Malnutrition Risk, Nutrition Impact Symptoms, and Dietary Intake in Community-Living Head and Neck Cancer Survivors Six Months to Three Years Post-Treatment: A Case Series

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A Dedication to All the Seven Head and Neck Cancer Survivors Who Participated in This Study

I want to express my deepest appreciation to each and every one of you. Thank you for your time, dedication, and unwavering commitment to every aspect of this research journey. The effort and devotion you have invested in this study have been invaluable and incredibly influential. It has truly been an honour and a privilege to get to know all of you. I deeply appreciate the trust you placed in me to share your personal journeys and experiences. Your contributions have positively impacted and inspired my thesis in more ways than one. This study would not have been possible without your involvement.

Abstract

Background: Head and neck cancer (HNC), characterised by malignant neoplasms originating in the oral cavity, upper aerodigestive tract, the sinuses, salivary glands, bone, and soft tissues of the head and neck, is diagnosed in approximately 600 people annually in New Zealand. Although HNC is a less common cancer, it has a profound effect on almost all aspects of the lives of those affected, particularly the nutritional and social domains. This is due to the common treatment modality being surgery and/or radiotherapy, which can result in major structural and physiological changes in the affected areas, which in turn affects chewing, swallowing, and speaking (Nilsen et al., 2020). Specific nutrition impact symptoms (NIS) of HNC have been identified and are significant predictors of reduced dietary intake and malnutrition risk (Kubrak et al., 2010).

Aim: We aimed to identify and describe the malnutrition risk, prevalence of NIS, and energy, macronutrient, and micronutrient intakes of community-living adult HNC survivors six months to three years post-treatment in New Zealand.

Methods: Participants were recruited through virtual HNC support groups in New Zealand. A descriptive observational case series design was used. Malnutrition risk was determined using the Patient-Generated Subjective Global Assessment Short Form (PG-SGA SF). NIS were obtained via a validated symptom checklist, and dietary data was collected using a four-day food record.

Results: Participants are referred to as PTP1-PTP7. PTP1 was well-nourished. PTP3 through PTP7 were categorised as mildly/suspected to moderately malnourished (PG-SGA SF scores of 2-7), and PTP2 was severely malnourished (score of 16). NIS were experienced by all seven participants, with “difficulty chewing,” “difficulty swallowing,” and “dry mouth” the most common. PTP2 scored loss of appetite, difficulty chewing, and difficulty swallowing as interfering “a lot.” Despite being well-nourished, PTP1 had inadequate energy intake (EI) (86% of their estimated energy requirement [EER]). PTP2, 3, 6, and 7 also had inadequate EI (79%, 79%, 73%, and 99%, respectively, of their EER). PTP1–PTP6 had adequate protein intake based on a range of 1.2-1.5 g/kg body weight per day, with PTP7 meeting 97% of their protein requirements. Deficiencies in dietary calcium and potassium were identified. PTP1, 2, 4, and 6 exhibited inadequate calcium intakes, corresponding to 74%, 73%, 72%, and 55% of their recommended dietary intake, respectively. PTP2, 3, and 6 demonstrated insufficient potassium intakes, reflecting 88%, 91%, and 91% of their adequate intake, respectively.

Conclusion: The prevalence of malnutrition, NIS, and micronutrient deficiencies in this case series indicates an urgent need for greater long-term support for HNC survivors post-treatment and research to identify the true extent of malnutrition in this vulnerable cohort.

Key words: Head and neck cancer; survivorship; malnutrition; nutrition impact symptoms.

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Thank you both for your endless support and encouragement, which have been instrumental in helping me along this journey. I feel so honoured to have been able to learn from you both. Your experiences, expertise, and guidance were influential in producing this piece of work.

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Table of Contents

A Dedication to All the Seven Head and Neck Cancer Survivors Who Participated in This Study I

Abstract II

Acknowledgements IV

List of Tables.....IX

List of Figures.....IX

List of Appendices.....X

Abbreviations XI

Chapter 1: Introduction 1

1.1 Background 2

1.2 Justification and Purpose of Study 5

1.3. Research Question 6

1.3.1 Aim 6

1.3.2 Primary Objectives 6

1.3.3 Secondary Objectives 6

1.4 Structure of the Thesis 7

1.5 Researcher's Contributions 7

Chapter 2: Review of the Literature 8

2.1 Introduction 9

2.2 Head and Neck Cancer 10

2.2.1 The Global and International Prevalence of Head and Neck Cancer 10

2.2.2 Head and Neck Cancer Histology and Clinical Presentations 10

2.2.3 The Risk Factors and Prevalence of Head and Neck Squamous Cell Carcinoma Development 12

2.2.4 Staging of Head and Neck Cancer and Treatment Management 13

2.2.5 Surgery 14

2.2.6 Radiation Therapy 14

2.2.7 Chemotherapy 15

2.3 Treatment-Related Toxicities 15
2.3.1 Radiation Therapy 15
2.3.2 Surgery 19
2.3.3 Chemoradiotherapy 23
2.4 Post-Treatment Consequences Head and Neck Cancer Survivors Face 26
2.4.1 Weight Status Post-Treatment 28
2.4.2 Physical and Functional Alterations 29
2.4.3 Altered Body Composition 30
2.4.4 Dietary Intake and Long-Term Nutrition Impact Symptoms 31
2.4.5 Dietary Intake in Head Neck Cancer Survivors Post-Treatment 31
2.4.6 Micronutrient Status 32
2.4.7 Nutrition Support 34
2.4.8 Lack of Protein and Energy Intake 34
2.5 Malnutrition Occurrence in Head and Neck Cancer Survivors 35
2.5.1 Malnutrition Diagnosis 40
2.5.2 The Validity and Reliability of the Patient-Generated Subjective Global Assessment Short Form in Oncology Settings 41
2.5.3 How Nutrition Impact Symptoms are Measured in Head and Neck Cancer Populations 43
2.5.4 Dietary Assessment Methods 44
2.6 Concluding Statement 46
Chapter 3: Research Study Manuscript 47
3.1 Abstract 48
3.2 Introduction 50
3.3 Methods 51
3.3.1 Study Design and Participants 51
3.3.2 Development of Online Survey 52
3.3.3 Nutrition Status using the Patient-Generated Subjective Global Assessment Short Form 52
3.3.4 Nutrition Impact Symptoms 54

3.3.5 Phase Two: Dietary Analysis 54
3.3.6 Phase Three: Final Online Survey 55
3.3.7 Data Collection 55
3.3.8 Methods for Data Analysis 55
3.4 Results 56
3.4.1 Participants and Cancer Characteristics 56
3.4.2 Presence and Interference of Nutrition Impact Symptoms 58
3.4.3 Clinical Presentation and Malnutrition Prevalence 58
3.4.4 Energy and Macronutrient Status 60
3.4.5 Micronutrient Status 60
3.4.6 Eating Adaptations and Coping Strategies 62
3.4.7 Eating Experiences Post Head and Neck Cancer Treatment 62
3.5 Discussion 63
3.5.1. Nutrition Impact Symptoms 63
3.5.2 Physical and Functional Alterations 64
3.5.3 Malnutrition in Head and Neck Cancer Survivors 65
3.5.4 Energy and Macronutrient Status 66
3.5.5 Micronutrient Status 67
3.5.6 Coping Strategies 68
3.5.7 Social Isolation 68
3.5.8 Strengths and Limitations 69
3.5.9 Conclusion 70
Chapter 4: Conclusion and Recommendations 71
4.1 Overview and Achievement of Study Aim and Objectives 72
4.1 Strengths 73
4.2 Limitations 73
4.4 Recommendations and Future Directions for Research 74

Summarised Final Future Applications of this Research 74

References 75

Appendix A: Patient-Generated Subjective Global Short Form Assessment 101

Appendix B: Phase One Online Survey 102

Appendix C: Head and Neck Cancer Symptom Checklist 109

Appendix D: Study Recruitment Poster 110

Appendix E: Participant Information Sheet 111

Appendix F: Eligibility Screening Questionnaire 114

Appendix G: Phase 3 Online Survey 115

Appendix H: Outlined Study Recruitment, Screening, and Enrolment 118

Appendix I: Participants Use of Over the Counter and Prescribed Supplements 119

Appendix 1: Figure 1. Self-Reported Nutrition Impact Symptoms During the Past 3 Days 120

Appendix 2: Figure 2. Self-Reported Nutritional Impact Symptoms Interfering with Oral Intake During the Past 3 Days 121

Appendix 3: Table 1. Participants Micronutrient Status 122

Appendix 4: Table 2. Participants Coping Strategies 124

Appendix 5: Table 3. Eating Experiences in Social Settings Described 126

List of Tables

Table 1. Research's Contributions……7
Table 2. Radiotherapy-Induced Side Effects and Nutritional Consequences……17
Table 3. Surgical Treatment and Nutritional Consequences.……20
Table 4. Chemotherapy-Induced Side Effects and Nutritional Consequences……23
Table 5. Chemoradiotherapy-Induced Side Effects and Nutritional Consequences……24
Table 6. Micronutrient Recommendations According to Demographic Characteristics and Life Stage……33
Table 7. Factors Contributing to Malnutrition in Head and Neck Cancer……37
Table 8. Demographic and Cancer Characteristics……57
Table 9. Current Nutrition Status of Participants According to the Patient-Generated Subjective Short Form……59
Table 10. Energy and Macronutrient Composition……61

List of Figures

Figure1. Search Strategy……9
Figure 2. Anatomical Sites of Head and Neck Squamous Cell Carcinoma Development……11
Figure 3. The Consequences of Nutrition Impact Symptoms and Malnutrition Development……27
Figure 4. Vital Structures of the Head and Neck that are Included in the Radiation Field in Treated HNC Patients……29

List of Appendices

Appendix A: Patient-Generated Subjective Global Short Form Assessment

Appendix B: Phase One Online Survey

Appendix C: Head and Neck Cancer Symptom Checklist

Appendix D: Study Recruitment Poster

Appendix E: Participant Information Sheet

Appendix F: Eligibility Screening Questionnaire

Appendix G: Phase 3 Online Survey

Appendix H: Outlined Study Recruitment, Screening, and Enrolment

Appendix I: Participants Use of Over the Counter and Prescribed Supplements

Appendix 1: Figure 1. Self-Reported Nutrition Impact Symptoms During the Past 3 Days

Appendix 2: Figure 2. Self-Reported Nutritional Impact Symptoms Interfering with Oral Intake During the Past 3 Days

Appendix 3: Table 1. Participants Micronutrient Status

Appendix 4: Table 2. Participants Coping Strategies

Appendix 5: Table 3. Eating Experiences in Social Settings Described

Abbreviations

AI	Adequate Intake
AMDR	Acceptable Macronutrient Distribution Range
BMI	Body Mass Index
BW	Body Weight
EER	Estimated Energy Requirements
EI	Energy Intake
ESPEN	European Society for Clinical Nutrition and Metabolism
FFQ	Food Frequency Questionnaire
HNC	Head and Neck Cancer
HNSCC	Head and Neck Squamous Cell Carcinoma
HNCSA	Head and Neck Cancer Support Aotearoa
HNSC	Head and Neck Cancer Symptom Checklist
HPV	Human Papillomavirus
MUST	Malnutrition Universal Screening Tool
NZ	New Zealand
NIS	Nutrition Impact Symptoms
PAL	Physical Activity Level
PG-SGA	Patient-Generated Subjective Global Assessment
PGS-GA SF	Patient-Generated Subjective Global Assessment Short Form
RDI	Recommended Dietary Intake
SLP	Speech and Language Therapist
SOP	Standard Operating Procedures
SCC	Squamous Cell Carcinomas
SCCHN	Squamous Cell Carcinomas of the Head and Neck
TEI	Total Energy Intake
UL	Upper Limit
WHO	World Health Organisation
GLOBOCAN	Global Cancer Observatory

Chapter 1 | Introduction

"I miss the ability to make ad hoc decisions on food on the run, to be creative cooking for friends and family, and most of all the joy of eating out and being invited to other people's homes. Food is such an important aspect of special events, holidays and celebrations - I experience grief at the loss of this." (PTP5)

Chapter 1: Introduction

1.1 Background

Head and neck cancer (HNC) is widely regarded as a devastating and complex disease (Cantwell et al., 2022), characterised by profound physical and functional impairments caused by the tumours' anatomical intricacy and critical location (Hammerlid et al., 1998). Despite advancements in early diagnostic techniques and therapeutic interventions, HNC continues to contribute substantially to global mortality and morbidity rates (Gupta et al., 2016). Annually, approximately one million and five hundred thousand new cases of HNC are diagnosed worldwide, with the disease accounting for over one million cancer-related deaths (Hunter et al., 2020). Notably, New Zealand (NZ) exhibits high incidence rates for HNC, with five hundred to five hundred and fifty new cases reported annually (Weaver et al., 2024).

Collectively, HNC describes a heterogeneous class of malignant neoplasms originating from a variety of sites in the upper aerodigestive tract and connective structures of the head and neck (Britton et al., 2012; Ferrao et al., 2020; Ragin et al., 2007). The invasive nature of HNC compromises nearby complex anatomical structures essential for several basic and innate functions, often impairing breathing function, coughing reflex, speech, communication, swallowing, and eating and drinking (Pezdirec et al., 2019; Richardson, 2016). Tumour features and stage of disease: early, locally advanced, or recurrent/metastatic determine the treatment pathway (Fortpied & Vinches, 2019). Notably, the primary therapeutic modalities for treating HNC neoplasms consist of surgical interventions, chemotherapy, radiation therapy, and concurrent chemoradiotherapy. While these treatments have become the standard of care for HNC patients, they are not without contraindications (Stefano et al., 2024). Tissue loss, excessive scarring, and altered anatomical positioning and function of affected organs are induced by treatment modalities (Pezdirec et al., 2019). It is well-documented that HNC survivors' ability to eat is negatively challenged and altered by the physical changes caused by HNC treatment (McQuestion et al., 2011), drastically altering essential structures and organs that facilitate food consumption (Hunter et al., 2020). Consequently, restricting and compromising oral intake results in the inability to maintain adequate nutrition status (Ferrao et al., 2020).

HNC survivors can experience a range of debilitating symptoms, collectively referred to as nutrition impact symptoms (NIS), which affect their desire and ability to eat and drink (Crowder et al., 2021). These symptoms often arise from the location of the malignancy and the effects of curative treatments. NIS can rapidly deplete nutrient stores and lead to declines in nutrition status, by impairing

the body's ability to perform key eating-related functions. Specifically, NIS impair essential physiological functions required for food processing, mastication, and swallowing (Nugent et al., 2013). Common NIS following treatment— are dysphagia (swallowing impairments), xerostomia (dry mouth), dysgeusia (taste disturbances), poor dentition, trismus (failure to properly open the oral cavity), mucositis (inflamed or ulcerated oral mucosal lining), and pain. These symptoms are often debilitating and typically develop as a result of radiation therapy, surgery, and/or chemotherapy (Crowder et al., 2018; Kristensen et al., 2019). Moreover, these oral comorbidities frequently persist after treatment (Crowder et al., 2018) and may develop years later, causing long-term challenges (Kristensen et al., 2019). Most late treatment side effects emerge within the first three years of completing HNC treatment (Trotti, 2000; van den Berg et al., 2014), although some may appear or progress after three years (Trotti, 2000). Together, these symptoms profoundly affect survivors' nutritional intake and status.

