copes with a situation is influenced by person factors and situational factors (e.g. social support, professional support and financial resources).

Inductive content analysis involved a process of open coding of the data followed by the grouping of codes into categories. Following this, coding from both the inductive and directed approaches were combined and grouped into higher order themes and categories to reflect patterns and relationships identified in the data. Rigour in analysis was ensured by the independent co-coding of transcripts by authors KP and PF (analyst triangulation). Categorisation of data was also discussed between the
authors to ensure it represented participant responses. All participants received a copy of the data analysis summary and were invited to provide feedback regarding the accuracy of analysis (respondent validation). 3/6 participants responded and confirmed accuracy of the author’s interpretation of their experiences. At all stages of the data collection and analysis process, a clear record and description of how the research was conducted to ensure procedural rigor.

Figure 5-2: Key concepts of stress appraisal and coping model (adapted from Lazarus and Folkman, 1984)
5.3 Results

5.3.1 Participants
Of the fourteen potential participants, six agreed to participate, five declined and three did not respond. The final sample was comprised of six participants: four men and two women and is described in Table 5-2, below.

Table 5-2: Participant characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Marital status</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Cancer site</th>
<th>Treatment modality</th>
</tr>
</thead>
<tbody>
<tr>
<td>P01</td>
<td>Married</td>
<td>Male</td>
<td>60</td>
<td>Oropharynx</td>
<td>Chemoradiotherapy</td>
</tr>
<tr>
<td>P05</td>
<td>Married</td>
<td>Male</td>
<td>72</td>
<td>Tonsil</td>
<td>Chemoradiotherapy</td>
</tr>
<tr>
<td>P06</td>
<td>Married</td>
<td>Male</td>
<td>50</td>
<td>Nasopharynx</td>
<td>Chemoradiotherapy</td>
</tr>
<tr>
<td>P02</td>
<td>Divorced</td>
<td>Female</td>
<td>67</td>
<td>Mandible</td>
<td>Surgery</td>
</tr>
<tr>
<td>P03</td>
<td>Married</td>
<td>Female</td>
<td>59</td>
<td>Parotid gland</td>
<td>Surgery &amp; radiotherapy</td>
</tr>
<tr>
<td>P04</td>
<td>Married</td>
<td>Male</td>
<td>60</td>
<td>Tongue</td>
<td>Surgery &amp; radiotherapy</td>
</tr>
</tbody>
</table>

5.3.2 Coping with changed oral health
Three themes describing participants’ experiences with changes to oral health and functioning as a result of HNC treatment were identified: the dimensions of eating; maintaining oral health after treatment; and adapting to the chronic side effects of treatment. A summary of the key themes and supporting participant quotes are listed in Table 5-3.

Dimensions of eating
The theme ‘dimensions of eating’ described the changed experience of food and eating as a result of treatment and was comprised of the sub themes: changed masticatory function; dysgeusia; dysphagia; sensitive mouth; and finding the motivation to eat and recover.
Chapter 5: Coping with an altered mouth & perceived supportive care needs post HNC

*Changed masticatory function.* The loss of teeth in addition to sensory and muscular changes to the oral cavity following surgery resulted in an impaired chewing ability, meaning participants had to adapt to new ways of eating and resulting in an increased time to eat following treatment. One participant described being unaware of food residue on her face when eating in public, which caused feelings of embarrassment and avoidance of social eating. Participants described the use of problem focussed coping strategies to overcome limitations in chewing. Strategies included having a conscious awareness of the movement of the lips and tongue while chewing and also modification of diet to include soft, easy to chew foods and avoidance of foods known to be difficult or cause discomfort to chew.

*Dysgeusia.* Participants described a disruption to their sense of taste that occurred soon after beginning radiation and chemoradiotherapy. An inability to taste the food once it was in the mouth led to a reduced appetite and added another limitation eating and recovery post treatment. Continued dysgeusia proved a persistent barrier to eating a wider range of foods in the months following treatment.

*Dysphagia.* Adapting to dysphagia caused diminished physical and psychosocial functioning during and post treatment. Learning to swallow again after months of relying on a PEG tube caused anxiety for one participant and resulted in social isolation and reduced quality of life due to an inability to eat socially while undergoing treatment. Participants coped with dysphagia during treatment by adding moisture to their food in the form of sauces and gravies and altering their diet to include soft foods rather than foods that might catch in the throat.

*Sensitive mouth.* Ulceration to the mouth and throat caused by radiotherapy severely inhibited food and liquid intake during treatment, and resulted in disturbed sleep. Returning to a ‘normal’ diet post treatment was additionally hampered by sensitivity to the oral mucosa caused by radiation and chemotherapy. Participants described continual difficulties with tolerating spicy, salty foods or crunchy foods in the months following treatment. Yoghurt was used by some participants to help lessen the spice in foods but in general many foods previously enjoyed were avoided.
Finding the motivation to eat and recover. The cumulative effects of dysgeusia, dysphagia, mucositis and xerostomia were most severe at the completion of treatment. Participants described struggling to persevere with food and fluid intake while experiencing a painful mouth and throat and lack of taste. Dysgeusia in particular contributed to a lack of motivation to eat and recover, leading to further weight loss and dehydration after treatment. This cumulated in two participants being readmitted to hospital due to dehydration and collapse post treatment. Both participants described the period prior to readmission as feeling ‘very low’ and hopeless.

Participants described consciously reappraising the role of food to overcome the lack of motivation to eat during and post treatment. Food took on a new meaning as it became less about desire and enjoyment and more about survival. As the time following treatment progressed, participants described emotions of hope and optimism for the continual improvement of salivary function and taste.

Maintaining oral health after treatment
Maintaining the health of the teeth and oral cavity became an essential part of the daily routine of participants following treatment. Fear of deterioration of the teeth and prioritisation of preventive dental care were commonly expressed issues. Pre-radiotherapy oral health education and counselling appeared to be important in shaping compliance with oral health care post treatment. Conversely, for one participant, uncertainty about the appropriate timeframe in which to start using a toothbrush post-surgery caused feelings of worry and self-consciousness about stained teeth post treatment.

Adapting to the chronic side effects of treatment
This theme describes the cognitive appraisals made by participants in evaluating the impact that chronic side effects of treatment had on an individual’s overall wellbeing and quality of life. Xerostomia was described as a reminder of treatment and an outcome that participants were forced to adapt to over time as they held little potential to change the outcome. When discussing xerostomia, participants described emotions of frustration and annoyance at its constant presence.
Xerostomia was an unexpected outcome for one participant, and posed an unknown long term threat to their oral health.

Participants described the use of positive reappraisal coping strategies to adapt to the permanent side effects of treatment by comparing their own situation to others worse off position and being grateful for a cure. In adapting to a changed diet post treatment, participants described shifting the focus away from foods that were no longer palatable; instead preferring foods that could be eaten easily and therefore enjoyed. An outcome of this coping strategy was a perception of living a healthier lifestyle post treatment, as xerostomia resulted in a changed diet and less desire to eat starch, dry and unhealthy foods such as bread and pastries.

5.3.3 Support needs
The support needs described by participants were categorised into support needs related to oral health and psychosocial support needs. A description of support needs and supporting participant quotes are provided in Table 5-4.

Support needs relating to oral health
Participants expressed a need for increased access to ongoing specialist dental oncology services post treatment. The inclusion of a routine post treatment dental review appointment was recommended to provide reassurance about the health of the teeth and mouth post treatment and to serve as an additional review for cancer recurrence. Participants identified a need for greater integration between dental services and the hospital, and described having to travel to a dental clinic separate from the hospital site as a potential barrier to following through with pre-treatment dental assessment.

Other information needs raised by participants included clear communication about the critical nature of complying with oral hygiene recommendations, strategies for dealing with dry mouth and a need for more general awareness of HNC to aid in early detection.
Psychosocial support needs

Three participants identified a need for additional psychosocial support while undergoing treatment, to help with cope with the psychological ramifications of cancer. The importance of social support was identified by several participants. Some accessed social support through existing networks of friends and family, while others joined peer support networks. Talking to others who had been in a similar situation provided a sense of camaraderie and deep understanding of the thoughts, feelings and emotions experienced as a consequence of dealing with cancer and treatment. Participants described barriers such as the location of meetings and also a group setting as deterrents to engaging in peer networks. One on one peer support was identified by one participant as integral to coping with cancer treatment.
### Table 5-3: Participant experiences of changed oral health

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
<th>Participant comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Dimensions of eating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a)  Changed masticatory function</td>
<td>Sensory and muscular impairment post-surgery caused difficulty with chewing.</td>
<td>P02 “I was really conscious of it initially, because I used to dribble, food would be all over me”</td>
</tr>
<tr>
<td></td>
<td>d)  Dysguesia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inability to taste food resulted in reduced appetite and was additional barrier to eating during and post treatment.</td>
<td>P04 “When I first had surgery, I could only eat like a beaver, you know…that was not something you can do long term”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b)  Dysguesia</td>
<td>Inability to taste food resulted in reduced appetite and was additional barrier to eating during and post treatment.</td>
<td>P06 “What is eating? It’s an enjoyment and if you can’t taste it, what’s the enjoyment? You’re only doing it for a bit of survival”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c)  Dysphagia</td>
<td>Swallowing dysfunction caused diminished physical and psychosocial functioning. Prevented participants from sharing meals in a social setting and led to feelings of social isolation.</td>
<td>P03 “It limited you, not so much the pain and that of your mouth it was more the taste of everything, to be able to find something that still tasted good”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d)  Sensitive mouth</td>
<td>Severe ulceration of oral mucosa limited ability to eat during treatment and also affecting sleeping. Continued sensitivity to salty, crunchy &amp; spicy foods limited returning to normal diet post treatment.</td>
<td>P05 “They’d have a lovely spread on the table, they’d be enjoying it and telling me how good it was, and I couldn’t touch any of it”</td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td>e)  Finding the motivation to eat and recover</td>
<td>An outcome of cumulative effects of dysgeusia, dysphagia, mucositis and xerostomia leading to further weight loss and dehydration post treatment. Coping by reappraisal of role of food.</td>
<td>P06 “I just couldn’t eat….my mouth was ulcerated….I’d wake up in pain cos the inside of my mouth was stuck to my teeth, and I’d pull it away and it was like skin ripping”</td>
</tr>
<tr>
<td></td>
<td></td>
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</tr>
<tr>
<td>2. Maintaining oral health after treatment</td>
<td>Became an essential part of participant’s daily routine, motivated by fear of the risk of deterioration of teeth following radiotherapy.</td>
<td>P01 “It just becomes another glob in my mouth. It’s food, I know I’ve got to eat it, so I eat it”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P01 “It’s mental, it’s really a mental thing at that particular period”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>P04 “I know I’ve got these extra things to do, it’s just as important and just as much part of my day as washing your face or anything else that you have to do”</td>
</tr>
</tbody>
</table>

Chapter 5: Coping with an altered mouth & perceived supportive care needs post HNC
3. Adjusting to the chronic side effects of treatment

Xerostomia described as frustrating outcome of treatment. Positive reappraisal of symptoms and impact on quality of life resulted in effective coping. Participants described benefit of ‘healthier’ diet post treatment due to inability to eat dry starchy foods.