While adjusting to life after treatment, HNC survivors are at elevated risk of acute NIS (symptoms that develop before, during, or immediately following therapy) developing into long-term symptoms that persist after therapy completion (Crowder et al., 2018). In contrast, late effects emerge months to years after treatment and become noticeable over time (Nilsen et al., 2020). Chronic NIS can have a lasting effect on survivors' daily lives, potentially persisting for years or even a lifetime (Kristensen et al., 2019). These long-term NIS significantly affect survivors' quality of life, with eating abilities possibly never returning to normal (Crowder et al., 2020). This forces survivors to adapt and relearn how to eat, often adjusting to a "new normal."

This is particularly problematic, as dietary intake is severely impacted by long-term and late-onset NIS. Despite their profound effects on nutritional intake, NIS have rarely been assessed in long-term HNC survivors (Crowder et al., 2018). Furthermore, the chronic burden of treatment-related outcomes in HNC survivors beyond six months post-treatment remains understudied (Crowder et al., 2021; Crowder et al., 2019b). Notably, most research exploring the impact of NIS has focused on the acute phase of HNC treatment, specifically during and immediately after therapy (Crowder et al., 2021). To gain a comprehensive understanding of long-term treatment effects, HNC survivors should be closely monitored, with a fundamental focus on significant clinical changes over at least five years post-treatment (Trotti, 2000).

Distinctly, multiple NIS are associated with malnutrition risk, weight loss, reduced dietary intake, and diminished quality of life (Zaid et al., 2022). The complex nature of NIS, which presents over time with the risk of remaining permanent, alters diet quality (Crowder et al., 2018), warranting further investigation into the lived experience of long-term NIS burden among HNC survivors post-treatment

(Crowder et al., 2020). Malnutrition is commonly observed in this group of oncology patients (Cristofaro et al., 2021), developing at any stage of the HNC trajectory due to the tumour location or treatment side effects. Malnutrition develops when a negative energy balance results from diminished ingestion or absorption of nutrients, triggering unintended weight loss (Cook et al., 2022). The incidence of malnutrition in HNC patients is estimated to be as high as 88-90% (Hunter et al., 2020; Li et al., 2021). Interestingly, despite the well-documented side effects of treatment on nutrition status over a longer period, there have been few studies reporting the impact of treatment on malnutrition risk and food intake in the long-term (more than 90 days post-treatment) (van den Berg et al., 2014), suggesting a knowledge gap regarding the true extent of malnutrition in HNC survivors.

At present, a link between the presence of NIS and inadequate nutrition status has been established (Omlin et al., 2013). Studies investigating the nutrition status and weight loss in HNC patients over an extended period of time following therapy are limited (Zaid et al., 2022). The influence of treatment toxicities on oral intake over time, and more importantly, post-treatment, is not well understood or extensively studied (Barnhart et al., 2018). Furthermore, Nilsen et al. (2020) reported that while "identification and management of late and long-term treatment-related repercussions" is a crucial component of "high-quality survivorship care," it is understudied. This is problematic, as HNC survivors may face an array of NIS for months or even years after treatment completion, viewing NIS as a chronic health issue (Crowder et al., 2020). Further investigation into the presence and onset of NIS after oncology treatment is needed to help facilitate the underlying cause of diminished dietary intake, weight loss, and malnutrition risk in this population group (Kubrak et al., 2010). Therefore, nutrition screening is paramount in recognising the risk and prevalence of malnutrition in HNC survivors post-treatment. Additionally, to assess health indicators, such as nutrition status and malnutrition risk, the dietary intake of key nutrients (energy and protein) is of particular interest, as these nutrients play an important role in achieving nutrition adequacy, maintaining weight status, and body composition (muscle and fat mass).

1.2 Justification and Purpose of Study

The primary focus of post-treatment cancer care has traditionally been overwhelmingly tailored to monitoring for recurrence of disease, rather than comprehensively assessing and managing survivors' symptom sequelae and pressing concerns (Nund et al., 2015). To date, relatively few in-depth qualitative studies have meticulously examined the chronic, long-term impact of NIS on everyday life (Crowder et al., 2020). Despite the well-documented effects of oral morbidities and subsequent malnutrition in HNC patients, there remains a lack of studies examining the duration and frequency of eating impairments (NIS) and malnutrition prevalence over longer periods (Larsson et al., 2005). This gap is further emphasised by the fact that acute and adverse oral outcomes are well-researched in HNC populations, compared to the late side effects of treatment that have often gone unreported or neglected (Ganzer et al., 2013). Furthermore, a recent study distinctly stated that long-term problems faced by HNC survivors are still inadequately understood and poorly documented (Taylor et al., 2023). Therefore, further exploration is needed into the profound impact of treatment modalities and the presence and severity of NIS on oral intake, nutrition, and malnutrition status post-treatment in community-living HNC survivors.

In light of these recognised gaps in the current literature, a descriptive case series design was used to determine the prevalence of malnutrition among adult community-living HNC survivors in NZ who were treated with surgery, radiation therapy, and chemoradiation. The purpose of this study is to evaluate malnutrition status, nutrient intake (including energy, macronutrients, and micronutrients), and the presence and severity of NIS impacting oral intake. These study parameters are important, given nutrition is one of the most crucial factors influencing quality of life factors (Crowder et al., 2021). We presume HNC survivors are at risk of malnutrition and altered food intake due to the lasting effects of NIS post-treatment and adjusting to a "new normal" (life after treatment). The chosen time frame for this observational study is six months to three years post-treatment. Within this period, we aim to assess the prevalence and severity of NIS (which are most prominent within the first three years after treatment) and evaluate the dietary intake and malnutrition status of HNC survivors living in the community post-treatment.

1.3. Research Question

What is the current nutrition status (including malnutrition risk, presence, and severity of NIS) and dietary intake (energy, macronutrients, and micronutrients) of community-living HNC survivors in NZ, six months to three years post-treatment (surgery, radiation therapy, and concurrent chemoradiation therapy)?

1.3.1 Aim

To assess and describe the current nutrition status (including intake of energy, macronutrients, and micronutrients), the presence and severity of NIS, and the prevalence of malnutrition in a cohort of HNC survivors residing in NZ, six months to three years post-treatment.

1.3.2 Primary Objectives

a. To assess nutrition adequacy (energy, macronutrients, and micronutrients) in HNC survivors six months to three years post-treatment using a four-day food record.
b. To assess malnutrition risk and occurrence in HNC survivors six months to three years post-treatment using a Patient-Generated Subjective Global Assessment Short form (PG-SGA SF) numerical score.
c. To determine the presence and severity of nutrition impact symptoms in HNC survivors six months to three years post-treatment using a validated and comprehensive HNC symptoms checklist (HNSC).

1.3.3 Secondary Objectives

a. To assess the eating experiences, social experiences, and coping strategies of HNC survivors' during mealtimes after treatment using qualitative methods.

1.4 Structure of the Thesis

Four chapters comprise this thesis. Chapter one introduces the background, describing the purpose of the presented study and highlighting the issue of declining nutrition status (undernutrition) and malnutrition risk among HNC survivors due to malignancy, treatment modalities, and long-term NIS. The study aim and objectives are also described here. Chapter two presents a literature review of current HNC research, discussing the prevalence of malnutrition among adult HNC patients and the detrimental effects of treatment-induced NIS. This chapter also explores long-term NIS and their detrimental side effects on body composition, weight status, protein, and energy intake (EI). Chapter three presents the study manuscript, containing the methods, results, and discussion. Chapter four presents the study's conclusions, strengths, limitations, and recommendations for future research. The appendices include the PG-SGA SF, eligibility questionnaire, recruitment poster, information sheet, and flow diagram of participant screening, recruitment, and enrollment, as well as phase one and two surveys and additional results not included in the study manuscript results section.

1.5 Researcher's Contributions

Table 1. Summary of Researcher's Contributions to the Study

Author	**Contribution to Thesis**
Danielle Oakes MSc (Nutrition and Dietetics) Student	The Primary Author of the Thesis The Primary Researcher Study Design, Data Collection and Handling, Descriptive Data Analysis, Interpretation, and Thesis Writing
Dr Maria Casale, NZ Registered Dietitian Primary Supervisor School of Sport, Exercise and Nutrition	Primary Supervisor Research Topic and Study Design Ethics Application
Professor Pamela von Hurst Co-Supervisor School of Sport, Exercise and Nutrition	Co-Supervisor Research Topic and Study Design Ethics Application

Chapter 2 | Review of the Literature

"Side effects from radiation treatment were awful. No blink function in eye is challenging." (PTP3)

2.1 Introduction

The purpose of this literature review is to critically evaluate current and existing HNC literature, exploring the nutrition status of HNC survivors post-treatment and the impact of long-term NIS on dietary intake and malnutrition status. The strength of this literature review lies in its ability to recognise and address current gaps in HNC rehabilitation and acknowledge the profound long-term effects of this debilitating disease. More specifically, it examines the nutrition status (energy, macronutrients, and micronutrients), the presence and severity of NIS on oral intake, and the risk of malnutrition development in HNC survivors six months to three years post-treatment. A literature search was conducted between November 2023 and October 2024. The search parameters for this review are shown in Figure 1. The article databases used to conduct the literature search were Massey Discover, Google Scholar, PubMed, Scopus, Web of Science, Science Direct and Semantic Scholar.

Figure 1. *Search Strategy*

Research Dates: November 2023 – October 2024

Search Criteria: head OR neck OR tongue OR sinus OR mouth OR larynx OR laryngeal OR nasal OR pharynx OR pharyngeal OR salivary OR paranasal OR oral cancer OR neoplasm OR carcinoma OR oncology OR malignancy

Dietary intake OR nutritional intake OR diet OR food intake OR food OR eat OR eating experiences

Malnutrition OR undernourishment OR undernourished

Protein OR energy OR intake OR consume OR eat

Post-treatment OR post-therapy OR post-radiotherapy OR post-surgery OR post-chemotherapy OR post-chemoradiation

Nutrition impact symptoms OR symptom burden

Survivorship OR cancer survivors OR survivors of cancer OR cancer survivorship

New Zealand OR Aotearoa OR NZ developed countries OR developing countries

Micronutrient status OR vitamins OR minerals OR trace elements

Case series

Time Period: Last 5 years, 10 years, 15 years, 20 years and 38 years

Article Databases: Massey Discover, Google Scholar, Scopus, PubMed, Web of Science, Science Direct and Semantic Scholar.

2.2 Head and Neck Cancer

2.2.1 The Global and International Prevalence of Head and Neck Cancer

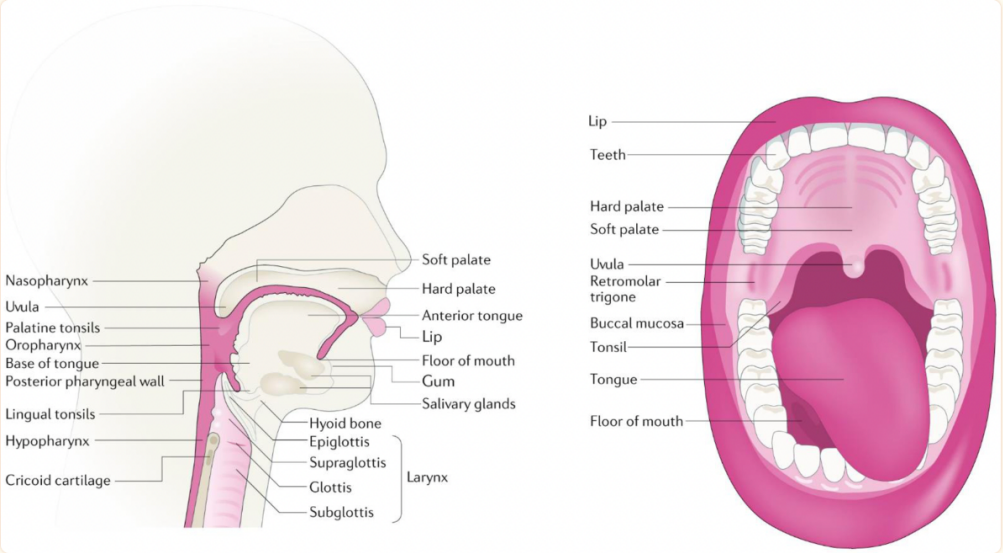
HNC contributes significantly to the global burden of cancer (Nund et al., 2015), with 1,464,550 cancer cases and 4,879 fatalities reported (Zhou et al., 2024). According to Zhou et al. (2024), HNC is regarded as the third most prevalent cancer type worldwide—a remarkable rise from the ninth most prevalent cancer in 2012, according to the Global Cancer Observatory (GLOBOCAN) (Gupta et al., 2016). Research efforts have identified HNC prevalence is highest between the fourth and seventh decades of life (Shaw, 2010), projecting a global mortality rate of 50% (Britton et al., 2012). Furthermore, the global prevalence of HNC incidence and fatality is estimated to rise, according to GLOBOCAN. In 2040, more than 1.2 million new cases of HNC are predicted worldwide, with approximately 680,000 fatalities anticipated (de Oliveira Faria et al., 2021). This estimated rise in prevalence makes HNC a significant global health concern. Internationally, the incidence rate of HNC is highest in South Asian populations, followed by European, North American, and Australasian populations (Auperin, 2020). Additionally, NZ ranks with one of the highest incidence rates for HNC, with 500 to 550 cases diagnosed annually (Weaver et al., 2024). HNC prevalence is increasingly more predominant in males than females, according to Belfiore et al. (2024), who reported that 10% of all malignancies occur in males compared to 5% in females. Furthermore, according to Teng et al. (2024), males in NZ have the highest incidence of HNC, with an estimated increase of 4,916 and 2,614 cases for men and women, respectively, predicted by the years 2040 and 2044 (Teng et al., 2024). Notably, applying the World Health Organization's (WHO) population standard, trends in age-standardised rate per 100,000 people varied by cancer type. Development of HNC in females showed the most significant relative increase trend, with an average annual percentage change of 2.1% between 2015-2019 and 2040-2044 (Teng et al., 2024). This suggests a growing incidence of HNC in NZ.

2.2.2 Head and Neck Cancer Histology and Clinical Presentations

HNC is a broad term that encompasses malignant neoplasms (Argiris et al., 2008; Garfield, 2020; Ihara et al., 2022) that originate in the superior and transitional sections of the body, the head and neck, respectively. Predominately, 90 to 95% of all HNC malignancies originate from epithelial squamous cell carcinomas (SCC) (Gorenc et al., 2015; Orell, 2018; Shaw, 2010). SCC primarily develop in the upper aerodigestive tract, affecting the oral cavity (35-40%), oropharynx (30%), larynx (25%), and hypopharynx (7%), respectively (Santos et al., 2013). Represented in Figure 2 are the anatomical sites of head and neck squamous cell carcinoma (HNSCC) development. HNSCCs arise from the epithelium of the mucosal layer (Johnson et al., 2020) surrounding the oral cavity (lip, buccal mucosa, hard palate, anterior portion of the tongue, floor of mouth, and retromolar trigone), nasopharynx, oropharynx

(palatine tonsils, lingual tonsils, base of tongue, soft palate, uvula, and posterior pharyngeal wall), and hypopharynx (bottom portion of the pharynx, extending from the hyoid bone to the cricoid cartilage), and larynx (consisting of three subdivided structures, supraglottis [including the epiglottis], glottis, and subglottis) (Findlay et al., 2021; Johnson et al., 2020; Keast et al., 2020; Sunderland et al., 2023; *Understanding Head & Neck Cancer*, 2023). Cancers of the brain, thyroid, or melanoma occurring in this region are not conventionally classified as HNCs and, therefore, are treated individually (Dobrossy, 2005).

Figure 2. *Anatomical Sites of Development in Head and Neck Squamous Cell Carcinoma*



Note. Figure retrieved from “Head and Neck Squamous Cell Carcinoma,” by D. E. Johnson, B. Burtness, C. R. Leemans, V. W. Y. Lui, J. E., Bauman & J. R. Grandis, 2020, *Nature Reviews Disease Primers*, *6*(1), 92. (https://doi.org/10.1038/s41572-020-00224-3). Copyright 2020 by Springer Nature Limited.

2.2.3 The Risk Factors and Prevalence of Head and Neck Squamous Cell Carcinoma Development

The risk factors for HNC development differ according to aetiological derivatives (such as viral infections) and prolonged exposure to alcohol and tobacco consumption (Crowder et al., 2018). Empirical literature demonstrates a developmental link between tobacco-derived carcinogens and excessive alcohol consumption (Argiris et al., 2008; Johnson et al., 2020; Santos et al., 2013). These aetiological derivatives contribute to 75% of all squamous cell carcinomas of the head and neck (SCCHN) (Argiris et al., 2008) and contribute to the growing incidence of HNSCCs in the developing world (Barsouk et al., 2023). Excessive alcohol consumption is an associated risk for the development of cancer in the mouth, throat and larynx (Namratha Pai & Urooj, 2014). The oral cavity, the hypopharynx, and the larynx are the primary sites for tobacco-related HNSCCs (Johnson et al., 2020; Namratha Pai & Urooj, 2014). The prevalence of alcohol consumption is much higher than tobacco usage in NZ, where four out of every five people consume alcohol and two out of every five use tobacco, putting these individuals at a higher risk of developing oral cancer (Yakin et al., 2017).

Increasingly, infection with human papillomavirus (HPV) strains, particularly HPV-16 and, to a lesser extent, HPV-18, has been associated with an increase in oropharyngeal malignancies, accounting for 25% of SCCHN (Johnson et al., 2020). The palatine and lingual tonsils of the oropharynx are the primary sites for HPV-associated HNSCCs (Johnson et al., 2020). This shows how the prevalence of HNSCCs varies across countries and regions depending on lifetime exposure to these HNC aetiological derivatives. Moreover, the development of HPV-related HNSCCs has significantly outpaced non-HPV-related tumours in the last decade (Nesemeier et al., 2017), with improved prognosis compared to the traditional alcohol- and smoking-related cases (Crowder et al., 2018). This enhanced prognosis is linked to how tumours respond to treatment in HPV-related cases (Yakin et al., 2017). Furthermore, HPV-positive HNC malignancies favour demographic characteristics, affecting younger individuals (Crowder et al., 2018), particularly during their third or fourth decade of life (Yakin et al., 2017). While HPV strains have been associated with increased oropharyngeal cancer cases, excessive alcohol consumption is the most prevalent risk factor in NZ, followed closely by tobacco use for oral and oropharyngeal cancer development (Yakin et al., 2017). Furthermore, Māori and Pacific Islander communities have a substantially higher prevalence of aetiological risk factors for developing HNC, including tobacco, smoking and HPV (Teng et al., 2016).

Furthermore, previous research has found numerous prognostic markers that can predict the development of HNCs and the prognosis of patients. These factors include age, gender, treatment approach, socioeconomic status, ethnicity, patient comorbidity(s) and various tumour-related characteristics (Patel & Brennan, 2012). Gender, age, and ethnicity are all non-modifiable risk factors influencing HNC mortality. Barsouk et al. (2023) reinforced the significance of age and socioeconomic status as prognostic markers, stating that HNSCCs occur more frequently among males and are suggested to be more prevalent in older adults and individuals from lower socioeconomic backgrounds. Furthermore, the link between ethnicity and HNC survival rates was further reported by *Head and neck cancer quality performance indicators* (2020), which found that NZ Māori have a 37% higher mortality rate for HNC compared to non-Māori individuals.

2.2.4 Staging of Head and Neck Cancer and Treatment Management

Stages of HNC (I-IV) reflect the size of the tumour at diagnosis, its location, and metastasis to surrounding structures in the head and neck region or other anatomical regions of the body. Early-stage (I-II) HNC is usually managed with monotherapy, either surgery or radiation therapy (Li & Margalit, 2020). Patients with locally advanced tumours (III-IV) are treated with a combination of surgery followed by supplementary radiation therapy, chemoradiation therapy, or definitive chemoradiation therapy (Riva et al., 2022). Yao et al. (2007) estimated that one-third of all tumours in patients with SCCHN are classified as stage I or II. Treatments for stage I and II HNC consist of local and/or regional therapy involving either radiation therapy, surgery, or a combination of both modalities. The prognosis and expected cure rates for stage I and stage II HNC are 80% and 65%, respectively (Yao et al., 2007). Approximately two-thirds of patients with SCCHN are diagnosed with stage III or IV. The prognosis for advanced-stage HNC is less favourable, with five-year survival rates ranging from approximately 10-40% and treatment success rates of 30% (Yao et al., 2007). Consequently, the more advanced the stage of HNC, the less favourable the outcomes in terms of survival and treatment success rates.

Clinical treatment considerations in HNSCC are complex, involving multiple specialists, including head and neck surgeons, medical oncologists, radiation oncologists, radiologists, cosmetic and reconstructive surgeons, and dental specialists (Argiris et al., 2008). The chosen therapy strategy is dependent on the primary tumour site, its features, and the stage of the disease: early, locally advanced, or recurrent/metastatic (Argiris et al., 2008; Fortpied & Vinches, 2019; Riva et al., 2022). Furthermore, patient-specific factors, such as swallowing and airway considerations, preference for

organ preservation, and associated health conditions, are taken into account to guide optimal care for this population (Argiris et al., 2008).

2.2.5 Surgery

Surgical management is frequently performed for resecting primary tumours or for "preventative, curative, palliative, or reconstructive purposes" (Hunter et al., 2020). Ablation and reconstruction procedures involve the removal of cancerous tissue or replacement of tissue lost due to tumour excision (Douglas et al., 2023; Main, 2022), respectively. Notably, the inherent invasiveness of such surgical procedures places HNC patients at risk of functional impairments and activity limitations (Douglas et al., 2023). As a result, physical appearance and basic behavioural and innate functions, such as eating and speaking, can become compromised (Douglas et al., 2023), along with swallowing (Alfaro et al., 2021). This was affirmed by the findings of Zhang et al. (2020), who highlighted the post-operative difficulties that HNC patients endure after receiving a complete or near-total glossectomy. A quality-of-life questionnaire was completed by 65 participants who were at least 12 months post-reconstruction. The study's findings revealed that chewing remained the worst-scored functional deterioration after treatment. Furthermore, all participants reported they were dissatisfied with chewing, speaking, and pain following their reconstructive surgeries (Zhang et al., 2020). These functional deteriorations can be attributed to the tongue's vital involvement in oral activities. Depending on the localisation and size of the tongue's tumour, as well as the amount of free flap tissue necessary to restore the tongue's morphological and dynamic functioning, oral rehabilitation, appearance, and nutrition can be affected by the surgical treatment, which can alter chewing, swallowing, and speech functions. Therefore, surgical management of HNC is largely dependent on the stage and location of the tumour at the time of surgery (Hunter et al., 2020).

2.2.6 Radiation Therapy

Radiation therapy plays a pivotal role in the comprehensive treatment of HNC (Guan et al., 2024), sometimes given alongside chemotherapy, serving as a radical approach to preserving organ function or as an adjuvant treatment after surgery (Guan et al., 2024). Approximately 75% of HNC patients receive radiation therapy as a primary treatment (Hunter et al., 2020). Radiation therapy destroys or slows the growth of cancerous cells using X-ray beams at varying dosages. The duration of these treatments can vary considerably; according to Richardson (2016), typical therapeutic sessions may occur once to twice per day, up to five days a week, for a period of five to seven weeks. Radiation therapy requires patients to wear a fitted mesh mask (Richardson, 2016) while being exposed to intensive and highly targeted radiation doses. The administration of radiation therapy is site-specific

and localised, causing direct damage to site-specific cells, including healthy cells in the targeted area (Hunter et al., 2020). This is problematic, as the radiation damage is applied to normal functioning cells, which can have a drastic effect after treatment completion, particularly affecting functional structures involved in food intake.

2.2.7 Chemotherapy

Chemotherapy is a medical therapy used either in isolation to destroy or slow the growth of cancer cells or in combination with radiation therapy. The effectiveness of chemotherapy depends on factors such as drug selection, dosage, and timing (Jacobs, 1987). It is commonly administered with radiation therapy to treat locally advanced-stage HNC malignancies (Nguyen et al., 2002). Organ-sparing surgery is a possible outcome when there is a favourable response to chemoradiation, such as a reduction in tumour mass. However, the long-term consequences of treatment side effects can be exacerbated by the radiosensitisation of chemotherapy drugs when administered with radiation, potentially outweighing the benefits of organ preservation (Nguyen et al., 2002).

2.3 Treatment-Related Toxicities

2.3.1 Radiation Therapy

The side effects of radiation treatments have a cumulative and detrimental effect on nutrition status, as detailed in Table 2. Treatment sites, radiation doses, and radiation fields are all contributing factors that impact nutrition status (Cook et al., 2022). As the radiation dose increases, eating difficulties worsen during radiation therapy (Paccagnella et al., 2010). The adverse side effects of radiation therapy are typically characterised as acute, chronic, or late, depending on when the symptoms appear (Larsson et al., 2005). Acute side effects typically occur during therapy, while late side effects appear months or even years later (Larsson et al., 2005). Acute complications, including mucositis and xerostomia, can become chronic and may persist for an extended period after therapy or never disappear (Larsson et al., 2005). Healthy non-cancerous tissues, such as mucous membranes and salivary glands, inevitably fall within the irradiation field (Larsson et al., 2005), exacerbating pain and discomfort upon swallowing due to the resultant ulceration of the mucus membrane lining the mouth and throat (Richardson, 2016). Additional treatment-induced side effects of radiation therapy include mouth dryness, taste alterations, swelling, oral and throat pain, dysphagia, thick saliva, tooth decay, skin redness, and poor appetite (Cook et al., 2022; Larsson et al., 2005; Richardson, 2016). These complications can jeopardise oral health and nutrition status by exacerbating the presence and severity of NIS, resulting in significant morbidity and increased risk of inadequate nutrient intake

(Larsson et al., 2005), including critical weight loss. In such cases, patients may require enteral feeding to support and maintain adequate nutrition (Richardson, 2016).

A longitudinal study conducted by Larsson et al. (2005) revealed that the majority of HNC patients continued to experience eating problems one year after treatment. It was proposed that the inability to ingest sufficient food and the ongoing need to modify food consistency were significant factors contributing to the patients' unintentional weight loss and their inability to regain the lost weight. This same study further highlighted that eating problems during radiation therapy are common and can be exacerbated by the accumulated radiation dose (Larsson et al., 2005), as further supported by Paccagnella et al. (2010). It is estimated that HNC patients lose between 6 and 12% of their body weight unintentionally from diagnosis to treatment completion (Ganzer et al., 2013). Thus, unintentional weight loss is a major concern for HNC patients receiving radiation therapy (Li et al., 2023), given the precise nature of mask fitting and the accuracy of treatment plans determined using body measurements (Cook et al., 2022). As a result, weight stability is essential during radiation treatment (Cook et al., 2022) to prevent the risk of ill-fitting radiation masks. Conversely, HNC patients who lose significant weight during active treatment are more likely to experience ill-fitting radiation masks as they will no longer fulfil pre-treatment body measures and, as a result, face an increased risk of treatment interruption or termination (Cook et al., 2022).

From the perspective of radiation oncology, preventing weight loss in HNC patients is critical. Weight loss negatively impacts patients' quality of life, can be directly or indirectly associated with radiation therapy failure and poor treatment outcomes, and is a risk factor for malnutrition (Li et al., 2023). Mathlin et al. (2023) further supported this, noting that HNC patients who become malnourished and struggle to tolerate radiation therapy often experience unplanned treatment gaps, which can be detrimental. Furthermore, Hopanci Bicakli et al. (2017) reported an increase in malnutrition rates before and after radiation therapy, with rates rising from 24% to 88%, respectively. This significant incidence of malnutrition as a direct consequence of radiation therapy is concerning, suggesting that HNC survivors are at a heightened risk of malnutrition during their post-treatment recovery.

Table 2. *Radiation Therapy-Induced Side Effects and Nutrition Consequences*

Author(s)	Side Effects	Symptoms	Aetiology	Nutrition Complications
Brook et al. (2020), Heal et al. (2024), Munro et al. (2024) and Shaw (2010)	Xerostomia	Dry mouth, sticky saliva, difficulty eating and swallowing	Salivary gland cells are damaged	Decreased dietary intake and weight loss
Heal et al. (2024), Munro et al. (2024) and Shaw (2010)	Mucositis	Pain, dysphagia, dehydration, local and systemic infections and copious oral secretions	Oral mucosal reaction	Difficulties in eating can reduce oral intake, cause nutrition deficiencies, lead to weight loss, and necessitate tube feeding
Munro et al. (2024) and Shaw (2010)	Taste changes	Foods taste metallic or like cardboard	Diminished, distorted, abnormal, and/or loss of taste	This can lead to food aversion and reduced intake, displacing nutrients in the diet
Shaw (2010)	Swallowing impairment of the oral phase	Causes difficulty chewing, taste changes, and fatigue during meals	Reduced range of lingual motion and strength	Impaired bolus formation and transport through the oral cavity. Causes prolonged transit time and increased residue formation at the floor of mouth resections

Author(s)	Side Effects	Symptoms	Aetiology	Nutrition Complications
Shaw (2010)	Swallowing impairment in the pharyngeal phase	Aspiration and swallowing disturbances (reduced laryngeal function)	Impaired tongue base movement and reduced opening of oesophageal sphincter	Causing delayed trigger of swallow, resulting in impaired bolus clearance and aspiration
Cristofaro et al. (2021), Heal et al. (2024) and Shaw (2010)	Dysphagia	Coughing, drooling, or gagging; regurgitation of foods or liquids; heartburn; trouble or painful swallowing	Acute and late complications of RT or 2^0 complications due to xerostomia, surgical changes, or concurrent therapies. Whereby, dysfunction of the digestive system and incorrect transit of the bolus in the upper digestive tract cause difficulty in swallowing function	The inability to swallow solid, liquid, or semi-liquid foods Decreased oral intake of foods and liquids
Brook et al. (2020), Heal et al. (2024) and Shaw (2010)	Trismus	Restricted ability to open the mouth	Pre-existing tumour obstruction, radiation-induced, or reduced mastication over a prolonged period of time	Challenges and impacts the ability to consume food. A severe oral morbidity
Brook et al. (2020), Heal et al. (2024) and Shaw (2010)	Osteoradionecrosis	Reduced ability to masticate and limited mouth opening	The mandible is incapable of healing itself or fighting infection due to poor blood supply	Reduced oral intake

Abbreviations: RT—Radiation Therapy; 2^0—Secondary.