[Re: xerostomia] P01 “I know I’ve got to get used to it, but it’s more frustrating than anything”
P03 “Now I find because it’s dry and claggy in my mouth I don’t have a desire for bread, I’ll have a wrap”
P04 “I probably eat more steamed veges and stuff now…so as much as I hate to admit it, I probably do feel a bit better if I’m not eating so much shit food”

Table 5-4: Perceived support needs

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
<th>Participant comment</th>
</tr>
</thead>
</table>
| Support needs related to oral health | Need for more integrated care between medical and dental disciplines to facilitate attending dental appointments. Need for access to specialised dental oncology services post treatment. Clear communication about critical nature of oral hygiene during and post radiotherapy. | P06 “It should be a necessity, not just if you would like to, because I nearly didn’t go to the dental hospital. That’s very scary”
P04 “If anybody were to start a practice where previous cancer patients, even though they’re free of disease, might still go there…just as a little bit of follow up so you’ve got peace of mind knowing someone who has seen many, many cases is having a look at you” |
| Psychosocial support needs         | Need for formalised peer support to help in psychological aspects of living with cancer • Accessible location • Relevant matching of people with similar backgrounds/experiences. | P06 [About a fellow patient] “He was really good, he was the first person I’d spoken to that had cancer and treatment….he was just a knock about bloke like myself”
P04 “Basically, the people who have been through it are the best people to talk to. I think that’s a better way…not having someone tell you who hasn’t been through it, because they don’t understand” |
5.4 Discussion

The findings of this study describe the broad impact of HNC on oral health, in addition to the appraisal and coping responses adopted by participants in adapting to oral dysfunction post HNC treatment. The health of the mouth and teeth play a crucial role in recovery following HNC treatment, however may be forgotten amongst the barrage of other factors individuals face while undergoing treatment. Once treatment begins, patients face several months of severely compromised oral health. Thus, well timed and appropriate oral hygiene education and dental assessment prior to the beginning of treatment is essential in the prevention of poor oral health outcomes during and post treatment\textsuperscript{20,175}.

In the present study, access to timely oral hygiene advice prior to radiotherapy was integral in shaping participant compliance with oral hygiene measures post treatment, however participants perceived a need for improved access to specialist dental oncology services post treatment.

One of the most salient risks to dental health following radiotherapy is the development of radiation caries. Radiation doses above 30 Grey cause irreversible damage to salivary glands, resulting in an increased risk of caries for all teeth, not only those included in the field of radiation\textsuperscript{16}. Thus, maintenance of life-long rigorous oral hygiene and adherence to an anti-cariogenic diet are essential in long-term preservation of the dentition\textsuperscript{20}. Education and support from experienced dental practitioners, including dental hygienists and oral health therapists (dual qualified dental therapists and hygienists) is essential in aiding patients to adapt and comply with these lifestyle changes post treatment\textsuperscript{162,176}.

The role of altered oral health and functioning on the impact of general wellbeing, especially to psychosocial outcomes, has been confirmed by previous studies\textsuperscript{72,106,177}. Chewing, salivary and swallowing dysfunction are stressful outcomes of treatment, threatening quality of life\textsuperscript{135}. The this study builds on the findings of Chapter 2, which described how survivors of HNC reappraised the impact of such chronic side effects on their QoL as time since treatment progressed due to psychological adaptation over time\textsuperscript{135}. As all participants of the current study were...
recruited at the same time point (six months following treatment), conclusions cannot be drawn about the influence of proximity to treatment on the cognitive appraisal process. Similarly, the majority of our sample (n=5) received radiotherapy as part of their treatment regime; therefore distinction is not possible between the treatment experiences and perceived support needs of people who receive surgery alone, versus surgery and adjunctive treatment.

Participants of the present study described an overwhelming use of positive coping strategies such as problem-focused coping and positive reappraisal. On the surface, positive outcomes following HNC treatment may conflict with findings of emotional distress associated with cancer diagnosis and treatment reported elsewhere\(^{178,179}\). Emerging literature has highlighted a subset people who report positive outcomes following cancer treatment, stemming from personal growth or finding benefit in adversity\(^{180}\). ‘Benefit finding’ may explain the strong use of effective coping reported in the present study and may also have influenced participants’ decision to take part in the study, therefore potentially excluding those people without benefit finding and introducing bias to the study sample. In studies involving people treated for HNC, benefit finding has been associated with optimism and coping by positive reappraisal of the situation\(^{181}\). Additionally, access to appropriate intervention from health care practitioners in addition to ongoing spousal, familial and peer support are likely to have contributed to the positive outcomes of HNC treatment described by participants. A recent review confirmed the importance of a supportive relationship with health care providers, family, and friends as well as others who have experienced HNC in adapting to the outcomes of HNC treatment\(^{182}\).

The present study identified several support needs that related to the delivery of information and social support at the appropriate time during the treatment process. Fang and colleagues\(^{183}\) described a diverse range of information needs reported by HNC patients, and a strong need for information about maintaining health after cancer treatment and treatment side effects. Greater understanding of the information needs specific to head and neck cancer is required, as unmet support needs are associated with negative quality of life outcomes and higher levels of distress\(^{184,185}\).
An unexpected finding of the present study was the unmet psychosocial support needs experienced by participants. Peer support helps patients cope with the ‘unreal world’ of HNC treatment, in addition to providing a source of emotional, social and informational support about what to expect while undergoing treatment. Peer delivered support and education programs have been shown to be effective in other fields of healthcare including managing health behaviours of people chronic health conditions such as diabetes, providing psychosocial support in mental illness and in supporting smoking cessation among disadvantaged groups. Therefore implementing formalised peer support programs in HNC may be useful in addressing the high burden of depression and anxiety in this group, in addition to supporting the modification of lifestyle related risk factors (alcohol and tobacco consumption) highly prevalent in this population.

**Limitations**

Although this study has expanded on existing research regarding adapting to oral health outcomes post HNC treatment, certain limitations must be noted. Data collection involved a face-to-face interview using a semi-structured interview guide. This approach enabled greater depth of understanding of oral health and its management post treatment as compared to quantitative assessment, however the data analysis was limited by the small sample. Alternate data collection strategies, such as illness narratives or case studies may have enabled a more detailed and descriptive analysis to be conducted and address the limitations of content analysis in a small sample such as this.

Sampling based on location and willingness to participate in the study led to a demographically homogenous sample and limited the breath of experiences that may have been reported if purposive sampling was used. Logistical constraints meant that only participants who lived in the metropolitan area were invited to participate in the interview. Living in close proximity to the hospital meant that participants were able to stay at home during treatment and had ready access to family and support networks, which may have influenced coping. The interview participants had a narrower age range than that of the larger study from which participants were drawn (range 28-89 years), which may have further narrowed the
focus of the support needs and experiences presented. Additionally, financial influences were unable to be explored as most participants were retired or nearing retirement and had strong financial support. The findings presented should be considered with caution, reflecting the sample size and recruitment of participants from a similar demographic background.

5.5 Conclusion
The findings describe the experience of a small group of survivors who found benefit in their HNC experience, and this may account for the narrow range of support needs identified. The study findings do not attempt to account for the experiences of all people with HNC, however provide insight into factors that may influence positive coping among this population. Future research should focus on exploring experiences from a demographically diverse population to further understand support needs related to managing oral health after HNC treatment.
Chapter 6
A culture shock in dental hygiene: Exploring the management of oral health after head and neck cancer
Chapter 6: Maintaining oral health after HNC

Chapter 6: \textit{A culture shock in dental hygiene: exploring the management of oral health after head and neck cancer}

6.1 Introduction

Oral health takes on new meaning after head and neck cancer (HNC). The life-long maintenance of oral health after HNC involves the performance of meticulous oral hygiene and regular access to professional dental care. Personal oral hygiene for this group, however, is more complex than simply toothbrushing and interdental cleaning. There is an ongoing requirement for the daily application of high concentration fluoride (toothpastes or gel loaded in medicament trays placed over the teeth) in addition to carefully managed oral hygiene and dietary behaviours. Additional products are often recommended to compensate for the reduced lubricating, remineralising and antimicrobial functions of the altered saliva, and include topical forms of calcium-phosphate, mouthrinses containing chlorhexidine, and salivary substitutes. Oral hygiene practices often need to be adapted to manage sensory loss, the presence of tissue grafts or limited mouth opening. For HNC patients with previous poor dental health behaviours, implementing the required preventive dental routines requires a sizeable behaviour shift.

Adding to the complexity of managing long term oral health after HNC is the tendency for this group of patients to have a history of infrequent dental attendance and dental problems requiring treatment prior to beginning cancer treatment. Australian data describing their oral health status or dental attendance is limited. Frydrych and Slack-Smith reported a majority of oral and oropharyngeal cancer patients reported a history of irregular dental attendance, with an average time since last dental visit of 5.6 years. However, the findings of this study were based on a chart-review, and were limited by a small sample size and incomplete records.

Access to healthcare is a multidimensional concept. Levesque et al. proposed a conceptual framework incorporating both supply (health services) and demand (utilisation by consumers) determinants. Patient-centered access is defined as the opportunity to have health care needs fulfilled, and is a combination of the approachability, acceptability, availability, affordability, and appropriateness of a health service, in addition to the ability to perceive, seek, reach, pay and engage by
individuals\textsuperscript{194}. Access to care is a dynamic and interrelated construct, and is additionally dependent upon the capacity for users to communicate as well as notions of health literacy, self-efficacy and self-management\textsuperscript{194}.

Oral health behavioural research is largely founded in social cognitive theory\textsuperscript{195}. Social cognitive theory is comprised of the core determinants of knowledge of health risks and benefits of health practices, perceived self-efficacy in exercising control over health behaviours, outcome expectations of the perceived costs and benefits of engaging in a health behaviour, in addition to the health related goals that people set for themselves, and perceived barriers or facilitators of making a behaviour change. Importantly, an individual's health behaviour does not exist in a vacuum, and is additionally influenced by social and structural factors\textsuperscript{196}.

Studies of oral health among HNC patients have focussed on clinical outcomes, management protocols\textsuperscript{197,198} or describing the impact of oral symptoms on quality of life\textsuperscript{51,52,193}. There is a deficit in the literature regarding the management of oral health after HNC treatment - from either an access to care or health behaviour perspective. This is an area requiring attention, as maintaining a functioning mouth is essential to preserving speech, eating, nutritional status, comfort, self-confidence and appearance. The findings of this thesis have so far described the influence of the appraisal of oral health changes on quality of life and the description of supportive care needs. A greater requirement to maintain oral health was a finding of the previous chapter and was associated with a higher need for professional support.

The aim of this study was to explore the management of oral health after HNC, by exploring factors that influenced oral health behaviours in addition to factors that influenced oral health care utilisation from the patient perspective.
6.2 Methods
Qualitative methods were used to explore experiences of oral health and oral health behaviours following HNC treatment. An exploratory, inductive approach was used for data collection and analysis. Participants (n=21) were patients who had received treatment for oral or oropharyngeal cancer through the maxillofacial clinic of a large, tertiary hospital in Brisbane, Australia. Semi-structured interviews were used for data collection. The interviews focused on two aspects of oral health care: personal oral health behaviours and access to dental care.