2.3.2 Surgery

The common nutrition consequences and social burdens of surgical management for treating HNC are outlined in Table 3. Surgical procedures are not without complications, with patients frequently experiencing difficulties eating and drinking due to swelling around their oral cavity and throat area (pharynx and larynx) caused by invasive and extensive surgical application to these anatomical areas. In such cases, enteral nutrition is often required, either through short-term support using a nasogastric tube (a tube inserted through the nasal cavity, down into the oesophagus, and into the stomach) or long-term nutrition support via a gastrostomy tube (a tube surgically inserted through the abdomen, feeding into the stomach) to facilitate nutrition support (Richardson, 2016). Additional complications include restricted airways induced by swelling, which makes breathing extremely difficult and painful, often requiring the placement of a tracheostomy or stoma (a small surgical opening in the windpipe) to help alleviate symptoms and is placed until the swelling abates (Richardson, 2016). Following HNC surgery, speech impairments can also emerge, particularly in patients who undergo a partial or complete laryngectomy (Richardson, 2016). Additional complications of HNC surgery include ongoing discomfort, pain, numbness, trismus, and significant facial disfigurements (Richardson, 2016). Additionally, surgery can trigger a stress response, prompting catabolic activity and exacerbating malnutrition post-operatively (Wang et al., 2024). Therefore, it is important to recognise the probable and debilitating side effects that can arise from the removal of anatomical structures, particularly the tongue (glossectomy) and larynx (laryngectomy), which alter normal eating and swallowing processes (Alfaro et al., 2021). This, in turn, impacts food intake and exacerbates negative effects on nutrition status.

Table 3. *Surgical Treatment and Nutritional Consequences*

Consequences of Surgery	Symptoms	Aetiology	Nutrition Concerns
Loss of taste	Reduced appetite and taste perceptions	Cosmetic surgery performed on the tongue, salivary glands, or olfactory nerve	Dramatically alters taste intensity. This affects oral intake and, in turn, impacts nutrition status
Loss of smell	Reduced olfactory sensation	Loss of nasal circulation via the olfactory nerve and receptors in the nasal cavity	Contributes to lessened enjoyment during times of eating and social interactions. Affecting food choice and further food intake
Difficulty chewing	The inability to masticate and trismus	Due to the loss of the bony supporting structure (mandible), or exacerbated by dental extraction, misalignment of the jaw, and trismus	Demanding textural modified foods and additional effort to eat can cause a lack of enjoyment of food (social isolation)
Drooling and pocketing of food and fluids	Inability to sufficiently hold food and fluids in the oral cavity	Caused by surgery or nerve damage, resulting in insufficient movement of the food bolus into the pharynx	Reduced oral intake: can be unpleasant and isolating, causing anxiety and despair
Oral regurgitation	Dyspepsia	Caused by reconstruction surgery or gastric transposition (pharyngo-laryngo-esophagectomy)	It necessitates small, frequent meals

Consequences of Surgery	Symptoms	Aetiology	Nutrition Concerns
Nasal regurgitation	Coughing and choking while eating	Functioning defect of the soft palate or the motor action of the graft	Causes humiliating and unpleasant experiences that necessitate correct posture when consuming food and liquids
Gastric regurgitation	Acid reflux or heart burn	The outcome of surgical reconstruction (laryngectomees)	Increasing the risk of inadequate nutrition intake over a prolonged period of time. Volume limitation may be required following surgery to limit the risk of tissue disintegration, as well as the consideration of post-pyloric feeding

Consequences of Surgery	Symptoms	Aetiology	Nutrition Concerns
Dumping syndrome	Nausea, bloating, abdominal cramps, and rapid diarrhoea	Pharyngo-laryngo-esophagectomy	Fear of food and eating is frequent. Leading to poor oral intake and reduced consumption of foods, displacing nutrients, and increasing the risk of poor nutrition status

Consequences of Surgery	Symptoms	Aetiology	Nutrition Concerns
Risk of wound infection	Pain, swelling, bleeding, or discharge from the wound	It can occur at the wound site or chest following extensive or revision surgery and a lengthy operation when entering the resecting part of the upper aerodigestive tract	Increased nutritional requirements post-operatively and to support wound healing

Note. Table adapted from "*Nutrition and Cancer*," C. Shaw, 2010, Blackwell. Copyright 2011 Blackwell Publishing Ltd.

2.3.3 Chemoradiotherapy

Predominately, treatment toxicity and oral morbidities are significantly exacerbated in HNC patients when chemotherapy is administered concurrently with external beam radiation treatment (Ihara et al., 2018; Richardson, 2016). Oral morbidities often persist long-term, with acute oral symptoms from radiation continuing after chemotherapy administration. Furthermore, additional therapeutic side effects may develop 90 days or more after treatment completion (Ihara et al., 2018), leading to significant complications that impair oral intake, as outlined in Tables 4 and 5, respectively. Acute oral symptoms from chemotherapy can be exacerbated by radiation therapy, causing chronic symptoms that can further impair oral intake and challenge nutrition status beyond the treatment period. This is further supported by a cross-sectional study by Susetyowati et al. (2024), who discovered that malnutrition in HNC patients is strongly predicted by cancer therapy, specifically chemotherapy or chemoradiation. Showing that the risk of malnutrition is five times greater in HNC patients receiving chemoradiation therapy compared to those who do not undergo this form of cancer treatment. In contrast, Crowder et al. (2018) reported that chemoradiation therapy is associated with an increased incidence of treatment-related morbidities compared to surgical treatments and radiation therapy management alone.

Table 4. *Chemotherapy-Induced Side Effects and Nutritional Consequences*

Consequences of Chemotherapy	**Nutrition Concerns**
Serve mucositis	Difficulties in eating can reduce oral intake, cause nutritional deficiencies, lead to weight loss, and necessitate tube feeding
Nausea and vomiting	Reduced food intake leads to nutritional deficiencies
Anorexia	Severe weight loss, which can lead to malnutrition
Taste and smell alterations	This can lead to food aversion and reduced food intake, which can exacerbate weight loss
Diarrhoea	If acute, it can contribute to malnutrition through a reduction in food intake, decrease in the absorption of nutrients, and an increase in the catabolism of nutrient reserves
Stomatitis	The cause of painful swelling and sores inside the mouth can reduce food oral intake (it is painful to eat)

Note. Table adapted from "*Nutrition and Cancer*," C. Shaw, 2010, Blackwell. Copyright 2011 by Blackwell Publishing Ltd.

Table 5. *Chemoradiotherapy-Induced Side Effects and Nutritional Consequences*

Author(s)	Consequences of Chemoradiotherapy	Symptoms	Aetiology	Nutrition Concerns
Kok et al. (2022) and Shaw (2010)	Pain	Difficulty eating	Pain inflicted by treatment	Can cause reduced food intake
Ihara et al. (2018), Karampela et al. (2021), Kok et al. (2022) and Shaw (2010)	Dysphagia	Difficulty swallowing	Location of tumour (s) in the upper aerodigestive tract	Difficulty swallowing can displace oral intake of foods and liquids, impacting nutrition status
Bell et al. (2024), Kok et al. (2022) and Shaw (2010)	Mucositis	Pain, eating difficulty, infection	CRT-induced tissues become injured, causing the death of BEC and the formation of ROS, resulting in cellular death and upregulation of inflammatory pathways that ultimately leads to ulceration of the mucosa	Pain and difficulties in eating can reduce oral intake, cause nutritional deficiencies, lead to weight loss, and necessitate tube feeding

Author(s)	Consequences of Chemoradiotherapy	Symptoms	Aetiology	Nutrition Concerns
Kok et al. (2022) and Shaw (2010)	Taste alterations	Ageusia and hypogeusia	Treatment-induced, causing diminished, distorted, abnormal, and/or loss of taste	Lead to food aversion and reduced food intake, which can exacerbate weight loss
Kok et al. (2022) and Shaw (2010)	Xerostomia	Dry mouth sticky saliva, affecting eating and swallowing	Reduced salivary production 2^0 to damaged salivary gland cells	Decreased nutritional intake and weight loss
Kok et al. (2022) and Winter et al. (2021)	Sticky saliva	Thick and stringy saliva and difficulty swallowing foods	Reduced salivary2^0 to irradiated salivary glands and exacerbated by CT	Avoidance of certain foods can cause the displacement of nutrients in the diet
Kok et al. (2022) and Shaw (2010)	Nausea	Feeling or wanting to be sick	Treatment-induced	Reduced food intake can alter nutrition status

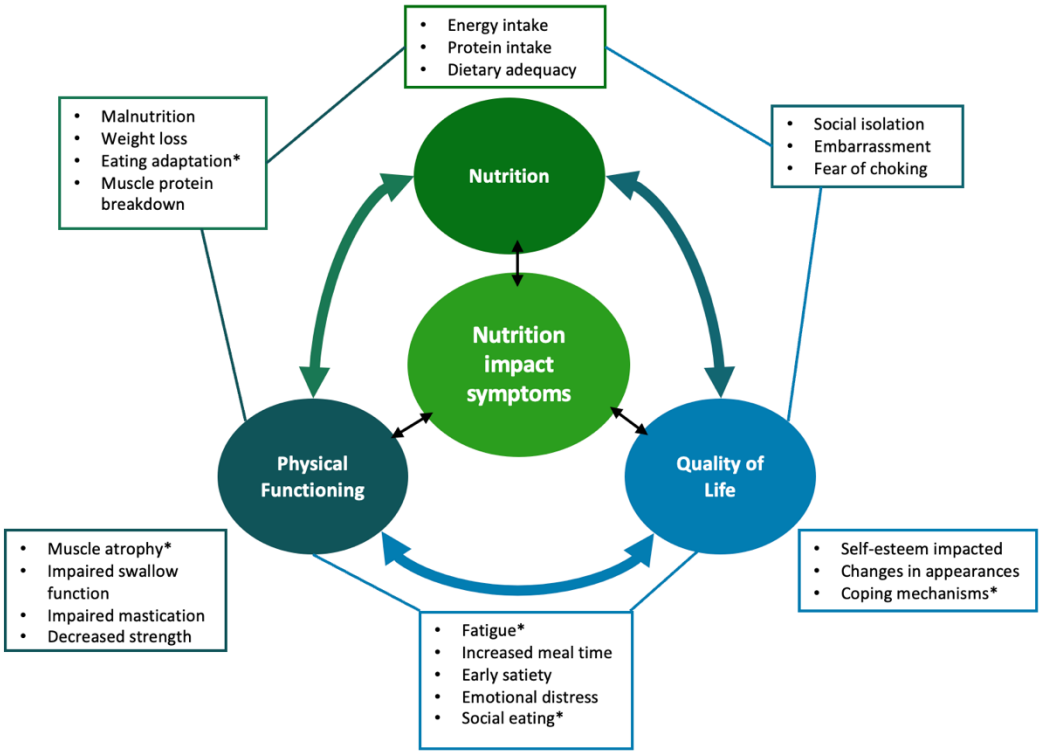
Abbreviations: CRT—Chemoradiation Therapy; BEC—Basal Epithelial Cells; ROS—Reactive Oxygen Species; 2^0—Secondary; CT—Chemotherapy.

2.4 Post-Treatment Consequences Head and Neck Cancer Survivors Face

NIS pose significant ongoing challenges to HNC survivors (Kubrak et al., 2013). The complex interplay of NIS and treatment consequences is illustrated in Figure 3. NIS can persist long-term or indefinitely and is considered a chronic health issue (Crowder et al., 2020). The prevalence and consequences of NIS are extensive among HNC survivors, extending well beyond the acute phase of cancer treatment (Crowder et al., 2018). Recent research indicates that a high rate (90%) of HNC survivors experience NIS (Crowder et al., 2020). Similarly, one or more NIS can develop in 90% of HNC survivors treated with chemoradiation therapy (Crowder et al., 2018). A study by Aghajanzadeh et al. 2023 showed that Fatigue, pain, and nausea/vomiting worsened from 12 months to 60 months after radiation treatment. Crowder et al. (2020) similarly demonstrated that chronic NIS remain a burden for HNC survivors six months to nine years after radiation treatment. More predominantly, dysphagia, xerostomia, taste disturbances, and chewing inability remained the most frequently reported NIS six months to nine years post-treatment (Crowder et al., 2020). The complexity of NIS post-treatment is devastating, as eating impairments and eating experiences may remain problematic for months or even years (Ganzer et al., 2015a), a finding also supported by Crowder et al. (2020). Furthermore, one-third of HNC patients will develop late toxicities that disrupt normal eating for the rest of their lives (Buntzel et al., 2019), which coincides with Ganzer et al. (2015a), who remarked eating abilities may never be fully restored after HNC treatments.

Survivors of HNC encounter a wide range of eating challenges that may persist long after cancer treatment has ended (Ren et al., 2021). Existing literature indicates that the late onset of NIS can vary among individuals, appearing as early as six months post-treatment or even several years later (more than three years post-treatment) (van den Berg et al., 2014). Importantly, research highlights that the prevalence of these symptoms in HNC survivors remains unclear (Pocobelli et al., 2019). Previous studies assessing symptom burden have typically included patients within two to three years of their cancer diagnosis (Pocobelli et al., 2019. Therefore, to fully understand the long-term impacts of treatment, it is essential to observe HNC patients over a longer period (van den Berg et al., 2014).

Figure 3. *Consequences of Long-Term NIS and Malnutrition Development*



Note. The author re-created this figure to highlight the complex interplay and associated consequences of long-term NIS and malnutrition development. NIS remain a challenge for HNC survivors, often exacerbating this vicious cycle .*Eating adaptations comprise physical measures taken to modify a survivor's diet before consumption. Examples consist of but are not restricted to, chopping food items into smaller, bite-sized pieces and combining gravies and sauces within meals to modify the food consistency. *Social eating is defined as the willingness or ability to eat in public when faced with feelings of embarrassment or anxiety. Survivors may experience this due to changes in eating habits, difficulties when eating, or altered dietary patterns. *Fatigue refers to the physical exhaustion associated with eating and experiencing long-term NIS that affects eating quality. Sometimes, survivors may finish meals because they are too exhausted to continue, not because they are full. *Atrophy of muscles can occur when NIS persists and prevents adequate EI needed for protein synthesis. This leads to loss or alteration of muscle structures and functions, which in turn affects nutrition and quality of life due to the existence of physical impairments. *Coping mechanisms refer to any coping strategy a survivor has adopted to cope with present NIS. This figure was adapted from "Nutrition Impact Symptoms and Associated Outcomes in Post-Chemoradiotherapy Head and Neck Cancer Survivors: A Systematic Review," by S. L. Crowder, K. G. Douglas, M. Yanina Pepino, K. P. Sarma, and A. E. Arthur, 2018, *Journal of Cancer Survivorship*, 12(4), 479–494 (https://doi.org/10.1007/s11764-018-0687-7). Copyright 2024 Springer Nature Limited.

2.4.1 Weight Status Post-Treatment

It is common for patients with HNC to experience substantial weight loss during and after treatment (Nejatinamini et al., 2018a; Zaid et al., 2022). This weight reduction is primarily attributed to two factors: increased energy expenditure and decreased dietary intake (Kubrak et al., 2010). However, research focusing on weight status beyond 12 months post-treatment in HNC survivors remains limited. Most studies investigating weight loss in HNC patients post-treatment cover periods before, during (Redwan et al., 2024), and immediately following treatment, with timelines including one month (Zaid et al., 2022), six weeks (Ihara et al., 2018), two months and two weeks (Kubrak et al., 2013), three months to six months (Berg et al., 2024), six months (van den Berg et al., 2006), one year (Berg et al., 2024; Larsson et al., 2005), and up to two years-post-treatment (Ganzer et al., 2013). Findings from Ferrao et al. (2020), indicate that significant weight loss (defined as a reduction of 5% body weight in one month or 10% in six months) can persist up to 12 months post-therapy. Similarly, Larsson et al. (2005) reported that weight loss was aggravated one-year post-radiation therapy. Highlighting the persistence of weight loss is a prominent issue beyond treatment completion. In contrast, Berg et al. (2024) did not observe a statistically significant difference in weight loss at six or 12 months post-treatment in HNC patients treated with radiation therapy. This discrepancy may be attributed to early intervention with enteral nutrition and dietetic support during and after treatment, which could have mitigated further weight reduction.