Participants and sampling
Participants were purposefully sampled using a maximum variation approach. This sampling approach aims to capture and describe the common themes that occur across a varied sample. This approach was additionally selected to encompass the multiple factors that influence perceptions of oral health and access to dental care in the Australian health care setting. The sampling categories included demographic and treatment factors that would potentially influence oral health status. These factors were derived from the social determinants of oral health that influence access to dental services and the impact of different treatment approaches on oral health and function. Each category is outlined below, with numbers of participants in each category in brackets.

a) Gender - Male (15); Female (6)
b) Age - 65 years of age or over (7); under 65 years of age (14)
c) Health care card status - HCC holder (8); non-HCC holder (13)
d) Location - Residing in rural or regional area (10); metropolitan area (11)
e) Treatment - surgery only (2); surgery with radiotherapy or chemoradiotherapy (19)
f) Presence of denture or prosthesis - denture/prosthesis wearer (5); no denture/prosthesis (16)

Potential participants were recommended by a specialist surgeon and were then approached by author KP with information about the study and an invitation to participate. Participants were offered an interview immediately following their clinic
appointment or at a separate time over the telephone. The recruitment of participants continued until sampling saturation was reached, and was defined as least one participant in each of the categories. Data saturation was reached after 19 interviews and data collection was finalised after two further interviews did not raise any new findings.

A total of 23 participants consented to interviews, however two participants were unable to be reached for a telephone interview so the final sample consisted of 21 participants.

**Interview procedures**

Nineteen participants were interviewed individually in a private room at the maxillofacial clinic and two were interviewed over the telephone. Several participants were accompanied to review appointments by their spouses. Spouses were advised of their choice to sit in the room while the interview was taking place or to wait in the waiting room. Spouses accompanied participants in five cases. Interviews were conducted over the period of December 2014 to January 2015 and ranged in duration from five to 40 minutes. The brief (five minute) interview was held with a participant who had finished radiotherapy one week earlier and was edentulous after having all his teeth extracted prior to treatment. The interview guide was shortened in this case to focus on previous dental care behaviours and access to care.

Subtle changes to the order of the questions on the interview guide after the first seven interviews. No further changes were made. The final interview guide is included as Appendix 4.

Detailed field notes and a project diary were kept throughout the data collection and analysis phase and were used to track key issues raised during interviews and changes to the interview schedule. Interviews were audio recorded and transcribed verbatim.
Data Analysis

Data analysis was performed by thematic analysis\textsuperscript{199}. Full transcripts were reviewed and coded inductively based on prominent concepts identified from the data. Each transcript was coded separately and then the coding structure was compared across transcripts to identify commonly occurring patterns in coding. This was followed by an ongoing process of categorisation of prominent codes (similarities across the dataset) and comparison with the full data set to identify deviant cases or categories that did not fit the coding structure. Finally, the coding structure was organised into themes and sub-themes, which were again compared to the full dataset to ensure they accurately represented the concepts identified through the interviews.

Author KP conducted the interviews and initial coding and categorisation of concepts and themes. To enhance qualitative rigour, transcripts were independently coded by AW, a dentist with prior experience in qualitative methods and access to care issues among populations with special care needs. The coding structure and formation of themes were discussed between the research team at regular intervals to ensure accuracy in analysis. After the initial coding phase themes were constantly compared with the full data set and also literature in the area to enhance interpretive rigour. Procedural and analytic transparency was ensured by the clear documentation of coding and theme formation and field notes. Nvivo 10 (© QSR International) was used to aid data management and coding.

Clinical oral health management

Standard care for oral oncology at the hospital is a pre-radiotherapy dental appointment for a comprehensive examination, treatment planning for any dental care required prior to cancer treatment, and education about the oral implications of upcoming treatment and about post-treatment preventive care practices. Patients are first assessed by a dentist at the multidisciplinary clinic and then are required to attend a follow-up appointment at a publically funded dental clinic that is off-site, but of close proximity to the hospital. At this appointment, patients receive a full dental examination and if applicable a treatment plan detailing procedures required to become dentally fit before radiotherapy. A follow up appointment is made to receive
pre-treatment dental care at the public hospital dental clinic or through a private
dentist in the patient's local area.

At the time of the interviews, the post-treatment home care recommendations
included the use of a high strength fluoride (1.0% NaF) toothpaste and the twice
daily use of medicament trays loaded with neutral sodium fluoride gel (2.0% NaF) in
the morning, and a casein phosphopeptide-amorphous calcium phosphate (CPP-
ACP) paste prior to sleep at night. Participants were instructed to brush their teeth
twice per day in addition to after each meal or snack. Additional products and
strategies for the symptomatic relief of dry mouth were discussed and dietary advice
provided.

Ethical considerations
This study was reviewed and approved by the University of Queensland Institutional
Human Research Ethics Committee (approval number 2014001611) and received
project and site-specific approval from the Royal Brisbane Hospital Research Ethics
Committee (project reference: HREC/14/QRBW/484).

6.3 Results
6.3.1 Participants
Participant characteristics are described in Table 6-1. Participants ranged in age
from 38 to 78 years (mean 58.4 years). Fifteen participants were married, four were
divorced, one widowed and two never married. Regarding the tumour, the tongue
was the most common site (n=8), followed by floor of mouth (n=4), mandible (n=2),
buccal mucosa (n=2), and maxillary sinus, mandibular alveolar mucosa, hard palate,
oropharynx and salivary gland (1 participant each, respectively.) This data includes
one participant who experienced two cancers that involved separate sites, the first
involving the neck from an unknown primary (treated in 2011) and the second
involving the floor of mouth (treated in 2013). Two participants were treated by
surgery alone, 18 were treated by surgery followed by radiotherapy and/or
chemoradiotherapy and one was treated by chemoradiotherapy without surgery. The
time since treatment ranged from 1 week to 16 years (mean 2.75 years since
treatment.) Three participants experienced osteoradionecrosis of the jaw.
### Table 6-1: Participant characteristics (total n=21)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
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<tr>
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</tr>
<tr>
<td>Female</td>
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</tr>
<tr>
<td>Age</td>
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<tr>
<td>≤45 years</td>
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<td>45-64 years</td>
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<tr>
<td>≥65 years</td>
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<tr>
<td>Prosthesis or denture</td>
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</tr>
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<td>No</td>
<td>16</td>
</tr>
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<tr>
<td>Tumour site</td>
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<td>Tongue</td>
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<td>Hard palate</td>
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<td>Mandible</td>
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<td>Oropharynx</td>
<td>1</td>
</tr>
<tr>
<td>Salivary gland</td>
<td>1</td>
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<tr>
<td>Buccal mucosa</td>
<td>2</td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
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<tr>
<td>Surgery only</td>
<td>2</td>
</tr>
<tr>
<td>Surgery &amp; (chemo)radiotherapy</td>
<td>18</td>
</tr>
<tr>
<td>Chemoradiotherapy</td>
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<tr>
<td>Time since treatment (of first cancer)</td>
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<td>&lt;12 months</td>
<td>8</td>
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<td>1 year to 2 years</td>
<td>4</td>
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<tr>
<td>3-5 years</td>
<td>7</td>
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<tr>
<td>&gt;6 years</td>
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ASGC = Australian Standard Geographic Classification Remoteness Index
6.3.2 Thematic analysis results

Oral health behaviours and utilisation of oral health services were influenced by individual and structural factors. Three overarching themes described the individual determinants of oral health: a cognitive shift towards life-long oral health; management of unexpected barriers; and management of competing priorities. Structural factors related to: location and availability of services; continuity of care; and relationships with health practitioners.

The ability to fund oral health emerged as an additional salient theme and influenced compliance with home care and also the ability to navigate barriers to accessing oral health services. Multiple and compounding barriers to engaging in oral health behaviours and accessing services were described in some cases, and were influenced by outcomes of treatment, experiences of distress or financial stress, or a combination of these. An overview of the key themes and relationships between themes is provided as Figure 6-1 and the final coding structure is provided as Appendix 6. A discussion of the individual determinants of oral health is presented first, followed by an exploration of the structural health system factors.
Figure 6-1: Overview of key themes and relationships between themes

- **Individual determinants of oral health**
  - Cognitive shift
  - Management of unexpected barriers
  - Competing priorities

- **Structural factors**
  - Continuity of care
  - Service availability: public vs. private sectors; regional vs. metropolitan areas
  - Relationships with health practitioners

- **Ability to fund oral health**

**Positive outcomes:**
- Improved oral health
- Frequent use of dental services

**Compounding individual and structural barriers**
Outcomes:
- Reduced compliance with oral hygiene
- Reduced frequency of profess. care
6.3.3 Individual determinants of oral health

Cognitive shift towards life-long oral health

The motivation to comply with oral health recommendations resulted from a belief that oral health was permanently altered post treatment. Participants described the various ways that treatment reduced the self-cleansing function and overall comfort of the mouth. Rinsing the mouth and physically removing food debris was a method to restore the mouth to a state of comfort or balance. Therefore personal oral hygiene was conceptualised as a functional necessity in response to an increased threat to the dentition following radiotherapy. There was an increased value attached to maintaining dental health to preserve chewing function and aesthetics, especially if some teeth were extracted prior to radiotherapy.

The changed motivation and increased value associated with retaining teeth resulted in an increased motivation to engage in preventive dental care practices. For participants who had previously neglected their oral health this was a complete shift away from previous behaviours, however for other participants who had always proactively managed their oral health this was aligned with maintenance of previously high levels of oral health. The shift between pre-and post-treatment oral health behaviours is illustrated by the following quote:

Respondent: “Yes, I only went to the dentist when I had to…I only brushed my teeth once in the morning and once at night and that was it, and probably not to the best of my ability, so I’ve had a few dental problems beforehand. So just with having teeth taken out and fillings and things like that. So yeah, this has really been a culture shock in dental hygiene.” Male, tongue cancer, three months post treatment.

A belief that the dentition was more at risk following radiotherapy resulted from the serious manner in which oral health education was delivered prior to treatment. Several participants made reference to being “scared” into compliance, for fear of total destruction of their teeth if neglected after radiotherapy, however regarded this as an effective strategy to communicate the serious nature of oral health management post treatment.
The timing of oral health education influenced the capacity for patients to comprehend what post-treatment care would entail. Participants described being in a state of mind that was focused on upcoming treatment and little ability to comprehend what their post-treatment oral health would be like, or how this should be managed. The limited ability to comprehend post treatment oral health needs are illustrated by the following quotes:

Respondent: “Probably they should make them more aware and when you have the first tests and have cancer you don’t really listen to everything that is said. So I found myself thinking, “oh shit”, and having to go back to the paperwork.” Female, tongue cancer, nine months post treatment.

Respondent: “The two guys from the dental hospital came across and gave me a whole raft of stuff. Which I didn’t really understand at that stage, you don’t get how big an impact it can have on you.” Male, floor of mouth cancer, one year post treatment.

The verbal instructions were accompanied by literature describing the various side-effects of radiotherapy to the oral cavity, and detailed preventive care recommendations. Participants referred back to this literature after treatment to answer questions about home care routines. Some participants noted that sound literacy and comprehension skills were required to filter through repetitive, generic information contained in the resources and apply it to their specific context.

Some participants described that having a spouse present at the dental appointment was essential to understanding post-treatment oral health care requirements on their behalf. These participants expressed reliance on their spouse to assist in finding information and managing new symptoms that arose during the recovery period, for example, an exacerbation of xerostomia when returning to work. Participants additionally found information about oral health from their previous experience in caring for others, internet searching, from maxillofacial clinic staff or through dental professionals. The following extract illustrates the importance of a spouse to take on information at a time when the participant could not focus clearly:

Respondent: “I think it’s more to educate my wife as well. Like just to know that, so she can understand what needs to be doing as well ‘cause I was in shock still, I didn’t take much notice, so I read it all a bit afterwards.” Male, tongue cancer, three months post treatment.
Participants generally believed they had received sufficient warning of the risks of failing to comply with dental care, and noted that they were reminded to manage dental care needs at various points by medical staff.

**Management of unexpected barriers**

Despite positive intentions to comply with oral hygiene recommendations, some participants experienced barriers to implementing the recommended home care routines. A highly sensitive oral mucosa prevented the use of the neutral sodium fluoride gel in 4 cases, and in one case, inability to use any toothpaste or product with mint flavouring. In these cases, participants used whatever products that were able to be tolerated even if they were not appropriate (tooth mousse as toothpaste, natural toothpaste, biotene toothpaste) or avoided the use of irritating products altogether. The frustration this caused for both the participant and his wife is highlighted by the following quote:

*Respondent:* “I wish they had a toothpaste like, if I clean my teeth with toothpaste I just about go through the ground.”

*Interviewer:* “Because it’s too strong?”

*Respondent’s wife:* “Nearly every toothpaste has got mint in it. I’ve bought every sort, I’ve bought all the Sensodynes, I’ve bought just about every toothpaste on the market trying to get one but all of them have that mint or peppermint or something flavoured in them.”

*Respondent:* “And that worries me because I can’t really have a fresh mouth.” Male, tongue cancer, one year post treatment.

Non-compliance with home care recommendations also resulted from discomfort caused by poorly fitting medicament carriers, trismus, lip incompetence that restricted the ability to use mouthrinses, or concern that interdental cleaning aids would damage the gingiva or delicate graft tissues.

Participants who described a greater a sense of mastery over managing treatment outcomes, such as regaining eating function, also described greater self-efficacy to overcome unexpected barriers to performing oral health behaviours. Sources of confidence were explained to be due to individual traits, such as determination, a strong sense of agency and being proactive in healthcare, or were influenced by spousal support and encouragement to persist with regaining eating function and maintaining oral health post treatment.
Management of competing priorities
For some participants, there were additional influences on how oral health recommendations were applied in light of their own social, financial and medical circumstances. Compliance was influenced by competing priorities and self-efficacy beliefs about managing oral health.

Self-efficacy beliefs to maintain long term oral health were eroded by stress caused by psychological outcomes of treatment, lack of employment, reduced social connectivity, or the need to manage ongoing medical problems post treatment. In two cases, psychological distress and depression negatively affected compliance with oral health behaviours. In one case, distress was caused by treatment difficulties and poor self-efficacy to manage outcomes of dysphagia, pain and aspiration when swallowing. In another case, a loss of income and reduced capacity for employment caused financial stress, which was amplified by low social connectivity and depression following treatment. The outcome of both instances was the reprioritisation of oral health needs to focus on immediate stressors, be that psychological or financial. One participant described how uncertainty about survival further contributed to the avoidance of oral health care:

Respondent: “You just don’t realise how bad things are going to be, so I didn’t look after my teeth because I didn’t know if I was going to live or die. So why worry about doing something that’s going to hurt if it mightn’t be necessary? It’s only after a while…” Male, tongue cancer, 16 years post treatment.

Visiting numerous specialists to manage ongoing health issues and a permanent feeding tube was the rationalisation for infrequently attending professional dental appointments in one case, and is illustrated by the following extract:

Respondent: “Seriously, I’ve seen 57 doctors…so sometimes when people say listen to this, listen to that, no just leave me alone [pause] just for a little while.”

Interviewer: “So it’s kind of information overload on what you should be doing?”

Respondent: “Yeah and like you have dentists and then something might be wrong with my PEG.”

Interviewer: “Yeah”

Respondent “And in-between that you still have a life” Female, tongue cancer, nine months post treatment
The short-term deprioritisation of oral health needs resulted in ongoing problems with dental decay and deterioration of the dentition for some participants. This caused further stress, as jagged teeth caused intra-oral pain and required ongoing dental management with limited success. Additionally, it further compromised chewing function, which affected nutrition, social eating, appearance and contributed to feelings of social isolation, as illustrated by one participant:

*Respondent: “I used to be very sociable but it’s pretty hard to go out and enjoy a meal when you can’t taste it. I’ve still got most of my good looks but not all of them so it’s a bit hard adapting to life.”*

*Interviewer: “Because of the teeth aspect?”*

*Respondent: “Yeah…”  Male, tonsil cancer, five years post treatment.*

**Ability to fund oral health**

The ability to fund dental care was a key determinant in the ability to perform home care routines and also to engage in regular professional care. Purchasing specialised toothpaste, fluoride gels and adjunctive aids as well as attending regular dental appointments was a considerable cost to participants. Private health insurance assisted in covering some of the professional costs, however participants acknowledged there was a large portion that they funded. Many participants accepted this cost as an unavoidable part of keeping their teeth after treatment. Others downplayed the impact of this cost in light of gratitude at receiving expensive, life-saving treatment through a publically funded health service. Factors that enabled the funding of dental care for some participants included income protection insurance and redundancy payments. These funding sources enable participants to be relieved of any potential financial stress associated with dental care and enhanced their frequency of dental service use. The following quote highlights how a considerable gap left to pay on an implant-retained denture was alleviated by a recent redundancy payout:

*Respondent: “On the bridge and plate they [private health insurance] paid a thousand bucks and it cost $12,000”*

*Interviewer: “Is that a concern for you, the financial side?”*

*Respondent: “No. I mean I was sort of prepared because I think my daughter said, “I bet you only get a thousand,” and I said, “I bet you do too”. So, and I got a golden handshake from Campbell Newman (laughs) [referring to redundancy package]” Female, mandibular alveolar mucosa cancer, three years post treatment.*
There was a stark difference described in accessing dental care depending on the participant’s financial capacity to seek private dental care. Economic capital enabled greater autonomy and efficacy in organising appointments at a private dentist, whereas lack of finances inhibited the ability to seek care outside of the public sector. Ongoing financial stress severely restricted the ability to engage in oral health behaviours in one participant’s case. Product choice was limited to what was available at the supermarket at a discounted price:

Respondent: “Lately, since I’ve been back butchering it’s whatever one is on special”
Interviewer: “Do you use anything extra, like dry mouth gels?”
Respondent: “I’ve got one ready to go but I mainly use the water, the gel you have to buy and the water is a lot cheaper. I don’t really taste it but it’s a financial thing.” Male, oropharyngeal cancer, five years post treatment.

6.3.4 Structural factors affecting oral health care utilisation

The structural factors that influenced oral health care utilisation related to the availability and accessibility of services and perceived quality and appropriateness of care. Participants residing in metropolitan or large regional areas who were able to seek dental care through the private sector perceived very few barriers to accessing dental care. Increasing barriers to care were identified by participants living in more regional areas and who relied on public sector services for ongoing general dental treatment.

Product and service availability in regional areas

Geographical area influenced access to products. Some products were available at a reduced cost through public dental clinics which increased access, however not all participants described being able to source products this way. Availability, choice and price of products was generally worse in smaller regional communities, compared to choice and availability in metropolitan areas.

Participants living in regional areas described delays in obtaining appointments for specialist services located in Brisbane. Multiple delays were encountered by one participant who described stress at waiting for an available emergency dental appointment at a regional clinic, and then additional delays in organising travel to
Brisbane. Another participant described the emotional distress of waiting for a specialist appointment to receive further information regarding treatment and prognosis of his tumour after receiving an initial diagnosis of oral cancer from his general medical practitioner.

**Accessibility of services: private versus public sectors**

Participants who were treated through the public sector for oral rehabilitation (replacement of teeth and prosthetic services after treatment) described a well-organised system after being referred from the public dental hospital in Brisbane, to a public dental clinic in their local area. There were few barriers to care described once this referral was made and their course of care had started. However, public oral health services did not meet the needs for ongoing general preventive dental care after treatment. Being placed back on a waiting list of twelve months or more for examination was judged to be inconsistent with the heightened need for frequent professional dental care post treatment. Additionally, losing touch with the public system or moving between health service districts meant that participants had to re-join waiting lists, which increased delays in receiving treatment. Participants with the financial capability to seek private dental care chose this pathway, even if eligible for publicly funded general dental treatment as there was a greater availability of appointments at more convenient times.

*Interviewer: “Would you consider going through the public system for your care?”*

*Respondent: Well you can, but you have to go on the waiting list. Like I can go as an emergency, but otherwise I’m just on the waiting list…I haven’t had a health care card for long, so I haven’t been on the list. I think when I rang the other day it’s about a year waiting list at the moment.” Female, parotid gland tumour, nine months post treatment*
Continuity of care

Overwhelmingly, participants viewed their treatment through the hospital and maxillofacial clinic as being of the highest quality and well-organised. In light of this, dental involvement in follow-up oncology care was described as “lacking”. A lack of continuity of care was described between pre-and post-treatment dental services, between medical and dental health practitioners and due to an absence of oral health follow-up at medical and allied health reviews.

At the completion of treatment, there was limited discussion about options for seeking dental care and many participants felt uncertain about where to find dental practitioners experienced in treating people post radiotherapy. Participants needed to self-manage their ongoing dental care needs post treatment. In lieu of a referral network, several participants described themselves as “lucky” to find a dental practitioner with experience in treating HNC patients.

A lack of communication between the different practitioners involved in dental management often meant that participants were required to fill in the gaps and relay clinical and treatment information. Participants identified the need for professional referral networks to be established to assist in finding a dental practitioner post treatment, and also to assist in referral pathways to expedite the diagnosis process.

There was little integration between medical and dental services after treatment. One participant viewed the lack of oral health follow up at radiation oncology and allied health review appointments as a missed opportunity:

Respondent: “I think if it was done in coordination with allied health, or the Cancer Council, or whoever, and simply met with the person when they have those...like at the end of a, you’ve now seen the radiation people, just come in here, how are you going or what’s happening with your mouth, can we talk about what you’re doing in terms of things. I think that’s the time. Because my appointment with the radiation people lasted about four minutes. It's not onerous.” Male, mandible cancer, three years post treatment.