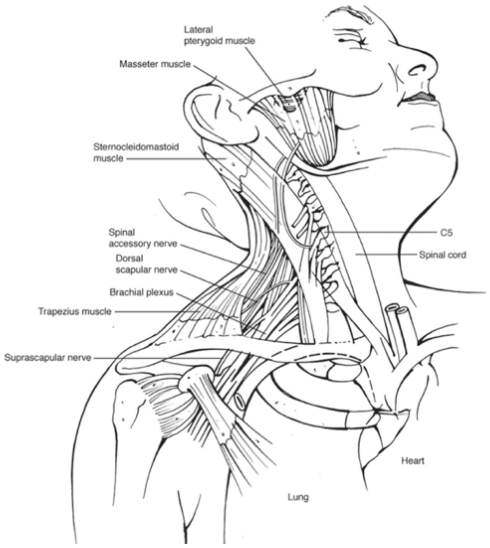
Frequent treatment-related NIS, as previously described, poses a significant risk for unintentional weight loss, as they profoundly impact dietary intake. Kubrak et al. (2013) identified an association between NIS, reduced dietary intake and weight loss. However, this finding contrasts with earlier research by Kubrak et al. (2010), who did not establish a clear relationship between NIS, dietary intake and weight loss. These discrepancies may be attributed to differences in study timeframes. Kubrak et al. (2010) assessed HNC patients before treatment, while Kubrak et al. (2013) assessed HNC patients who were more than two months post-treatment. The variation aligns with existing literature, as NIS often emerge or worsen during the late post-treatment period. Consequently, the rehabilitation period following treatment attenuates the ongoing support required to manage unintentional weight loss and long-term NIS (McQuestion et al., 2011).

2.4.2 Physical and Functional Alterations

Mastication and swallowing are intricate processes involving both voluntary and reflexive activities, coordinated by over 30 nerves and muscles (Matsuo & Palmer, 2008) (Figure 4). Mastication consists of rhythmic movements that facilitate the manipulation and crushing of food between the teeth (van der Bilt et al., 2006). Saliva plays a vital role in this process by moistening food particles, forming a cohesive bolus, and aiding in swallowing. The act of swallowing transfers food from the mouth, through the pharynx, and into the oesophagus and stomach (Mittal et al., 2003). The tongue is particularly crucial as it involuntarily propels the food bolus into the back of the pharynx (throat). Swallowing is largely automatic unless disrupted by damage or impairment (Mittal et al., 2003).

Radiation-induced toxicity has been identified as a significant contributor to long-term impairments following HNC treatment, leading to complications such as neck muscular atrophy, swallowing difficulties, trismus, and subcutaneous soft tissue fibrosis (Kim et al., 2015). Notably, radiation therapy has been empirically shown to cause substantial atrophy in muscular structures (Zhang et al., 2015). While both radiation therapy and surgical treatment are associated with muscle atrophy and soft tissue fibrosis, these structural impairments have received limited attention in the clinical literature (Kim et al., 2015). Furthermore, there is currently no experimental data regarding the effects of radiation therapy on tendons or ligaments (Stubblefield, 2011).

Figure 4. *Vital Structures of the Head and Neck that are Included in the Radiation Field in Treated HNC Patients*



Note. Figure retrieved from "Radiation Fibrosis Syndrome: Neuromuscular and Musculoskeletal Complications in Cancer Survivors," by M. D. Stubblefield, 2011, PM & R: *The Journal of Injury, Function and Rehabilitation*, *3*(11), 1041–1054 (https://doi.org/10.1016/j.pmrj.2011.08.535). Copyright 2011 by the American Academy of Physical Medicine and Rehabilitation.

2.4.3 Altered Body Composition

Currently, little is known about changes in body composition among patients with HNC (Jager-Wittenaar et al., 2011a). Body composition, an area of growing interest in oncology, is considered an important clinical indicator of malnutrition risk, as it reflects the amount and distribution of lean tissue to adipose tissue (Ferrao et al., 2020). Loss of lean mass is a stronger predictor of poor outcomes compared to weight loss changes alone (McCurdy et al., 2019). Traditionally, weight loss has been used to identify cancer patients at risk for malnutrition (McCurdy et al., 2019). Nejatinamini et al. (2018a) reported that low muscle mass before treatment and muscle loss during treatment are associated with adverse outcomes, including a poorer response to therapy and decreased survival rates. Therefore, specific measures of body composition are essential, as muscle loss can occur in HNC patients even if they are not losing weight (Nejatinamini et al., 2018a). Jager-Wittenaar et al. (2011a) found that body weight, body mass index (BMI), and lean muscle mass decreased significantly ($p<0.05$) during radiation therapy, whether administered alone, combined with chemotherapy, or following surgery. A key finding of their study was that HNC patients did not recover lean mass during treatment. This observed loss of body weight and lean mass during cancer treatment may point towards insufficient dietary intake (Jager-Wittenaar et al., 2011a). Additionally, treatment-related NIS have been identified as a leading cause of low dietary intake and subsequent muscle loss in HNC patients (Nejatinamini et al., 2018a). Beyond insufficient food intake, inflammation may further exacerbate muscle loss after cancer therapy. This can occur directly due to surgery or indirectly due to treatment-related oral mucositis caused by (chemo)radiation (Jager-Wittenaar et al., 2011a), which can impair physical performance and contribute to abnormal changes in body composition (Ferrao et al., 2020). Furthermore, Nejatinamini et al. (2018a) observed a trend towards greater skeletal muscle loss in patients with mucositis compared to those without (−14.7 ± 8.2% vs. −7.5 ± 8.6%). However, these findings were accompanied by a trending p-value (0.07), indicating a 7% probability that the observed result could have occurred accidentally. Therefore, monitoring changes in body composition is of clinical importance in HNC patients (Jager-Wittenaar et al., 2011a).

2.4.4 Dietary Intake and Long-Term Nutrition Impact Symptoms

The presence and severity of NIS can drastically compromise dietary intake (Kubrak et al., 2013), whereby HNC survivors often continue to experience eating challenges due to lingering treatment sequelae at nine months (Ottosson et al., 2013), one year (Larsson et al., 2005; McQuestion et al., 2011), and two years post-treatment (Einarsson et al., 2019). A late treatment side-effect that has been extensively studied in HNC survivors is dysphagia. Dysphagia commonly occurs or persists for more than three months post-radiation treatment (Huynh et al., 2024) or can develop frequently as a long-term consequence of chemoradiation therapy (Crowder et al., 2018; Karampela et al., 2021). Approximately 50% to 70% of HNC patients experience dysphagia as an immediate or long-term outcome of treatment (Ihara et al., 2022). The onset of dysphagia has been reported to be more prevalent among patients with advanced-stage HNC cancer, combined radiation therapy, and surgical resection of the suprahyoid musculature (Sadakane-Sakuramoto et al., 2021). The suprahyoid musculature is critical for controlling the upper oesophageal sphincter opening, relaxation of the cricopharyngeal muscle, and laryngeal closure (Hara et al., 2018). Notably, HNC patients who have undergone a total glossectomy and chemoradiation therapy exhibit the highest rate of dysphagia (Cristofaro et al., 2021). Additionally, malnutrition has been reported in 20% to 50% of HNC patients presenting with dysphagia (Cristofaro et al., 2021). Therefore, this demonstrates how long-term NIS can affect diet quality and development and compromise nutrition status.

2.4.5 Dietary Intake in Head Neck Cancer Survivors Post-Treatment

Food is fundamental for sustaining daily life functions and health, as it contains essential nutrients for the maintenance of body tissues and the regulation of vital organ functions. However, for many HNC survivors, eating challenges and nutritional complications may persist or never resolve. Whereby some individuals may never return to normal eating habits, patterns, or behaviours after treatment completion (Ottosson et al., 2013). This was further supported in a cross-sectional study by Crowder et al. (2018), where one-third of HNC survivors treated with chemoradiation therapy relied on modified diets (soft or pureed) to meet caloric needs six months to five years post-treatment. This finding is consistent with the results from Rinkel et al. (2016), who reported varying degrees of food modification and dietary adaptation in 52 HNC survivors six months to five years post-chemoradiation treatment. Normal dietary intake was reported by 45% of HNC survivors, compared to 35% and 20% who relied on diet modification (soft, pureed, or tube feeding), respectively, to meet caloric needs (Rinkel et al., 2016). Unfortunately, both cross-sectional studies by Crowder et al. (2018) and Rinkel et al. (2016) failed to identify at which time point during the rehabilitation period (six months to 60 months post-chemoradiation treatment) these dietary adaptations occurred. In comparison, Almstahl

et al. (2018) reported that most HNC patients had regained the ability to consume foods and drinks, but often with difficulty, within one to two years post-treatment. Similarly, findings by van den Berg et al. (2014) showed that HNC survivors failed to achieve eating habits consistent with a normal diet (no eating constraints). Food fortification varied from mild to serious for all 32 HNC survivors 44 months post chemoradiation therapy. These findings were further supported by Beeken and Calman (1994), who reported that 72% of HNC survivors who underwent curative chemoradiation treatment for oropharyngeal cancer required food modification at a mean follow-up of three and a half months post-treatment.

The difference in study findings can be attributed to varying study parameters. For example, Beeken and Calman (1994) and van den Berg et al. 2014 assessed HNC survivors eating habits three and a half years and three years and eight months post chemoradiation treatment, respectively, compared to the two-year follow-up conducted by Almstahl et al. (2018). Furthermore, Beeken and Calman (1994) and van den Berg et al. (2014) focused on HNC survivors diagnosed with predominately oropharyngeal and oral cavity cancers, whereas Almstahl et al. (2018) primarily studied survivors with a history of tonsil cancer. Furthermore, Almstahl et al. (2018) was the only study to assess salivary secretion rates and found that 50% of HNC survivors had an expectable salivary secretion rate of >7.0 mL/min at their two-year follow-up. These survivors showed improvement with eating over time, compared to participants who presented with hyposalivation (<7.0 mL/min). This study foreshadowed the importance of regaining a salivary flow rate of 0.7 mL/min, which may contribute to improved eating functions after treatment. This could explain why some participants regained the ability to eat and drink while others did not. Therefore, it is evident that further studies are needed to identify variations in diet quality and dietary adaptations in long-term HNC survivors. Additional research would provide a deeper understanding of diet quality among NZ-based HNC survivors.

2.4.6 Micronutrient Status

To date, there is very limited data evaluating cancer treatment toxicities concerning dietary micronutrient status (Nejatinamini et al., 2018a). Micronutrient status in HNC survivors can be exacerbated by altered diet quality and restricted dietary intake related to NIS, which studies have demonstrated can persist during the survivorship period. Additionally, altered physical functions can further impact diet quality, displacing micronutrients and ultimately leading to deficiencies. Table 6 illustrates the recommended dietary intake (RDI), adequate intake (AI), and upper limit (UL) of key vitamins, minerals, and trace elements according to demographic and life stage characteristics.

Table 6. *Micronutrient Recommendations According to Demographic Characteristics and Life Stage*

Vitamins & units		Vitamin A Retinol equivalents µg/day		Thiamin mg/day	Riboflavin mg/day	Niacin equivalents mg/day		Folate µg/day		Vitamin B6 mg/day	Vitamin B12 µg/day	Vitamin C mg/day	Vitamin E Alpha-tocopherol equivalents mg/day	
Gender & Age Group (years)		*RDI*	*UL*	*RDI*	*RDI*	*RDI*	*UL*	*RDI*	*UL*	*RDI*	*RDI*	*RDI*	*AI*	*UL*
Men	51-70	900	3,000	1.2	1.3	16	35	400	1,000	1.7	2.4	45	10	300
Women	31-50	700	3,000	1.1	1.1	14	35	400	1,000	1.3	2.4	45	7	300
Women	51-70	700	3,000	1.1	1.1	14	35	400	1,000	1.3	2.4	45	7	300
Women	>70	700	3,000	1.1	1.3	14	35	400	1,000	1.5	2.4	45	7	300

Minerals, trace elements & units		Calcium mg/day		Phosphorus mg/day		Zinc mg/day		Iron mg/day		Magnesium mg/day		Iodine µg/day		Selenium µg/day		Potassium mg/day	Sodium mg/day
Gender & Age Group (years)		*RDI*	*UL*	*RDI*	*UL*	*RDI*	*UL*	*RDI*	*UL*	*RDI*	*UL**	*RDI*	*UL*	*RDI*	*UL*	*AI*	*AI*
Men	51-70	1,000	2,500	1,000	4,000	14	40	8	45	420	350	150	1,000	70	400	3,800	460-920
Women	31-50	1,000	2,500	1,000	4,000	8	40	18	45	320	350	150	1,000	60	400	2,800	460-920
Women	51-70	1,300	2,500	1,000	4,000	8	40	8	45	320	350	150	1,000	60	400	2,800	460-920
Women	>70	1,300	2,500	1,000	4,000	8	40	8	45	320	350	150	1,000	60	400	2,800	460-920

Note. Table adapted from "*Nutrient Reference Values for Australia and New Zealand Executive Summary*," by National Health and Medical Research Council, Australian Government Department of Health and Ageing, & New Zealand Ministry of Health, 2006, National Health and Medical Research Council. Copyright 2016 Commonwealth of Australia. Note an AI is set when an RDI cannot be established. The UL only exist for nutrients in the table that have it allocated. The age groups and genders allocated in the table are representative of the age groups and gender of the seven participants in this case series.

Abbreviations: µg—Micrograms; mg—Milligrams; RDI—Recommended Dietary Intake; UL—Upper Limit; AI—Adequate Intake.

*The UL of magnesium intake represents the recommendations for magnesium supplement use.

2.4.7 Nutrition Support

Nutrition care, including enteral nutrition, plays a critical role in the nutritional management of this vulnerable population (Przekop et al., 2022). Enteral nutrition through feeding tube placement is often necessary when oral intake is insufficient to meet nutritional needs (Cook et al., 2022). This may be due to the disease's location, which can impair chewing and swallowing, compromising the ability to consume sufficient calories orally to meet increased nutrition requirements (Cook et al., 2022).

2.4.8 Lack of Protein and Energy Intake

The preservation of skeletal muscle mass in cancer patients remains a key treatment challenge in terms of clinical and functional outcomes (McCurdy et al., 2019). Loss of lean muscle mass and body weight in cancer patients is often caused by negative energy and protein balances (Jager-Wittenaar et al., 2011a; Nejatinamini et al., 2018a). Maintaining a positive energy balance is essential for optimal muscle protein synthesis (McCurdy et al., 2019). Inflammatory activity related to disease or treatment may increase energy expenditure and protein breakdown, necessitating higher protein and energy requirements in cancer populations (Jager-Wittenaar et al., 2011a). The European Society for Clinical Nutrition and Metabolism (ESPEN) has developed evidence-based guidelines for dietary intake of energy (25-30 kcal/kg body weight (BW)/day) and protein (1-1.5 g/kg BW/day) in cancer patients (McCurdy et al., 2019). However, these guidelines are based on low to moderate evidence and more research is needed to support these recommendations and reduce the risk of malnutrition in cancer patients (McCurdy et al., 2019). In research involving individuals undergoing therapy for HNC malignancies, weight reduction and skeletal muscle loss were associated with energy and protein intakes exceeding 30 kcal/kg BW/day and 1.0 g/kg BW/day, respectively (Martin et al., 2022). This suggests that HNC patients may require higher energy and protein requirements than those recommended by ESPEN to prevent weight loss and altered body composition.