*Relationships with health practitioners*

Both positive and negative perceptions of patient-practitioner interactions influenced participant attitudes towards seeking regular dental maintenance and care. Dental practitioners who went the extra mile to be educated about how to treat patients post HNC or established communication with the oncology team were valued. However, practitioners who recommended treatment plans that contradicted the recommendations of the hospital or public dental clinic, or who made flippant remarks about concerns raised by participants caused a sense of distrust. Trust in dental professionals was further reduced by perceptions of practitioners who viewed health as a business, rather than recommending only the necessary procedures. This is highlighted by the experience of one participant:

*Respondent:* He [public hospital dentist] said my mouth was good, my teeth were fine, there was nothing that needed doing immediately. Maybe one crown a couple of years down the track, but everything else was good. And this other fellow said no, you need all this work done, about $5000 worth. So I thought “oh this is conflicting” So I rung [public hospital dentist] back and said this is what I’ve been told...so it’s just very hard to say whether the dentist was after by my interests or after my dollars.” Female, parotid gland tumour, nine months post treatment.

In contrast, the care provided through the public dental hospital was regarded as high quality and trustworthy due to the extensive experience of practitioners in managing the oral health care of people following HNC. The sense of trust built from receiving treatment from an experienced practitioner is highlighted by the following quote:

*Respondent:* “I would have liked to have seen the dental hospital picking this up. Even if I went there a couple of times after the operation you know because they’ve got all the knowledge these people. More so than the average dentist. I’m not saying he’s no good, he’s the bloke that picked this [cancer] up in the first place, but I felt very good at the dental hospital...And when we finished the operation and I said well will I go to the dental hospital, no, no, no you go back to your own dentist. And I thought that was a bit, you know, funny, really because they had all the knowledge of me before hand.” Male, tongue cancer, one year post treatment.
6.4 Discussion
This study aimed to identify the factors that influenced oral health behaviours in a broad manner, by exploring both personal oral health behaviours and utilisation of professional care. Participants described a range of oral health outcomes, attitudes and behaviours, however central determinants of oral health were identified. Strong self-efficacy, financial support and spousal support enhanced the management of oral health, whereas difficulty managing competing issues post treatment, including psychological distress and financial stress limited compliance with preventive oral hygiene behaviours and engagement with professional dental services.

Employing such a broad perspective has enabled the identification and discussion of the range of factors affecting oral health within a single context. A more holistic view has highlighted the multiple points where difficulties in managing oral health emerge, at both the individual and the structural levels. Exploration of such factors may assist in identifying circumstances or attitudes that place individuals at higher risk of poorer oral health post treatment. A lack of social support, difficulty in adjusting to disease outcomes and financial stress appear to be the most salient factors identified by this study.

Self-efficacy emerged as a strong theme that influenced home care and also utilisation of dental services. Studies of oral health behaviour among the general population have found self-efficacy to predict oral health behaviours200-202 with lower self-efficacy correlated with dental neglect203.

The results suggest that oral health behaviour change post HNC requires more than possessing the knowledge and strong self-efficacy to engage in oral hygiene practices. Needing to manage a range outcomes including functional recovery, ongoing medical appointments and financial problems were issues that required the reprioritisation of oral health. Psychological distress also negatively affected the capacity to self-manage oral health needs. HNC patients experience among the highest rates of major depressive disorder of all oncology patients40. Depression has implications for lower quality of life, impaired immune function, longer hospital stays and reduced self-care abilities40. Higher rates of distress are reported towards the
end of treatment, however may persist into survivorship for a minority of patients\textsuperscript{40,204}.

Qualitative studies of health behaviour change following HNC have described central themes of empowerment, productiveness and the ability to motivate oneself to manage the psychological and physical difficulties as a result of treatment\textsuperscript{205,206}. A focus group study involving HNC survivors identified that emotional state was an important facilitator for engaging in health promoting behaviours, particularly the ability to stay optimistic and positive in the face of treatment side-effects and functional difficulties\textsuperscript{206}. The importance of a positive attitude and problem focussed and meaning focussed coping to adjust to changes to the mouth are highlighted in other research forming part of this thesis\textsuperscript{155}. This suggests that emotional outcomes may both positively and negatively affect self-care behaviours, including oral health.

While not designed to investigate this factor, spousal support in this study appeared to have a positive influence on oral health behaviours, specifically in supporting comprehension, problem solving and in some cases acting as a referral pathway to oral health services. The close bond between participants and spouses was clear, and some participants raised that their spouses had been present at each step of the treatment and recovery process, and therefore should be present for the interview as well. This added to the depth of data gained during the interviews, as spouses reminded participants of missed issues or experiences. Specific questions regarding the role of spouses or other caregivers in supporting oral health were not asked of participants who were interviewed independently. As a result this finding should be approached with caution and regarded as an area requiring future research. Future study designs that involve the collection of data separately from patients and spouses may enable greater understanding of the role that spouses play in supportive oral health care and offer greater understanding of how this potentially influences patient behaviours and experiences.

Among the literature, higher perceptions of social support are associated with increased quality of life and better mental health\textsuperscript{207}, and single males experience poorer survival outcomes and performance status compared to partnered males, and
either single or partnered females. However, the role of spousal support as a buffer to unmet information needs and barriers to accessing oral health care may not be straightforward. Not all spouses may be capable or wish to perform this role and there are additional problems with patients who lack this type of close support. HNC causes disruption to the lives of both patients and caregivers, and may result in unmet needs, increased caregiver distress and relationship challenges. Thus, post-treatment oral health information to be delivered in a patient-centred manner and requires a system that is responsive and tailored to individual circumstance, including the desired involvement of spouses or caregivers. This also includes offering a follow-up appointment with the same practitioner or clinic that offered the advice to review compliance and meet the needs of patients who do not fully comprehend the post-treatment care requirements.

Oral diseases occur along a social gradient, whereby those experiencing socioeconomic disadvantage also experience a higher burden of health problems including dental decay and periodontal diseases. Oral health disparities mirror the differences in general health outcomes based on socio-economic status and are partly due to lifestyle risk factors, (e.g. tobacco and alcohol consumption, dietary factors) but also due to less frequent utilisation of dental services. In regards to HNC, socio-economic status is also linked to increased disadvantage in survival and performance outcomes. A striking contrast emerged in this study between the experiences of participants who could financially afford to promote their oral health, compared to those who could not. Some people coped very well and described their oral health as better than ever, while others experienced ongoing problems with tooth decay and infection. Although the latter group represented a smaller proportion of participants, it does suggest that the existing disparities in oral health status are amplified by the outcomes of HNC in terms of financial status and ongoing psychological impact of the disease.

The findings have highlighted structural factors that further influenced participants' ability to maintain oral health. Unacceptable waiting times for general examination and preventive appointments was a commonly identified barrier to seeking care through public dental clinics, and indicate that the availability of services through
publically funded clinics does not meet the increased preventive care requirements of HNC patients post treatment.

A surprising finding was the lack of continuity of care between pre- and post-treatment dental services for participants who sought care through the private sector. Uncertainty about where to find oral health services that met the perception of higher needs caused feelings of unease for some participants. This belief about needing specialised oral health services after treatment may have been influenced by the oral health information provided pre-treatment and also the context of the highly specialised medical and allied health management of HNC. Establishing a network of dental practitioners with the expertise to care for patients who have received radiotherapy of the head and neck region may alleviate these issues and may foster a sense of trust between patients and practitioners, especially in instances where there is history of distrust of health practitioners due to diagnostic delay.

There were aspects of the study design that potentially influenced the findings. Data was gathered from a single interview and particularly for those participants with more recent experience of HNC, this limited the study’s ability to explore factors that may have changed over time within each participant’s circumstance. The maximum variation sampling enabled description of experiences at various points along the treatment and recovery trajectory, however longitudinal explorations of oral health following HNC treatment are needed. The interview guide was designed to capture multiple issues that affected oral health and access to care and also to be administered in a fast-paced oncology clinic setting. This meant that there was limited capacity to engage in theoretically guided analysis or a deeper exploration of the themes within the social or environmental context of an individual. The findings of this study should be investigated further by qualitative studies from a psychological and sociological perspective. The study design and sampling approach yielded a high participation rate and is a strength as it enabled the inclusion of participants with a range of oral health outcomes. However, the study findings reflect the experiences of participants and therefore may not be generalisable to the wider HNC population.
The timing and setting of the interview may also have influenced the findings. The participants were overwhelmingly positive about the high quality of treatment received at the maxillofacial clinic and this may have translated to the positive feelings about self-efficacy to manage oral health outcomes. Additionally, the maxillofacial clinic was a source of information about oral health, which may have affected perceived needs.

A majority of participants of this study received surgery as part of the treatment approach. Surgery increases the risk of loss of sensory and musculature function and this may have influenced the findings of motivation to frequently clean the mouth and teeth. The motivations to promote oral health for people who are treated by nonsurgical approaches may differ from those presented here, and should be investigated further.

### 6.5 Conclusion

Oral health is complicated after HNC and may be influenced by a number of factors relating to a person’s medical, social, and financial circumstance. The potential influence of competing priorities on the reprioritisation of oral health requires further investigation in the context of other self-care behaviours following treatment. The ability to self-fund dental care appears to be an important factor in enhancing compliance with oral health maintenance recommendations. The structural factors that limited access to dental services may be addressed through professional education and establishing a referral network between hospital dental oncology services and public and private sector dental practitioners; and establishing policy initiatives that integrate dental care into medical and allied health follow-up services. Additionally, the eligibility requirements to receive dental care through the public health dental services require revision, as do the lack of services available for ongoing general and preventive dental care. Future research is required to explore access to dental care from a health service provider and health practitioner perspective as well as potential differences between oral health services in different jurisdictions or countries.
Chapter 7
General discussion
Chapter 7: General discussion

7.1 Discussion of findings in relation to overall thesis aims

This thesis aimed to explore changes to perceived oral health following head and neck cancer (HNC) treatment, and identify the supportive care needs and quality of life (QoL) implications that arose across the HNC trajectory. The findings described support needs and QoL in a broad sense and included a discussion of the environmental, social and individual factors that influence QoL and perceived need for supportive care. This was complemented by findings of subsequent chapters that described oral health outcomes and needs in the context of other changes to physical, emotional and social wellbeing that occurred after treatment for HNC. Thus, the thesis has contributed to the limited literature describing oral health and how individuals appraised and coped with their experience of oral health in the context of general wellbeing and QoL.

The mixed methods approach to exploring oral health, QoL and supportive care needs is novel and complements the existing body of literature that has described QoL using structured questionnaires. Furthermore, this approach enabled the identification of psychosocial issues that affected capacity to engage in oral health care. It also examined the role of individual cognitive factors such as appraisal and motivation in shaping oral health behaviours and perceived impact of outcomes on QoL after treatment. This framework has not previously been applied to oral health. A range of oral symptoms and side effects were raised through the findings in addition to the influence of oral health issues on general health outcomes, for example sleep disruption caused by oral pain and xerostomia. The reappraisal of the threat of oral symptoms over time is an additional novel finding and one of significance that should be addressed by future research in this area.