McCurdy et al. (2019) note that several studies have attempted to quantify the energy required to prevent weight loss in HNC, but results have been inconsistent due to patient heterogeneity and varying therapeutic approaches. A prospective study conducted by Kipouros et al. (2023) found that despite consuming the minimum suggested amounts of protein and EI recommended by ESPEN (≥ 25 kcal/kg BW/day) and (≥1.0 g/kg BW/day), HNC patients still experienced weight and skeletal muscle loss. These findings indicate that the minimum calorie (25 kcal/kg BW/day) and protein (≤1.0 g/kg BW/day) guidelines may not be sufficient to prevent skeletal muscle loss and maintain a positive protein balance in HNC patients (McCurdy et al., 2019). The optimal protein intake to reduce weight and muscle loss of HNC patients during treatment is suggested to be greater than 1.7 g protein/kg

BW/day (Jager-Wittenaar et al., 2011a). Recent literature suggests that a protein intake of 2g/kg BW/day might be the optimal dose to maintain a positive protein balance in cancer patients (Kipouros et al., 2023). The amount of energy and protein required to preserve lean muscle mass in patients with HNC remains unclear (Jager-Wittenaar et al., 2011a). Therefore, further research is necessary to establish optimal protein and energy requirements for oncology patients, as these requirements can vary depending on the degree of metabolic alterations caused by different cancers and treatment modalities. Therefore, nutritional care decisions must consider each patient's unique needs (Kipouros et al., 2023).

2.5 Malnutrition Occurrence in Head and Neck Cancer Survivors

The prevalence of malnutrition in HNC survivors is not well-studied, despite a well-established prevalence of malnutrition in HNC populations (Steer et al., 2020). The physiological consequences of malnutrition develop gradually over time when food and nutrient intake are insufficient to meet the body's nutritional requirements. This leads to a decrease in lean muscle tissue, unintentional weight loss and deterioration of physical function (Di Bella et al., 2020). To diagnose malnutrition, Cederholm et al. (2015) state that unintentional weight loss is defined as more than 10% of habitual weight, indefinite of time, or more than 5% over three months, with at least one of the following present: reduced BIM, less than 18.5 kg/m^2, or a low fat-free mass index of less than 15 kg/m^2 and less than 17 kg/m^2 in females and males, respectively. The ESPEN guidelines state that malnutrition is defined as a corresponding BMI of less than 18.5 kg/m^2 (Deng et al., 2023). In this context, HNC patients presenting with a lower BMI are at increased risk of malnutrition (Susetyowati et al., 2024). However, BMI alone in isolation is insufficient for diagnosing malnutrition, as it has been recognised to have low sensitivity in identifying malnourished HNC patients (Buntzel et al., 2019). Therefore, the weight status of individuals should be clinically assessed to determine unintentional weight loss.

The incidence of cancer-related malnutrition in HNC patients is attributed to a variety of factors (Heal et al., 2024), including tumour obstruction, which impedes oral intake, and NIS associated with multimodality treatment (Brown et al., 2023; Nejatinamini et al., 2018b). As a result, there is an increased risk of inadequate nutritional intake, leading to reduced energy consumption and altered energy utilisation, which exacerbates weight loss and the development of malnutrition (Hunter et al., 2020). Malnutrition can occur at any stage of the patient’s cancer trajectory and has been reported in 60% of HNC patients before treatment, increasing to 86% at the end of chemoradiation (Cook et al., 2022). The effects of surgery, chemotherapy, and radiation therapy exacerbate symptoms in HNC patients, making it more difficult to attain adequate EI and maintain weight status (Giles et al., 2016), which in turn heightens the risk of severe malnutrition (Dechaphunkul et al., 2013).

Studies assessing malnutrition beyond post-treatment in HNC patients are limited. However, the author found two studies that assessed malnutrition risk in post-treated HNC survivors. Einarsson et al. (2020) prospectively determined the prevalence of malnutrition using the GLIM phenotypic and etiological diagnostic criteria in a heterogeneous cohort of HNC patients undergoing a variety of treatments at different periods: during treatment and six months and one-year post-treatment. Results showed a malnutrition prevalence ranging from 0.5 to 32.4%, depending on the time point and combination of diagnostic criteria used. Another study by van den Berg et al. (2014) found that six of 32 patients, at a median follow-up of 44 months post-chemoradiation therapy, were at risk of malnutrition. Interestingly, all 32 study participants had advanced-stage HNC (stage III-IV), a known risk factor for malnutrition development (Silander et al., 2013b). Further, this study highlighted that 75% of participants had dysphagia at 44 months, and weight loss was observed in 50% of participants (n = 16) (van den Berg et al., 2014). Weight loss and dysphagia are clinical risk factors that can exacerbate malnutrition development, and this is evident from similar studies, which have shown that dysphagia is a long-lasting burden after HNC treatment, particularly post-chemoradiation therapy (Crowder et al., 2018; Karampela et al., 2021). In particular, Hopanci Bicakli et al. (2017) reported that high-dose radiotherapy-induced dysphagia and mucositis resulted in a vicious cycle of malnutrition. These findings suggest a link between the presence of dysphagia and an increasing risk of malnutrition development. In contrast, both Einarsson et al. (2020) and van den Berg et al. (2014) used different diagnostic criteria to determine malnutrition and malnutrition risk, making it difficult to compare and evaluate the true extent of malnutrition in HNC survivors with limited studies available.

Notably, a considerable portion of malnutrition was reported in 44-88% of HNC patients after treatment completion and during the rehabilitation period (Frydrych et al., 2023; Susetyowati et al., 2024; Tomasz et al., 2021). This varying prevalence reflects the negative impact of HNC and its associated therapies on the nutritional state of HNC survivors post-treatment. This increasing prevalence raises growing concerns, foreshadowing a widespread variance in malnutrition among this population due to the vast contributing factors outlined in Table 7. Therefore, it is imperative to assess the prevalence of NIS and dietary adequacy and routinely screen for malnutrition in community-living HNC survivors.

Table 7. *Factors Contributing to Malnutrition Development in Head and Neck Cancer*

Author(s)	Contributory Factors	Aetiology	Nutritional Concerns and Outcomes
	Physical		
Cook et al. (2022)	Tumour Characteristics and Disease	Mechanical Obstruction and Altered Anatomy • Aspiration (passage of food and fluids into the lungs) • Dysphagia (difficulty swallowing) • Odynophagia (pain commencing swallow) • Limitations on dietary textures Metabolic Demands of the Disease • Utilisation of nutrients for tumour growth	• Increased nutritional requirements due to tumour burden • Reduced appetite • Unintentional weight loss • Muscle wasting • Loss of muscle mass and strength
Cook et al. (2022), Crowder et al. (2021) and Shaw (2010)	Difficulty Chewing 2^0 to Cancer Therapies	• Lack of teeth • Ill-fitting dentures (associated with mucosal change, altered anatomy and weight loss) • Physical problems with jaw movement	Can markedly affect food choices by becoming limited to soft or liquid foods. This, in turn, can impact dietary intake and nutrition status, posing a significant risk of malnutrition development
Crowder et al. (2021) Shaw (2010)	Difficulty Swallowing 2^0 to Cancer Therapies	• Presence of the tumour mass obstructing functional structures involved in swallowing • Pain while eating • Ulcerated mouth • Fear of chocking	It compromises the safety of swallowing and results in the composition of a diet restricted in variety, texture, and nutritional content. Increasing malnutrition risk
Shaw (2010)	Weight Loss and Changes in Body Composition	• Presence of tumour • Tumour stage • Tumour therapy • Severity and occurrence of NIS	Disruption in energy balance with alterations in resting energy expenditure, utilisation of glucose, mobilisation of both protein and fat reserves, and release of muscle protein

Author(s)	Contributory Factors	Aetiology	Nutritional Concerns and Outcomes
	Behavioural		
Cook et al. (2022) and Shaw (2010)	Poor Dietary Habits	• Cost of food • Limited support network • Limited nutrition knowledge	Consumption of unbalanced meals causes protein and micronutrient deficiencies, exacerbating malnutrition risk
Cook et al. (2022) and Shaw (2010)	Excessive Alcohol Intake	• Displacing nutrients (reducing absorption or increasing losses) compromising nutrition status	Displaces nutrients and suppresses appetite, leading to inadequate uptake of nutrients. This causes a direct effect on weight status and development of malnutrition
	Physiological		
Cook et al. (2022) and Shaw (2010)	Anxiety and Depression	• Cancer diagnosis and treatment • Limited support network	Food aversions and/or loss of appetite impact oral intake and nutrition status, exacerbating malnutrition risk
	Social		
Cook et al. (2022) and Shaw (2010)	Limited Support Network	• Patients who live alone • Patients who have no family	Can become less motivated, thus rendering it more difficult to maintain adequate nourishment

Author(s)	Contributory Factors	Aetiology	Nutritional Concerns and Outcomes
	Overall Health Status		
Shaw (2010)	Higher Risk of Hospital Admission	• Nutritional deterioration • Malnourished	Feeding management is required with the increased length and cost of hospital stays
Shaw (2010)	Poor health-Related Quality of Life	• Altered body composition • Facial disfigurements • Problems eating, breathing, and speaking • Negative body image • Depression, anxiety, and fatigue • Impaired communication • Disrupted social relationships, social isolation, stigmatism, and work impairments	Altered nutrition status, exacerbating malnutrition risk
Shaw (2010)	Increased Morbidity and Mortality	• Poor nutrition status combined with malnutrition	Reduced tolerance to cancer treatments limits the alternatives and choices for cancer therapy, contributing to reduced tumour control and poorer survival

2.5.1 Malnutrition Diagnosis

Currently, there are no specific guidelines for nutrition screening of HNC patients (Li et al., 2021), despite the high prevalence of malnutrition in this population, ranging from 20% to 74% (Steer et al., 2020). Nutrition screening tools are considered necessary to predict the risk of malnutrition in oncology patients (Susetyowati et al., 2022). To effectively identify malnutrition risk in HNC survivors, it is critical to select a validated and appropriate nutrition screening tool for oncology populations. Several malnutrition screening tools have been developed, including the Malnutrition Universal Screening Tool (MUST), Nutrition Risk Screening-2002, Mini Nutrition Assessment, Subjective Global Assessment, and Patient-Generated Subjective Global Assessment (PG-SGA) (Emir et al., 2024; Siregar et al., 2022). ESPEN recommends all the above screening tools to assess malnutrition risk (Siregar et al., 2022). However, evidence-based practice guidelines specifically recommend the PG-SGA for assessing nutrition status and diagnosing malnutrition in adult HNC patients. The PG-SGA is a validated, gold-standard-scored nutrition assessment tool (Abbott et al., 2016; Brown et al., 2023), designed for oncology populations (Farhangfar et al., 2014; Gabrielson et al., 2013; Zhang et al., 2021). The PG-SGA is recommended by ESPEN and the American Dietetic Association (Zhang et al., 2021), and endorsed by the Oncology Nutrition Dietetic Practice Group of the Academy of Nutrition and Dietetics (Siregar et al., 2022). Known for its high sensitivity and specificity (Susetyowati et al., 2022), the PG-SGA evaluates weight loss history, dietary intake, 14 NIS (as present or absent), performance status (Farhangfar et al., 2014), metabolic stress, and a subjective physical assessment of fat, muscle mass, and fluid—all key factors influencing nutrition and malnutrition risk. Based on combined assessment, malnutrition is classified as follows: well-nourished (PG-SGA-A), moderate or suspected malnutrition (PG-SGA-B), or severely malnourished (PG-SGA-C) (Susetyowati et al., 2022; Zhang et al., 2021).

Several studies have validated the use of the short version, PG-SGA SF (Appendix A), for detecting the risk and presence of malnutrition in oncology inpatients and outpatients, demonstrating its sensitivity, specificity, and accuracy (Abbott et al., 2016; Azevedo et al., 2024; Carrico et al., 2021; De Groot et al., 2020; Gabrielson et al., 2013; Jager-Wittenaar et al., 2020). Additionally, the PG-SGAA SF has been shown to be comparable to the full-length PG-SGA tool in terms of sensitivity and specificity for oncology populations (Gabrielson et al., 2013). The PG-SGA SF is the most studied proactive screening instrument and multidimensional nutrition assessment tool (Dewansingh et al., 2021). It is limited to the first section (Part A) of the PG-SGA, which addresses weight loss history, food intake, 14 NIS (present or absent), as well as the patients activities and functional abilities (Abbott et al., 2016; Azevedo et al., 2024; Dewansingh et al., 2021). Together, the domains in Part A of the PG-SGA-SF reflect 80 – 90% of the total score of the full PG-SGA version (Azevedo et al., 2024). The PG-SGA SF excludes

the physical examination, disease/condition, metabolic demand, and physical assessment components of the full PG-SGA (Abbott et al., 2016).

2.5.2 The Validity and Reliability of the Patient-Generated Subjective Global Assessment Short Form in Oncology Settings

The validity and reliability of the PG-SGA SF for detecting malnutrition risk in an oncology setting have been assessed by Abbott et al. (2016), Gabrielson et al. (2013) and De Groot et al. (2020), who utilised this tool in an outpatient setting, compared to Azevedo et al. (2024) and Carrico et al. (2021) who utilised this tool in an inpatient setting. Among these five studies, Azevedo et al. (2024) was the only study to independently investigate a population of HNC oncology patients, whereas the other four studies examined mixed tumour locations. The PG-SGA SF cut-off scores for diagnosing malnutrition also varied between studies.

Gabrielson et al. (2013) demonstrated a PG-SGA SF cut-off score of 6 or greater achieved 94% sensitivity and 78% specificity, respectively, for diagnosing malnutrition. These results were slightly lower compared to the full PG-SGA, which yielded 97% sensitivity and 86% specificity, respectively, for detecting malnutrition (Gabrielson et al., 2013). Gabrielson et al. (2013) also demonstrated that increasing the cut-off score to 7 or greater improved specificity (reducing the misclassification of well-nourished participants as malnourished) at the cost of compromising sensitivity (resulting in malnourished cases going undetected). As a result, they proposed that a cut-off score of 6 or greater is sufficient for diagnosing malnutrition in oncology populations. In contrast, De Groot et al. (2020) found that a PG-SGA SF cut-off score of 5 or greater achieved 89% sensitivity and 80% specificity, respectively, when compared to the reference PG-SGA. Abbott et al. (2016) reported that a PG-SGA SF cut-off score of 3 or greater yielded a sensitivity and specificity of 80.4% and 72.3%, respectively, for predicting malnutrition according to the PG-SGA global rating. Recent studies by Azevedo et al. (2024) and Carrico et al. (2021) demonstrated that a final PG-SGA SF score of 9 or greater had the best performance in diagnosing malnutrition. Findings from Azevedo et al. (2024) highlighted that this cut-of score generated a high sensitivity and specificity of 84.96% and 85.83%, respectively, indicating that a score of 9 or greater can predict a high proportion of true positives for malnutrition while minimising false negatives. Similarly, Carrico et al. (2021) reported sufficient sensitivity and specificity of 95% and 67%, respectively, with a cut-off score of 9 or greater when compared with the completed version of the PG-SGA. Furthermore, irrespective of age, gender, or geographic region, a final scored PG-SGA SF of 9 or greater was consistently associated with diagnosing malnutrition (Azevedo et al., 2024).

The cut-off score proposed by Carrico et al. (2021) demonstrated higher sensitivity compared to the scores suggested by Abbott et al. (2016), De Groot et al. (2020), Gabrielson et al. (2013), and Azevedo et al. (2024), indicating that a cut-off score of 9 or greater may be more effective and sensitive in diagnosing malnutrition in oncology populations. Although sensitivity is statistically important, the accredited literature has validated that a scored PG-SGA SF that achieves 80% sensitivity and 60% specificity, respectively, is sufficient for diagnosing malnutrition in oncology patients (De Groot et al., 2020). Therefore, the PG-SGA SF cut-off scores proposed by all five studies would be sufficient for diagnosing malnutrition in oncology patients.

The optimal cut-off scores for diagnosing malnutrition in an oncology population varied considerably between studies. The observed variations depend on several factors, including the method of administration (e.g., PG-SGA SF completed by the patients vs. a trained dietitian), the formatting of the PG-SGA SF (e.g., the removal of the activity box), the study population (inpatients vs. outpatients), the type and stage of malignancy, and the treatment received. These factors are important to consider, as the stage of disease, severity, and number of NIS can exacerbate insufficient oral intake, unintentional weight loss, and malnutrition risk. Despite these disparities, a PG-SGA SF cut-off score of 9 or greater is deemed sufficient to diagnose malnutrition in an oncology setting. Therefore, the PG-SGA SF can be regarded as a practical, informative, and valid tool for detecting malnutrition in an outpatient oncology setting (Gabrielson et al., 2013).

2.5.3 How Nutrition Impact Symptoms are Measured in Head and Neck Cancer Populations

The PG-SGA SF can identify the presence or absence of 14 prevalent NIS (Carrico et al., 2021). However, the PG-SGA SF does not assess the severity of the symptom or how the symptom interferes with dietary intake (Schmidt et al., 2013). Identifying the presence and interference of NIS is critical for appropriately analysing their impact on oral intake. This, in turn, may help to identify and manage symptoms associated with reduced EI and weight loss, thereby monitoring and reducing malnutrition risk in HNC survivors (Kubrak et al., 2013). A more comprehensive and specific tool for measuring symptoms in HNC patients is called the HNSC. This tool was specifically designed to assess the NIS related to reduced dietary intake in individuals with HNC. The HNSC tool evaluates 17 symptoms, compared to 14 in the PG-SGA SF (Schmidt et al., 2013). The HNSC provides a list of symptoms that the literature associates with reduced dietary intake (Schmidt et al., 2013). Additionally, the HNSC has additional space to record NIS not listed, which may be interfering with oral intake. Furthermore, Kubrak et al. (2013) proposed that the HNCSC should ideally be utilised alongside the assessment of weight and nutritional consumption to strengthen and target nutrition care. Moreover, the specificity and sensitivity of this tool were assessed in a sample of 368 treated HNC patients, demonstrating a scored sensitivity of 79-98% and specificity of 99-100% (Schmidt et al., 2013). Kubrak et al. (2013) further validate this tool in post-treated HNC patients, assessing the effects of NIS on EI and malnutrition. This study confirmed that the HNSC is an effective instrument for identifying and evaluating symptoms that impact dietary intake in HNC populations during and after treatment.

2.5.4 Dietary Assessment Methods

An individual's nutrition status is determined by adequate nutrient consumption that fulfils nutrition requirements, allowing nutrients to be used to compensate for losses and maintain reserves. In light of the diversity of factors and the variability of mechanisms involved in the nutritional balance of each individual, it is critical to employ rigorous measures to guide a more precise and accurate evaluation of nutrition status (Fernandez-Lazaro & Seco-Calvo, 2023). Therefore, accurate and reliable estimates of dietary intake, particularly protein, energy, and micronutrients, are imperative. In research, however, measuring individual dietary intakes is notoriously complex and subject to both random and systematic error (Bailey, 2021). To analyse key malnutrition-specific nutrients (protein and energy) and key micronutrients in HNC survivors post-treatment, a precise and validated dietary assessment method is necessary to assess the quality of the diet as well as measure and efficiently analyse macro- and micronutrient intake from foods and beverages, respectively.

Traditionally, dietary assessment techniques are categorised based on the scope of interest and can include both retrospective and prospective methods. The food frequency questionnaire (FFQ) and single- or multiple-pass 24-hour dietary recalls are examples of retrospective dietary evaluation methodologies (FAO, 2018). These methods rely heavily on the participants' memory and ability to recall all foods eaten and portion sizes consumed in the past. Prospective methods include food records, which provide a more comprehensive level of specificity and detailed information regarding foods consumed and meal patterns compared to other traditional dietary assessment methodologies (FAO, 2018). A dietary recall consists of a detailed list of all foods, beverages, and supplements consumed within a specified period of time. It is generally recommended that three to four days of intake be recorded, as recording more days tends to diminish the quality of the information recorded due to a higher participant burden (Bailey, 2021). Ideally, dietary intake is weighed and measured, but in practice, it is more commonly estimated by participants before and after consumption, as weighing adds a significant burden on participants, which may lead to fatigue and incomplete records. To use dietary records effectively, a population that is both literate and motivated is required (Bailey, 2021).

Both retrospective and prospective methods differ considerably when assessing dietary intake, particularly in terms of diet quality, participant burden, underreporting of food intake, and true representation of participants' habitual intake (Fontana et al., 2020). However, all dietary assessment methods share the limitation of relying on self-reported information (Fontana et al., 2020). Therefore, careful evaluation of traditional dietary assessment procedures used to measure dietary intake is essential.

Although a dietary record imposes a greater participant burden, the validity of a four-day food record was assessed by Kristal and Potter (2006), who reported that a four-day food record possessed superior predictive validity compared to an FFQ. Similarly, Prentice et al. (2011) reported that a four-day food record provided a stronger estimate for energy and protein intake estimate than an FFQ, with 24-hour recalls demonstrating an intermediate effect. Single- or multiple-pass 24-hour recalls are advantageous because they are not dependent on the participants' literacy and numeracy skills, thus imposing less burden on participants since the recall pertains only to the last 24 hours (FAO, 2018). Consequently, a 24-hour recall is beneficial, as it places less strain on the participants' memory and results in better accuracy and response rates (FAO, 2018). However, despite the reduced participant burden, more than one 24-hour recall is necessary to represent participants' habitual intake accurately. Therefore, 24-hour recalls still pose the risk of recall bias, whereby participants may selectively only report on some foods during the recall (FAO, 2018). A prospective study by Kipouros et al. (2023) assessing the nutrition status of cancer patients used a multiple-pass 24-hour recall instead of an FFQ or weighed dietary record to reduce participants' burden in terms of completion and knowledge of nutrition. Despite the advantages of lower participant burden, Kipouros et al. (2023) reported that one 24-hour recall had the potential to limit the representation of patients' energy and protein intake. To identify HNC survivors at risk of malnutrition, an adequate representation of protein and EI is paramount. Therefore, it is evident that a more precise dietary assessment method is needed to detect a true representation of protein and EIs and malnutrition risk. A weighed dietary record is considered the gold standard in dietary assessment, as it offers far greater precision than both FFQ and 24-hour recalls. Capturing the quality and amounts of foods consumed minimises reliance on participants' recollection and further enhances data validity, providing a detailed dietary assessment that is indicative of current dietary intake (Namratha Pai & Urooj, 2014) in HNC survivors.

2.6 Concluding Statement

HNC possesses and mirrors the characteristics of a chronic illness (Karampela et al., 2021), exhibiting long-lasting treatment side effects that invade and compromise everyday functions. In light of this, it is imperative to understand how treatment consequences affect and impair daily functioning (Morton, 2003), especially the nutrition and social domains, which, when compromised, are known to profoundly exacerbate malnutrition development. Studies have extensively shown that malnutrition can develop at any stage of a person's cancer trajectory, as it is caused not only by the cancer but also by the accumulative side effects of the treatments administrated (Barrios et al., 2014). Therefore, malnutrition must be prevented and diagnosed early in treated HNC patients (Hopanci Bicakli et al., 2017). Notably, there is a considerable gap in both international and national research regarding the relationship between persistent NIS and malnutrition risk in community-living HNC survivors post-treatment. This is concerning as the growing number of HNC survivors underscores the pressing need for effective prevention and intervention strategies for long-term NIS. This highlights the urgent necessity for routine screening and symptom monitoring by healthcare professionals, particularly general practitioners, to identify and address clinical signs of malnutrition risk in community-living HNC survivors. Given the lack of current research on the relationship between persisting NIS and malnutrition risk, this study serves as a crucial step in filling this gap and emphasises the importance of targeted interventions to improve the quality of life and nutritional outcomes of HNC survivors. To the author's knowledge, this is the first scoping case series study in NZ to assess the presence and severity of NIS, nutrition status, dietary intake (macro- and micronutrients), and the prevalence of malnutrition among a cohort of HNC survivors living in NZ six months to three years post-treatment.

Chapter 3 | Research Study Manuscript

"I always feel I should be doing a lot better, and that everyone thinks I should be. (I often feel like crying) It's 8 months since surgery and I'm still only managing hyper pureed food." (PTP2)

Chapter 3 has been submitted as a long abstract for the Nutrition Society Conference 2024, peer-reviewed and accepted for publication in a scientific journal in abstract form, but has not yet been published.

Chapter 3 Research Study Manuscript

3.1 Abstract

Background: Head and neck cancer (HNC), characterised by malignant neoplasms originating in the oral cavity, upper aerodigestive tract, the sinuses, salivary glands, bone, and soft tissues of the head and neck, is diagnosed in approximately 600 people annually in New Zealand. Although HNC is a less common cancer, it has a profound effect on almost all aspects of the lives of those affected, particularly the nutritional and social domains. This is due to the common treatment modality being surgery and/or radiotherapy, which can result in major structural and physiological changes in the affected areas, which in turn affects chewing, swallowing, and speaking (Nilsen et al., 2020). Specific nutrition impact symptoms (NIS) of HNC have been identified and are significant predictors of reduced dietary intake and malnutrition risk (Kubrak et al., 2010).

Aim: We aimed to identify and describe the malnutrition risk, prevalence of NIS, and energy, macronutrient, and micronutrient intakes of community-living adult HNC survivors six months to three years post-treatment in New Zealand.

Methods: Participants were recruited through virtual HNC support groups in New Zealand. A descriptive observational case series design was used. Malnutrition risk was determined using the Patient-Generated Subjective Global Assessment Short Form (PG-SGA SF). NIS were obtained via a validated symptom checklist, and dietary data was collected using a four-day food record.

Results: Participants are referred to as PTP1-PTP7. PTP1 was well-nourished. PTP3 through PTP7 were categorised as mildly/suspected to moderately malnourished (PG-SGA SF scores of 2-7), and PTP2 was severely malnourished (score of 16). NIS were experienced by all seven participants, with “difficulty chewing,” “difficulty swallowing,” and “dry mouth” the most common. PTP2 scored loss of appetite, difficulty chewing, and difficulty swallowing as interfering “a lot. “Despite being well-nourished, PTP1 had inadequate energy intake (EI) (86% of their estimated energy requirement [EER]). PTP2, 3, 6, and 7 also had inadequate EI (79%, 79%, 73%, and 99%, respectively, of their EER). PTP1–PTP6 had adequate protein intake based on a range of 1.2-1.5 g/kg body weight per day, with PTP7 meeting 97% of their protein requirements. Deficiencies in dietary calcium and potassium were identified. PTP1, 2, 4, and 6 exhibited inadequate calcium intakes, corresponding to 74%, 73%, 72%, and 55% of their recommended dietary intake, respectively. PTP2, 3, and 6 demonstrated insufficient potassium intakes, reflecting 88%, 91%, and 91% of their adequate intake, respectively.

Conclusion: The prevalence of malnutrition, NIS, and micronutrient deficiencies in this case series indicates an urgent need for greater long-term support for HNC survivors post-treatment and research to identify the true extent of malnutrition in this vulnerable cohort.

Key words: Head and neck cancer; survivorship; malnutrition; nutrition impact symptoms.

3.2 Introduction

HNC is recognised as one of the most challenging and complex malignancies to exist (Richardson, 2016) due to the persistent long-term challenges caused by the location of the malignancy and its treatments (Saeidzadeh et al., 2021). With advances in treatment, HNC survivors are living longer (Crowder et al., 2021) and, therefore, are more susceptible to enduring the long-term impacts of this disease. Approximately 550 people are diagnosed with HNC in NZ annually (Weaver et al., 2024). Although HNC is a less common cancer, it profoundly impacts every aspect of the lives of those affected, particularly the nutrition and social domains. This is due to the common treatment modality being surgery and/or radiotherapy, which can result in major structural and physiological changes in the affected areas, which in turn affects chewing, swallowing, and speaking (Nilsen et al., 2020).

These structural and physiological impairments, collectively known as NIS, can jeopardise the functional structures involved in food intake. NIS can persist long-term after treatment, develop years later, and may never resolve. Physiologically, NIS can restrict food intake, contributing to weight loss, diminished skeletal muscle mass, and, subsequently, malnutrition (Einarsson et al., 2024). Psychologically, NIS can affect social interactions, causing withdrawal during mealtimes (Einarsson et al., 2024). Despite eating difficulties being among the most commonly reported disturbances in HNC survivors (Andreassen & Hadler-Olsen, 2023), nutrition-related problems have received little attention in the post-treatment survivorship period (Crowder et al., 2021; McQuestion et al., 2011). This is concerning, given that specific NIS have been identified as significant predictors of reduced dietary intake and increased malnutrition risk (Kubrak et al., 2010). These challenges pose serious concerns for HNC survivors, especially since NIS can remain chronic and negatively impact overall health and quality of life (Ganzer et al., 2013). Despite the high prevalence of NIS and reported eating problems in HNC survivors, malnutrition screening following treatment for oral and oropharyngeal cancer remains scarce (Jager-Wittenaar et al., 2011b). Furthermore, Taylor et al. (2023) note that although HNC survivors experience long-term negative side effects from both the disease and its treatments, these ongoing eating issues are often under-recognised in this population.

Limited surveillance and attention to long-term NIS and malnutrition in HNC survivors is concerning, given the potential repercussions of nutritional inadequacy, malnutrition, and subsequent deconditioning. This places an already vulnerable population at high risk, particularly if there is a recurrence of disease or the development of other medical conditions. While several studies have examined HNC survivorship and the negative effects of long-term NIS on nutrition, to the authors' knowledge, only two studies have assessed the nutrition status of HNC survivors post-treatment by screening for malnutrition risk using instruments like the MUST (van den Berg et al., 2014), and

applying the GLIM criteria to diagnose malnutrition in treated, community-living HNC survivors (Einarsson et al., 2020). These findings suggest that HNC survivors are not routinely assessed for malnutrition risk.

Notably, previous research has established a link between the presence of NIS and reduced food intake, exacerbating weight loss (Granstrom et al., 2022; Kubrak et al., 2013; McQuestion et al., 2011; Payakachat et al., 2013). Reduced food intake and weight loss exacerbate deconditioning and contribute to malnutrition development. The impact of long-term NIS on nutrition status, particularly the increased risk of malnutrition, has been well documented. Despite this, malnutrition screening remains infrequent in community-living HNC survivors, who are more vulnerable to enduring NIS. Therefore, the primary aim of this study is to determine and describe the prevalence of malnutrition, NIS, and dietary intake in community-living HNC survivors in NZ.

3.3 Methods

3.3.1 Study Design and Participants

The study was an observational descriptive case series involving seven adult survivors of HNC. Case series typically comprise five to ten participants, according to the empirical literature. The inclusion of seven participants in this case series was therefore appropriate. The case series participants were described individually, utilising a three-phase design. Phase one involved the development of an online survey to assess malnutrition status and NIS, along with cancer characteristics and demographic data. In the second phase, participants completed a four-day food record to analyse their energy, macronutrient, and micronutrient status. The final phase of the study involved a concluding survey to further assess long-term NIS, coping strategies, and eating experiences, both socially and post-treatment. Participants were individuals who had been diagnosed with HNC and completed medical treatment within the previous six months to three years. All participants were over 18 years old, completed an online consent form before completing the survey, were diagnosed and treated in NZ, and currently resided in NZ. Data was securely stored on a Massey University SharePoint site, with access limited to the research team. The study was reviewed and evaluated as a low risk by the Massey University Human Ethics Committee.