The thesis findings suggest that at a cognitive, behavioural, social and structural level, oral health care needs for people treated for HNC are complex and wide ranging. These needs and the extent to which they are met are profoundly influential on an individual’s wellbeing and experience of their life after cancer.
A detailed discussion of the findings, strengths and limitations of each of the studies of this thesis is included in each chapter, therefore this section will address the overall thesis findings and its contribution to further understanding of oral health, QoL and supportive care needs after HNC.

**Cognitive appraisal and its relationship to perceived QoL**

The cognitive appraisal process is a core construct of the stress, appraisal and coping theory. This theory was applied as a framework to understand QoL perceptions and perceived supportive care needs in Chapter 2, and to understand adjustment to changed oral health in Chapter 5. A finding common to both studies was the reappraisal of the threat to overall wellbeing posed by chronic outcomes of treatment, such as xerostomia. Over time, the threat of oral symptoms was downgraded as participants described problem-focused coping strategies and acceptance of a ‘new normal’ in oral health and function. Across both chapters, participants favoured the use of social-seeking, problem and meaning focussed coping responses and described strong social support networks, which are likely to have contributed to the positive outcomes described.

In Chapters 3 and 4, changes in QoL were measured prospectively over the first six months following diagnosis and treatment. The pattern of symptom change over time mirrored the results of other longitudinal studies of symptom experience and QoL. QoL deteriorated and there was more difficulty with symptoms at one-month post treatment compared to before treatment, and QoL scores and symptom issues improved across most domains between one-month and six-month measurements. However, responses to some domains (HRQoL before cancer and HRQoL over the past 7 days) at six months post treatment exceeded the mean scores at baseline. The potential influence of attrition on these findings is discussed in Chapter 3, however when considered alongside the qualitative findings in Chapter 4, they suggest a more complex relationship between individual quality of life perceptions and their measurement. Chapters 5 and 6 described the influence of cognitive factors on the adjustment to oral health outcomes and a shift towards increased engagement in self-care and oral health promoting behaviours. Therefore, cognitive
Chapter 7: Discussion and recommendations

Appraisal appears to be an important factor that influenced quality of life evaluations, perceived supportive care needs and additionally contributed to oral health behaviour change.

Quality of life is a dynamic and highly subjective construct and as part of this dynamic process, the terms of reference one uses to judge his or her quality of life constantly change\textsuperscript{212}. Schwartz and Rapkin\textsuperscript{213} argue that ‘all quality of life assessment involves some degree of cognitive appraisal,’ however note that most evaluative QoL scales lack the capacity to measure appraisal. The findings of this thesis support this argument and are highlighted by the additional factors identified from open-ended responses to the UW-QoL described in Chapter 4. Some respondents described how QoL was negatively affected by experiencing unexpected or difficult to manage side effects, or conversely, QoL was improved due to a renewed appreciation for social support.

The differences in QoL assessment between people and the dynamic process of QoL appraisal over time is explained by a response-shift phenomena\textsuperscript{213}. Changing evaluations may result from a change in internal standards of measurement, a change in the values regarding the relative importance of the component, or redefinition of the meaning of QoL itself\textsuperscript{213}. Certainly, receiving a cancer diagnosis is a life-altering experience and may result in the re-evaluation of QoL and the relative importance of domains that contribute to its appraisal. With regard to HNC, this change in appraisal may be even more pronounced, due to the almost total loss of function that often occurs as a result of treatment. The slow recovery process and adjustment by focusing on the establishment of a ‘new normal’ of baseline functioning may be conceptualised by a new frame of reference for QoL evaluations to be made. This is likely to underpin the appraisal of chronic outcomes affecting the oral cavity, such as xerostomia, as a mere ‘frustration’ and less of a threat to overall QoL. The memory of previous threatening experiences during treatment, for example periods of time where no solids or liquids could be consumed by mouth, inability to sleep or reliance on a PEG tube may reinforce these new benchmarks for QoL.
The differences in QoL appraisal and evaluation between people, and over time, call into question the relevance of using global QoL or HRQoL scores to guide clinical counselling or to act as indicators of treatment effectiveness. This is not to dispute the relevance of objective and subjective measures of symptom burden; rather reinforces that QoL is different for each patient, both in the wide determinants and cognitive processes involved in how each respondent will decide which score represents their own QoL.

**Quality of life appraisal and its relationship to the communication of supportive care needs**

The cognitive appraisal process is also likely to influence the perception and communication of supportive care needs. Perceived needs for supportive care may be downplayed in response to gratitude for survival and the uncertain landscape of symptom and function recovery post treatment. Successful communication of supportive care needs involves an appraisal of the requirement for care from the patients’ perspective and also the opportunity to for those needs to be effectively heard and managed by health practitioners. From an appraisal point of view, a lack of knowledge about expected recovery timeframes and usual care pathways may inhibit a patient’s ability to clearly identify their needs and subsequently seek care. There is, therefore, a greater onus on health care practitioners to establish open communication and deliver information specific to each patient’s circumstance and screen for unmet needs. As discussed in Chapter 4, the format of supportive care screening warrants attention, as different modes of assessment may yield different responses. The thesis findings suggest that a combination of open-ended and structured responses may be beneficial; and strike a balance between informing patients of expected outcomes and issues and offering individual flexibility in responses.

A difference in expectations for rehabilitation between HNC survivors, family members and health care professionals was identified by a recent qualitative study. A lack of knowledge of rehabilitation options, as well as feelings of not wanting to nag, or happiness for being alive, were barriers to engaging in
rehabilitative services described by survivors\textsuperscript{172}. In the context of this thesis, a combination of patients not wanting to appear ungrateful and also a general lack of awareness around oral health supportive care options, resulted in an internalised management of oral health needs. As an example, during the interview process a number of participants posed questions to the interviewer and PhD candidate (KP, an oral health therapist) surrounding their dental product use. Where appropriate, advice was offered, but participants were also advised to consult their managing dental practitioner with these questions. This suggests that greater communication is required between health practitioners and patients regarding symptomatic management of oral health, both in the dental surgery and hospital setting.

7.2 Methodological reflections and implications for future research

Research involving supportive care and quality of life following HNC is a highly emotive area, as it involves asking participants to reflect on an extremely difficult time in their lives. Subsequently, there are likely to be a large proportion of people who are unwilling talk about their experiences, which may make conducting qualitative research difficult. Additionally, and conversely, during some interviews it was observed that participation in the research represented a rare opportunity for a participant to talk about issues faced during treatment. Many participants used the opportunity to divulge other important information relating to their supportive care needs that were outside the research question. At times this was difficult to keep interviews to time and also focused on the interview guide.

Participation in this research as an outlet for patients to express concerns was also observed in the responses to the quantitative QoL study in Chapter three. In addition to completed surveys, letters were returned that detailed experiences or concerns that affected quality of life more broadly, or explained reasons for declining or discontinuing treatment. In one case, a letter was received outlining the unsatisfactory living conditions in hospice care as a reason for discontinuation of radiotherapy. This presents a dilemma for researchers in the field when handling data, and creates a need to distinguish between what is related to the research question and what is extraneous information in this regard.
A limitation inherent to this field of research is the limited generalizability of the results to the entire population and certainly, this was a limitation described throughout the present thesis work. In addressing some of the limitations in sample size outlined in Chapters two and five, interviewing participants after their review appointment was a successful approach to improving the sample size of Chapter six. Many participants involved in Chapter six indicated that they were happy to volunteer their time to assist a graduate student and also to improve the treatment and recovery process for future patients. However this approach is suited to shorter interviews with a semi-structured instrument and therefore limited in the type of analysis that may be conducted. In progressing research in this area, some methodological modifications are necessary. From a qualitative standpoint, offering flexibility in the form of data collection may assist in participation. Offering an opportunity for written data in addition to interviews may assist, and include the use of different modes of written responses (e.g. using both paper-based and electronic versions). This approach also reflects a need for future qualitative research in this area to extend beyond semi-structured interviews, face to face interviewing and thematic data analysis. Approaches such as auto-ethnography or illness narratives may be appropriate and build on the findings of the existing literature in this area.

To enhance the collection of prospective quantitative data, the high attrition rate is the area perhaps requiring the most immediate attention. Observations from this thesis were that a greater response was achieved by approaching participants to complete follow up questionnaires in person when attending a clinic appointment, as compared to completion via post. While this may increase retention in prospective studies, it requires dedicated time on a researcher’s behalf, particularly if the sample is recruited across varying specialty clinics.

7.3 Policy implications

The following policy implications reflect the main thesis findings of the importance of the cognitive appraisal process to overall adjustment to the outcomes of disease treatment (and therefore reappraisal of the threat of chronic outcomes to overall
wellbeing), and the need for more integrated oral health and medical care. Initiatives aimed at influencing or supporting the cognitive appraisal process may have positive outcomes for both overall quality of life and also oral health related quality of life and oral health promoting behaviours.

1. **Initiatives to support individual adjustment to outcomes through peer support**

The thesis findings suggested support from social networks facilitated positive adjustment to chronic outcomes of treatment. Meaningful engagement with social and peer support networks may enable information sharing about practical aspects of daily living and provide support for coping with cancer. There is a need to increase the accessibility of peer and social support networks for individuals who may otherwise lack these. In the Australian context, a multi-platform delivery involving both face-to-face and online modes of peer support may increase the reach of programs to people who are geographically isolated or who choose not to participate in face-to-face support group meetings. Future research should involve exploration of the use of online forums or communities to provide peer support and investigate the potential integration of online peer support programs into existing supportive care services.

2. **Ongoing psychosocial screening and support**

Although this thesis primarily focused on oral health and associated support needs, participants frequently raised a need for greater psychosocial support. The absence of psychological support at critical times and the ramifications for overall coping and QoL were highlighted throughout the thesis findings. This is likely to reflect a broader need for psychological support among the general HNC population. Recent Australian guidelines recommend routine screening for distress at key points of the HNC care pathway. The requirement for ongoing dental examination and preventive care means oral health practitioners should have ongoing contact with HNC patients post-treatment. Therefore, oral health practitioners should be trained in the screening of distress and to feel confident in referring to appropriate services.

3. **The integration of medical and oral health services**
Chapter 7: Discussion and recommendations

Access to dental services post-treatment was an issue identified by the thesis findings. Oral health is integral to general health and there is overwhelming evidence to support this statement from a biological, nutritional and social standpoint. However the structure of the Australian health care system does not reflect the close relationship between oral health and general health. There is a need to integrate oral health services into cancer care including in the hospital setting and this could be achieved by the following initiatives:

3a) Oral health clinicians as part of the allied health team
This thesis found a lack of integration between oral health patient reviews and medical and allied health review appointments post HNC treatment, in the hospital setting. This resulted in multiple appointments at various locations and for some participants, meant that oral health care was deprioritised in favour of medical appointments. This may be addressed by a greater availability of dental services on-site, and further integration of dental professionals into the multidisciplinary team. The oral health therapist (OHT) and dental hygienist (DH) workforce is skilled in preventive oral health care and therefore well positioned to perform this role, yet is currently underutilised in the Australian health care setting. This is despite the routine involvement of DH in oncology care in countries such as the United States of America. Greater involvement of OHT/DH in the hospital setting may improve access to oral health information and assessment for people who may experience difficulty in organising this care independently. In Australia, OHTs and DHs work in a structured professional relationship with a dentist. This supports the capacity for OHTs and DHs to be used in a screening role, and therefore to identify oral problems and refer where necessary for management to other members of the dental team.

3b) Education and establishment of referral networks
There is a need to build the capacity of the dental workforce to manage the needs of HNC patients. One strategy to achieve this is through the education of general dental practitioners, and the establishment of a network of clinicians with the interest and expertise to manage people following HNC treatment. The formation of a referral network is likely to assist both consumers and practitioners and enhance
communication between medical and dental practitioners to manage oral health needs in complex medical cases.

3c) **Enhanced access to public dental services for all HNC patients**

The ability to fund private dental care may change over the survivorship trajectory. Currently, in the local context, patients who hold a health-care card, pension card, or other eligibility for publicly funded dental care are placed on waiting lists that exceed the recommendations for frequency of dental care post treatment. Alternatively, if people do not meet the eligibility criteria for publicly funded treatment, yet experience financial disadvantage, professional care may be altogether inaccessible. Policy initiatives that enhance the ability for all patients treated for HNC to access the quality and frequency of dental care they require are necessary. Strategies may include the establishment of a separate or expedited recall list for people who have received treatment for HNC and a widening of the public oral health services eligibility criteria to include all patients treated for HNC, irrespective of health care card or pension card status.
7.4 Recommendations for future research

This thesis has identified a number of directions for future research. This body of work represents one of the few mixed-method contributions to the literature in HNC. As such, the findings may be conceptualised as a foundation of evidence that should be built on by future studies. The finding that cognitive reappraisal influenced perceived QoL, supportive care needs and a contributed to oral health behaviour change may have important implications for future research and outcomes in this field. While this is an important finding in the context of this thesis, further research should be directed at empirical data collection and critical analysis to investigate the role of the appraisal process role more broadly. If future studies support the finding of this research, it may lead to the development of supportive care interventions that address constructs of appraisal and coping as a means to improve QoL post treatment.

There is a need for future research in this area to further explore QoL and the influence of social identity, roles and social support systems. A particular focus should be on influence of medical and socio-environmental determinants that may predispose individuals to greater supportive care needs and reduced quality of life. Shifting away from a biomedical paradigm and exploring QoL and its determinants through a broader, sociological lens will strengthen this field of research and its application to the individual. There is also scope to explore the finding surrounding the influence of the cognitive appraisal process on the ability to perform self-care in a cross-disciplinary setting. For example, future research may explore the influence of this process on patients’ adherence to self-care activities that support speech and swallowing rehabilitation, and identify common factors or determinants of self-care behaviours.

Future research surrounding the structure and delivery of integrated health services is required, and should focus on integration of medical, allied health and oral health services, and also service delivery in regional areas. In the local context, a teleoncology model of service delivery has improved access to specialised allied health follow-up care for patients living in regional areas\textsuperscript{131}. Exploration of the
potential of a ‘teledentistry’ model of assessment and triage is required, and how this may be integrated into existing service models.

The thesis findings suggested that financial eligibility, service availability and the quality and appropriateness of dental care services influenced access to oral health care. The investigation of these findings on a wider scale is required and should address the potential influence of state-based differences in oral health service provision, and health services utilisation in regional and remote areas. While there is a push for research to be applicable on a global scale, there are factors unique to the Australian setting that justify a national approach. The thesis findings are positioned from a patient’s perspective and there is a need to also explore access to oral health care from a health systems and policy context.
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Appendix 1: Systematic review search strategies adapted for each data base (other than pubmed)

CINAHL

2. Support need*
3. Exp/ Mouth Neoplasm
4. ((Mouth OR Oral) AND (cancer* OR malignan* OR carcinoma* OR tumor OR tumour OR neoplasm*))
5. Exp/ Quality of Life
6. “Quality of life” OR “health related quality of life” OR QoL OR HRQOL OR “lived experience”
7. #1 OR #2
8. #3 OR #4
9. #5 OR #6
10. #7 AND #8 AND #9

Embase

1. Exp/ Financial Management OR Exp/ Nutritional Support OR Exp/ Psychosocial Care OR Exp/ Social Support
2. Support need OR social support
3. Exp Mouth Cancer OR Exp/ Mouth Tumor
4. ((Mouth OR Oral) AND (cancer* OR malignan* OR carcinoma* OR tumor OR tumour OR neoplasm*))
5. Exp/ Quality of Life
6. “Quality of life” OR “health related quality of life” OR QoL OR HRQOL OR “lived experience”
7. #1 OR #2
8. #3 OR #4
9. #5 OR #6
10. #7 AND #8 AND #9
1. Support need* or social support
2. Exp/ Support Groups OR Exp/ Social Support
3. ((Mouth OR Oral) AND (cancer* OR malignan* OR carcinoma* OR tumor OR tumour OR neoplasm*))
4. Oral Cancer
5. Exp/ Quality of life OR Exp/ Well being
6. “Quality of life” OR “health related quality of life” OR QoL OR HRQOL OR “lived experience”
7. #1 OR #2
8. #3 OR #4
9. #5 OR #6
10. #7 AND #8 AND #9
Appendix 2: Semi-structured interview guide, head and neck cancer support group

Semi-structured interview schedule – Past patients

Participant: 
Venue: 
Time: 

- Questions today will relate to cancer treatment and experience, and how it has influenced your quality of life. We will also be talking about the support needs you may have experienced in the past, or may still experience.

- Confidential interview. You or anyone mentioned will not be identifiable in the research.

- I’d like to record the interview as well, to make sure I don’t miss anything you say.

- Welcome to stop the interview or take a break at any time.

Do you have any questions before we begin?

.................

We’ll start by going over some background questions

- What type of cancer were you diagnosed with?
  o How old were you when you were diagnosed?
  o In what year were you diagnosed?
  o What type of treatment did you receive?

Quality of life questions

How would you describe your overall quality of life currently?

How does this differ from when you were newly diagnosed and undergoing treatment?

How would you describe the physical effects of treatment and their impact on your quality of life?
  - Oral/dry mouth? Taste?

How would you describe the mental aspects and their impact on your quality of life?
  - Were you offered counselling support during treatment?

Were you prepared for the effects that radiation/chemotherapy/surgery would have on you?
**Support needs questions:**

Thinking about your day-to-day life now, how would you describe your current support needs?

- How do these influence your quality of life?
- Are these needs being met?
- Where or who do you draw support from to meet these needs?

I’d like to know some more about your support needs while you were undergoing treatment. What were your biggest support needs at:

- Diagnosis
- While undergoing treatment
- After treatment was completed?
- Were these support needs met? How?
- Where did you draw support from while undergoing treatment?
- Was there anyone or any health professional you felt you didn’t have access to when you should have?

How could you have been better supported during your treatment?

Thank you, that brings us to the end of my questions. What should I have asked you that I didn’t ask?
Appendix 3: University of Washington Quality of Life Questionnaire, version 4

Name:
Date:

University of Washington Quality of Life Questionnaire (UW-QOL)

This questionnaire asks about your health and quality of life over the past seven days. Please answer all of the questions by checking one box for each question.

1. Pain. (Check one box: ☑)
   - I have no pain.
   - There is mild pain not needing medication.
   - I have moderate pain - requires regular medication (codeine or nonnarcotic).
   - I have severe pain controlled only by narcotics.
   - I have severe pain, not controlled by medication.

2. Appearance. (Check one box: ☑)
   - There is no change in my appearance.
   - The change in my appearance is minor.
   - My appearance bothers me but I remain active.
   - I feel significantly disfigured and limit my activities due to my appearance.
   - I cannot be with people due to my appearance.

3. Activity. (Check one box: ☑)
   - I am as active as I have ever been.
   - There are times when I can't keep up my old pace, but not often.
   - I am often tired and have slowed down my activities although I still get out.
   - I don't go out because I don't have the strength.
   - I am usually in bed or chair and don't leave home.

4. Recreation. (Check one box: ☑)
   - There are no limitations to recreation at home or away from home.
   - There are a few things I can't do but I still get out and enjoy life.
   - There are many times when I wish I could get out more, but I'm not up to it.
   - There are severe limitations to what I can do, mostly I stay at home and watch TV.
   - I can't do anything enjoyable.
5. **Swallowing.** (Check one box: ☑)
- ☐ I can swallow as well as ever.
- ☐ I cannot swallow certain solid foods.
- ☐ I can only swallow liquid food.
- ☐ I cannot swallow because it "goes down the wrong way" and chokes me.

6. **Chewing.** (Check one box: ☑)
- ☐ I can chew as well as ever.
- ☐ I can eat soft solids but cannot chew some foods.
- ☐ I cannot even chew soft solids.

7. **Speech.** (Check one box: ☑)
- ☐ My speech is the same as always.
- ☐ I have difficulty saying some words but I can be understood over the phone.
- ☐ Only my family and friends can understand me.
- ☐ I cannot be understood.

8. **Shoulder.** (Check one box: ☑)
- ☐ I have no problem with my shoulder.
- ☐ My shoulder is stiff but it has not affected my activity or strength.
- ☐ Pain or weakness in my shoulder has caused me to change my work.
- ☐ I cannot work due to problems with my shoulder.

9. **Taste.** (Check one box: ☑)
- ☐ I can taste food normally.
- ☐ I can taste most foods normally.
- ☐ I can taste some foods.
- ☐ I cannot taste any foods.

10. **Saliva.** (Check one box: ☑)
- ☐ My saliva is of normal consistency.
- ☐ I have less saliva than normal, but it is enough.
- ☐ I have too little saliva.
- ☐ I have no saliva.
11. **Mood.** (Check one box: ☑)
   - My mood is excellent and unaffected by my cancer.
   - My mood is generally good and only occasionally affected by my cancer.
   - I am neither in a good mood nor depressed about my cancer.
   - I am somewhat depressed about my cancer.
   - I am extremely depressed about my cancer.

12. **Anxiety.** (Check one box: ☑)
   - I am not anxious about my cancer.
   - I am a little anxious about my cancer.
   - I am anxious about my cancer.
   - I am very anxious about my cancer.

Which issues have been the most important to you during the past 7 days?
**Check up to 3 boxes.**

- Pain
- Appearance
- Activity
- Recreation
- Swallowing
- Chewing
- Speech
- Shoulder
- Taste
- Saliva
- Mood
- Anxiety

**GENERAL QUESTIONS**

**Compared to the month before you developed cancer,** how would you rate your health-related quality of life? (Check one box: ☑)

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

In general, would you say your health-related quality of life during the past 7 days has been? (Check one box: ☑)

- Outstanding
- Very good
Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being, rate your overall quality of life during the past 7 days. (Check one box: ☑️)

- Outstanding
- Very good
- Good
- Fair
- Poor
- Very poor

Please describe any other issues (medical or nonmedical) that are important to your quality of life and have not been adequately addressed by our questions (you may attach additional sheets if needed).
Appendix 4: Semi-structured interview guide, oral health six months post treatment

Oral health related support needs and quality of life
Semi structured interview schedule

Name: Date:

Research questions:

a) How does changed oral health and function impact on overall wellbeing?
b) How have patients coped with changed oral health since treatment?
c) What support do people need to improve their coping potential in managing the oral health related side effects of treatment?

Interview schedule

1. Background questions

a) Type of treatment received
   - Chemotherapy
   - Radiotherapy
   - Surgery
   - Experience with treatment

2. Influence of oral health on QoL (stressor and appraisal process)

a) Have your mouth/teeth been affected by treatment? If so, how?
   - taste
   - chewing
   - problems with saliva or dry mouth
   - teeth taken out
   - Pain
   - Other?

Have these issues affected your QoL?
   - Discuss acute vs chronic effects and influence they have on wellbeing.

3. Coping with changed oral health (coping preferences)

a) How did you cope with the changes to your mouth as a result of treatment?
   - Discuss acute treatment period vs post treatment period.
c) When you had a problem with your mouth, what did you do?

b) Where did you look for information?
   - Explore support networks, professional/peer/other sources of information

4. Perceived support needs

a) Were there any gaps in information you needed about your oral health during or after treatment? - Did you need more help with managing the side effects?

b) In an ideal world, what kind of services or support do you think would be helpful in managing your oral health:
   - During treatment
   - After treatment

c) Looking ahead, what support do you need in looking after your teeth and mouth in the future?

5. Role of dentist/oral health therapist in managing oral health after treatment (perceived role).

a) Before treatment, did you regularly visit a dentist or dental hygienist?

b) Have you seen a dentist or dental hygienist since you finished treatment?
   - If yes, what is their involvement in your care? Has this met your needs?
   - If no, why? How can seeing a dentist or hygienist be made easier for you?
   - What have you been told to do to look after your mouth and teeth post treatment?
Appendix 5: Semi-structured interview guide, maintaining oral health and access to dental care post treatment

Oral health and access to dental care following head and neck cancer treatment

Semi-structured interview schedule & demographic form

Participant name:
Interview date:
Interview details:

Part 1: Participant demographic form

In order to learn about the range of people taking part in this research we would be grateful if you could answer the following questions. All information is confidential. Please either write your answer in the space provided or ticking the answer that best applies to you.

<table>
<thead>
<tr>
<th></th>
<th>What is your age?</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>What is your gender?</td>
</tr>
<tr>
<td>3</td>
<td>What is your postcode?</td>
</tr>
<tr>
<td>4</td>
<td>What is your marital status?</td>
</tr>
<tr>
<td>5</td>
<td>Do you hold a concession or pension card?</td>
</tr>
<tr>
<td>6</td>
<td>Do you wear a prosthesis or denture?</td>
</tr>
</tbody>
</table>

If yes, please specify:

7 Please provide details of your treatment, including year completed:

8 Please provide details of your cancer type and location:
Part 2: Interview guide

- **To start, I'd like to know more about how cancer treatment has affected your mouth**
  - How has your mouth changed since treatment? Has this affected your quality of life?
  - Do you have any current problems with your mouth? Or teeth?
  - How do you think people need to be supported in looking after their mouth following HNC?

- **Oral hygiene**
  - What do you currently do to care for your mouth? E.g toothbrushing, flossing, rinses, gels.
  - Has this changed from your routine prior to treatment?
  - Where did you find information about caring for your mouth/teeth post treatment?
  - What information was most helpful to you?
    - Do you feel you need more information?

- **Previous experiences with dental care**
  - How do you feel about seeing the dentist?
  - How often do you normally visit the dentist?
    - Do you have a dentist or clinic that you normally visit? Public or private?
    - Do you see a hygienist as well?
    - When was the last visit and what was the nature of the visit?
    - Were you satisfied with the care that you received?
  - Do you think people you need more specialised dental treatment after HNC? (compared to general population)
  - How often do you think people treated for HNC should be seen by a dentist/hygienist?

- **Barriers to access**
  - Is there anything that makes it difficult or stops you from visiting a dentist when you need to?
    - Cost
    - Location
  - At your usual dental clinic are there appointments available when you need them? For toothache, general concerns, preventive questions or needs?

How could access to dental care be improved for people after HNC treatment?

What advice would you give to dentists or hygienists about meeting your dental care needs?

- **That wraps up all the questions I have for you, is there anything I have missed that you would like to add?** Is there anything you wanted to ask me?
## Appendix 6: Theme, sub-theme and coding structure – oral health behaviours and utilisation of dental care results

<table>
<thead>
<tr>
<th>Individual determinants of oral health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key theme:</strong> Cognitive shift towards life-long oral health</td>
</tr>
<tr>
<td><strong>Behavioural outcomes</strong></td>
</tr>
<tr>
<td>Avoid denture-too much cleaning</td>
</tr>
<tr>
<td>avoid snacking-annoying to clean teeth</td>
</tr>
<tr>
<td>comply with recommendations</td>
</tr>
<tr>
<td>Frequency of oral care</td>
</tr>
<tr>
<td>No problems with mouth or teeth</td>
</tr>
<tr>
<td>Non consent-exo, implant placement</td>
</tr>
<tr>
<td>OH improved</td>
</tr>
<tr>
<td>strict routine around oral health</td>
</tr>
<tr>
<td><strong>Enabling factors</strong></td>
</tr>
<tr>
<td><em>Spousal support</em></td>
</tr>
<tr>
<td>force eating</td>
</tr>
<tr>
<td>Force socialisation</td>
</tr>
<tr>
<td>oral health literacy</td>
</tr>
<tr>
<td>'we'</td>
</tr>
<tr>
<td><em>Timing of pre-tx education</em></td>
</tr>
<tr>
<td>Carer education essential</td>
</tr>
<tr>
<td>during tx-unable to examine teeth</td>
</tr>
<tr>
<td>Needed more discussion about OH post tx</td>
</tr>
<tr>
<td>pre-tx limited ability to comprehend info</td>
</tr>
<tr>
<td>pt in shock</td>
</tr>
<tr>
<td><strong>Motivating factors</strong></td>
</tr>
<tr>
<td>always looked after teeth</td>
</tr>
<tr>
<td>benefit-retaining teeth</td>
</tr>
<tr>
<td>changed outlook on life</td>
</tr>
<tr>
<td>healthier lifestyle</td>
</tr>
<tr>
<td>struggle with motivation to eat</td>
</tr>
<tr>
<td><em>symptom cue</em></td>
</tr>
<tr>
<td>Make up for lost function</td>
</tr>
<tr>
<td>uncomfortable not to care for mouth</td>
</tr>
<tr>
<td><em>threat</em></td>
</tr>
<tr>
<td>@ higher risk of decay</td>
</tr>
<tr>
<td>Influenced by pre-tx education</td>
</tr>
<tr>
<td>Threat-can’t lose any teeth</td>
</tr>
<tr>
<td><strong>Competing priorities</strong></td>
</tr>
<tr>
<td><em>Financial stress</em></td>
</tr>
<tr>
<td>Limits product choice</td>
</tr>
<tr>
<td>Limits social eating</td>
</tr>
<tr>
<td>unable to replace teeth</td>
</tr>
</tbody>
</table>
Negative efficacy beliefs
  low confidence to remain decay-free
  unable to maintain OH long-term

Other priorities
  post surgery

Outcomes
  delayed-avoided dealing with OH problems
  no enjoyment in eating post tx
  social isolation

Poor coping or adverse psych outcomes
  disappointment-self blame
  traumatic tx experience
  unsure if going to survive

Key theme: management of unexpected barriers

Barriers to compliance
  dental products expensive
  lip incompetence-mouthwash
  medicament trays-discomfort
  need specialised products
  numbness-increased concentration
  product availability
  Products burn mouth
  teeth tender to pressure
  worry cleaning will damage tissue

Self-efficacy
  Ask questions of specialists
  change diet
  confident in eating socially
  Confident in home care ability
  self-manage barriers to OH
  will make the time for dental care

Key theme: Ability to fund OH care

Barriers
  Cost
    loss of income post tx

Enabling
  able to afford private dental care
  Income-disability insurance coverage
  private health insurance
  redundency package
<table>
<thead>
<tr>
<th>Structural factors affecting oral health care utilisation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key theme: Location and availability of services</strong></td>
</tr>
<tr>
<td><strong>Private dentistry</strong></td>
</tr>
<tr>
<td>convenient</td>
</tr>
<tr>
<td>low fees</td>
</tr>
<tr>
<td>Cost - implant-retained bridge</td>
</tr>
<tr>
<td>differing TP</td>
</tr>
<tr>
<td><strong>Public dentistry</strong></td>
</tr>
<tr>
<td>wait to be seen</td>
</tr>
<tr>
<td>reduced autonomy</td>
</tr>
<tr>
<td>quality of care improved after cancer</td>
</tr>
<tr>
<td>no direct follow up plan</td>
</tr>
<tr>
<td>lack of treatment choice</td>
</tr>
<tr>
<td>public dental care-time consuming</td>
</tr>
<tr>
<td>lack of consistency</td>
</tr>
<tr>
<td>inconvenient location</td>
</tr>
<tr>
<td>gratitude for tx through public system</td>
</tr>
<tr>
<td><strong>Geographical barriers to care</strong></td>
</tr>
<tr>
<td>availability of specialised services</td>
</tr>
<tr>
<td>Regional area-reduced services</td>
</tr>
<tr>
<td>pre-tx limited ability to comprehend info</td>
</tr>
<tr>
<td>Needed more discussion about OH post tx</td>
</tr>
<tr>
<td>during tx-unable to examine teeth</td>
</tr>
<tr>
<td>Carer education essential</td>
</tr>
<tr>
<td>pt in shock</td>
</tr>
<tr>
<td><strong>Key theme: Relationships with health practitioners</strong></td>
</tr>
<tr>
<td>dentist diagnosed cancer</td>
</tr>
<tr>
<td>inappropriate manner-communication</td>
</tr>
<tr>
<td>biopsy-traumatic</td>
</tr>
<tr>
<td>Long term r'ship w GDP</td>
</tr>
<tr>
<td>Lack experience with HNC</td>
</tr>
<tr>
<td>misinformation</td>
</tr>
<tr>
<td>now understands needs</td>
</tr>
<tr>
<td>Motivated by money</td>
</tr>
<tr>
<td><strong>Key theme: Continuity of care</strong></td>
</tr>
<tr>
<td>Need dentist with HNC experience</td>
</tr>
<tr>
<td>High quality care at BDH</td>
</tr>
<tr>
<td>Public dent hospital - more specialised service</td>
</tr>
<tr>
<td>High quality care @ RBH</td>
</tr>
<tr>
<td>Valued dentist with HNC experience</td>
</tr>
<tr>
<td>Coordinated dental follow-up</td>
</tr>
<tr>
<td>Timeline-pre tx dental care</td>
</tr>
<tr>
<td>regional referral to allied health</td>
</tr>
<tr>
<td>Unsure of link between RBWH and BDH</td>
</tr>
</tbody>
</table>