3.3.2 Development of Online Survey

The main online survey was developed to assess malnutrition status and NIS prevalence alongside cancer characteristics and demographic data. The initial survey underwent an expert peer-review process to ensure content validity and readability.

A team of three NZ-based researchers, including two Senior Lecturers in Exercise and Sport Science (one with a PhD in Nutrition Science and the other a Professor of Human Nutrition) and a second-year Master of Science (Nutrition and Dietetics) student, developed the first version of the survey. The 2023 NZ Census, a validated malnutrition screening tool (PG-SGA SF), and the HNSC were individual demographic and assessment tools that were discussed and reviewed before the initial draft of the survey. The initial draft was reviewed by a NZ Registered Dietitian; suggested changes and feedback were discussed between the research team members, and the required adjustments were implemented. The readability of the online survey was checked by a research team member during a trial run of the survey.

The main online survey (Appendix B) was divided into five sections: Part A encompassed demographic questions derived from the 2023 NZ Census for the purpose of describing each participant by age, ethnicity, level of education, and living situation. Part B covered cancer information questions to capture the clinical characteristics of the participants' HNC, including heterogeneity, location, stage, and treatment modalities received. Part C covered self-reported body measures, capturing current weight status, height, weight prior to diagnosis, and weight status one month and six months ago to calculate percentage change in weight. Part D addressed NIS and changes in food intake. Part E covered activities and functions. Part C – E incorporated the necessary questions to complete both the PG-SGA SF and HNSC.

3.3.3 Nutrition Status using the Patient-Generated Subjective Global Assessment Short Form

To assess nutrition status, each participant received a total score from the PG-SGA SF. This descriptive nutrition screening tool (Abbott et al., 2016) evaluates domains of nutrient balance (presence or absence of NIS and diet quality), weight status, and function (Dewansingh et al., 2021). A self-reported instrument, the PG-SGA SF, was used in the present investigation to meet the requirements of an online survey. The PG-SGA SF generates a total score ranging from 0-36, derived from the first four domains of the scored PG-SGA (Abbott et al., 2016; Azevedo et al., 2024). Higher scores indicate a greater risk of malnutrition (Gabrielson et al., 2013).

Domain one describes current weight status (Abbott et al., 2016) and changes in body weight, including percentage weight loss, with scores ranging from 0 to 5 (Abbott et al., 2016; Azevedo et al., 2024). Domain two assesses change in food intake, using descriptors such as 'unchanged', 'more than normal', and 'less than normal', 'little solid food', 'only liquids or nutritional supplements', 'very little of anything', and 'only tube feeding or only nutrition by vein.' This domain has a total score ranging from 0-4 points (Azevedo et al., 2024). Domain three examines the existence of NIS in the last two weeks, encompassing symptoms that affect oral intake, such as mouth sores, pain, dysphagia, xerostomia, vomiting, and constipation, among several others, with a possible score of up to 24 (Azevedo et al., 2024). Finally, domain four evaluates the changes in functionality over the previous month, assessing the participant's ability to perform daily activities, with scores ranging from 0 to 3 (Abbott et al., 2016; Azevedo et al., 2024; Gabrielson et al., 2013); Appendix A.

All seven PG-SGA SF assessments were completed by the primary researcher using the self-reported measures obtained from the main online survey. The allocated PG-SGA SF scores were checked by a secondary researcher. In the event of a disagreement in scoring, the research team reviewed the PG-SGA SF score from the source data, and a consensus decision was made. Through extensive evaluation and critique of the current literature, optimal PG-SGA SF scores varied. After an extensive literature review and feedback from two NZ Registered Dietitians, participants with a score of 0-1 were defined as well-nourished, 2-3 mild/suspected malnutrition, 4-8 moderately malnourished, and ≥9 severely malnourished (Azevedo et al., 2024; Fu et al., 2022).

Anthropometric parameters required for domain one of the PG-SGA SF included self-reported body measures: weight (kg), height (cm), and weight status one month and six months ago, as obtained from the main online survey. The percentage of weight loss was calculated using the following formula: [(normal body weight -actual body weight)/normal body weight] x 100. The participants' self-reported weight status from one month ago was considered the most recent and recommended assessment of weight status to calculate % change in weight loss, compared to weight status from the previous six months (*How to guide: Patient-generated subjective global assessment*, n.d.). BMI (kg/m^2) was calculated using the following formula:[current self-reported body weight/(current self-reported height $(m)^2$] (Weir & Jan, 2024). BMI was classified according to the cut-off points proposed by the World Health Organisation (WHO) (Weir & Jan, 2024).

3.3.4 Nutrition Impact Symptoms

Each participant electronically completed the HNSC (Appendix C). A validated version of this instrument includes 17 NIS commonly experienced by HNC patients and has been validated to determine NIS that interfere with their dietary intake (Kubrak et al., 2013; Schmidt et al., 2013). The HNSC evaluates two important components related to nutrition intake, each rated on a separate five-point Likert scale (1 = not at all, 5 = a lot) (Kubrak et al., 2013; Nejatinamini et al., 2018b). The first section measures symptom presence (the frequency of the symptom in the last 3 days), while the second section measures the interference of the symptom with oral intake (whether the symptom affects the ability to eat) (Einarsson et al., 2024). A symptom was classified as present if a participant self-reported a score of 2.

3.3.5 Phase Two: Dietary Analysis

A dietary record detailing oral intake for four consecutive days was used to assess EI (kJ/day), macronutrients (protein, carbohydrates, total fat, and fibre g/day), and micronutrients (vitamins, minerals, and trace elements) status. Macronutrient and micronutrient intakes were compared to their corresponding acceptable macronutrient distribution range (AMDR), RDI, and AI (National Health and Medical Research Council et al., 2006).

Estimated energy requirements (EER) were calculated using the Henry Oxford equation (Henry, 2005) and self-reported physical activity level (PAL). Participants' self-reported age, weight, and height were used to determine basal metabolic rate, which was then multiplied by each participant's described PAL to arrive at EER (kJ/day). A weight gain factor was not applied to participants' EER when classified as mild/suspected, moderately, or severely malnourished due to inadequate data available to make this inference. Each participant's protein requirements were calculated using a range of 1.2-1.5g/kg BW per day. Considering this cohort has had cancer in the six months to last three years and has received treatment, it was deemed reasonable to estimate this protein range, as malnutrition risk and occurrence are high in this population group.

Supplements purchased over the counter were omitted from the nutrient analysis to determine which nutrients were adequate and inadequate with food intake alone. Multivitamins, protein powder, dissolvable supplements, fish oil, and fibre supplements were all classified as over-the-counter supplements. Fortisip liquid, Ensure powder, and Sustagen powder were defined as prescribed supplements and were part of the participants' daily dietary intake for those who relied on them; therefore, they were included in the nutrient analysis.

3.3.6 Phase Three: Final Online Survey

The final online survey included a mix of quantitative and qualitative open- and closed-ended questions. The purpose of this final phase was to explore and encompass personal eating experiences, adjustments made after treatment, and dietary preferences that participants may have adopted due to possible treatment side effects.

3.3.7 Data Collection

All participants were invited to complete both online surveys and the four-day food record between June 1st and July 31st. To facilitate participant recruitment, a study recruitment poster (Appendix D) was posted in two private, members-only Facebook support groups: Head and Neck Cancer Support Aotearoa (HNCSA) and NZ Head and Neck Cancer Support Group—The Explorers. The study poster was also advertised in the June edition of the HNCSA newsletter. The case series began with an information sheet (Appendix E) outlining the purpose of the research, participants' involvement, and the benefits of the study. A pre-screening eligibility questionnaire was completed by all participants before phase one of the study was made available to ensure they met the study's inclusion criteria (Appendix F). Food and drink consumption could be recorded on paper or digitally using the provided food record template, or participants could use WhatsApp to upload photos of their meals before and after consumption, along with a description. All participants received an instruction guide to facilitate measurable and reliable descriptions of food and drink consumed. Once the four-day food record was completed, the final online survey was individually sent to each participant (Appendix G). Additionally, a final email was sent to each study participant to clarify any missing information regarding their last active treatment received and PAL. Appendix H summarises the study's recruitment, screening and enrolment of participants.

3.3.8 Methods for Data Analysis

Data was collected in Qualtrics Survey software and exported into Microsoft Excel. Data collected from phases one and three surveys were cleaned, sorted, and translated. The PG-SGA SF and HNSC were completed by a single researcher using self-reported data from the primary survey. An experienced member of the research team double-checked and verified the self-reported responses from the main online survey against the completed PG-SGA SF and HNSC forms. One research team member entered data into FoodWorks using standard operating procedures (SOP) and a prepared study handbook (Excel file) to ensure uniformity across all foods entered. To ensure reliable entry of food records, all seven records were quality-checked before data entry. An additional researcher performed a final quality

check. Implementing SOP for data entry, utilising the study handbook, and cross-checking entries before and after data entry enhanced the accuracy and dependability of the entered data.

3.4 Results

3.4.1 Participants and Cancer Characteristics

This study recruited and enrolled seven adult HNC survivors living in NZ, six months to three years post-treatment. Participants were diagnosed with a range of HNCs affecting different areas of the head and neck. All seven participants were treated surgically, followed by either radiation therapy or chemoradiation therapy. All participants completed treatment between seven months and three years prior to data collection. The participant demographic data and cancer characteristics are shown in Table 8.

Table 8. *Demographic and Cancer Characteristics*

Participants	PTP1	PTP2	PTP3	PTP4	PTP5	PTP6	PTP7
Gender	Female	Female	Male	Female	Female	Female	Male
Ethnicity	NZE	NZE	NZE	British	NZE	NZE	NZE
Age (years)	43	76	69	54	66	74	60
BMI (kg/m^2)	20.1	21.0[a]	24.1	24.4	22.2	24.4	29.2[b]
Living situation	Family	Family	Family	Family	Family	Family	Alone
Education	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary	Tertiary	Secondary
Employment status	Business owner	Retired	Part-time	Full-time	Retired	Retired	Beneficiary
Tumour site	Salivary glands	Tongue	Salivary glands	Oropharynx	Oropharynx	Tongue	Oropharynx
Cancer type	MEC	Lichen Planus	SCC	SCC	ADCC	SCC	SCC
Tumour stage	III	Unknown	Unknown	II	IV	II	Unknown
Cancer diagnosed	December 2020	July 2023	April 2022	Jan 2022	November 2017	October 2021	March 2022
Treatment history	Surgery + RT	Surgery + RT	Surgery + RT	Surgery + CRT	Surgery + RT	Surgery + CRT	Surgery + RT
Time since treatment Completed *	3 years	7 months	1 year and 11 months	2 years	3 years	2 years and 5 months	1 year and 11 months

Note. The BMI classifications used were set by the WHO: Underweight[a] is considered <20 kg/m^2 for individuals under 70 years old and <22kg/m^2 for individuals 70 years and older. Normal weight ranges between 20–24.9 kg/m^2 for individuals <70 years old and 22–30 kg/m^2 for individuals 70 years and older. Overweight[b] is considered to range from 25–29.9 kg/m^2 for individuals <70 years old (Weir & Jan, 2024). Age-appropriate cut-off BMI scores for malnutrition risk were assessed. A BMI of <20 kg/m^2 in participants under 70 years and <22 kg/m^2 in participants 70 years and over deemed malnutrition was present (Corish & Bardon, 2019). Abbreviations: PTP—Participant; NZE—New Zealand European; BMI—Body Mass Index; MEC—Mucoepidermoid Carcinoma; SCC—Squamous Cell Carcinoma; ADCC—Adenocarcinoma; RT—Radiation Therapy; CRT—Chemoradiation Therapy; WHO—World Health Organisation.

*Post-treatment status was calculated using the last known active HNC treatment received (the date this treatment ended) to June 2024 (the time of this study).

3.4.2 Presence and Interference of Nutrition Impact Symptoms

NIS that were present and the degree to which NIS interfered with oral intake are presented in Figures A1 and A2. Difficulty swallowing, sore mouth, and difficulty chewing were the most common NIS reported as interfering with oral intake. For example, PTP5 stated, “Swallowing is so effort-filled, and while eating, I’m working so hard not to aspirate it.” The act of mastication was defined as “tiresome” by PTP7. Furthermore, PTP2 reported that living with symptoms that affected their eating and drinking as “extremely tiring and even more extremely frustrating.” The participant who experienced the greatest burden was PTP2, who scored loss of appetite, difficulty chewing, and difficulty swallowing as having the highest impact, interfering “a lot” with oral intake. PTP7 scored lack of energy, anxiety, and depression as present “quite a bit," stating, “These traits are many features of my life as conditions I am having to cope with postoperatively.” However, PTP7 scored all 17 NIS with an interference score of 1 (“not at all”), reporting that none of these interfered with oral intake.

3.4.3 Clinical Presentation and Malnutrition Prevalence

Six of the seven participants were classified as malnourished, with the details presented in Table 9. PTP2 was severely malnourished and reported the highest NIS burden, and correspondingly, was the only participant with observed weight loss. PTP1, 3, 4, and 6 reported their weights had remained unchanged over the past two weeks, while PTP7 reported a decrease in weight during this timeframe. Symptom burden varied for each participant. The PG-SGA SF identified NIS that impacted participants’ ability to eat enough but did not allow expressing to what degree these NIS impacted oral intake. PTP2 scored highly for NIS burden, identifying mouth sores, problems swallowing, pain in their tongue, dry mouth, and feeling full quickly as preventing them from eating enough. PTP3’s total PG-SGA SF score of 6 was entirely derived from symptom burden. PTP3 identified swallowing problems, sore mouth, and pain in the jaw. Dry mouth, fatigue, and time available for lunch were reported by PTP4, while problems swallowing, feeling full quickly, and foods that taste funny or have no taste were reported by PTP5. While PTP 1, PTP6, and PTP7 reported “no problems eating.” PTP2, 5, and 6 ate a pureed, minced and moist, and easy-to-chew diet, respectively. While PTP1, 3, 4, and 7 ate a normal textured diet. The functional capability of PTP2, 5, and 7 had reduced in the past month.

Table 9. *Current Nutrition Status of Participants According to the Patient-Generated Subjective Global Assessment Short Form*

Participants	**PTP1**	**PTP2**	**PTP3**	**PTP4**	**PTP5**	**PTP6**	**PTP7**
Weight Status:	Unchanged	Decreased	Unchanged	Unchanged	Unchanged	Unchanged	Decreased
Food Intake Described as:	Unchanged	Less than usual Little solid food	Unchanged	*Normal food*, but less than normal amount	Little solid food	Less than usual *Normal food*, but less than normal amount	Less than usual
Symptoms Present:	0	**5**	**3**	**3**	**3**	0	0
Activities and Functions:	Normal	Reduced	Normal	Normal	Reduced	Normal	Reduced
Total Score	0	16	6	4	7	2	3
Nutrition Status	Well-Nourished	Severely Malnourished	Moderately Malnourished	Moderately Malnourished	Moderately Malnourished	Mild/Suspected Malnutrition	Mild/Suspected Malnutrition
Under the Care of Dietitian	No	Yes	No	No	Yes	No	No

Note. A PG-SGA SF score of 0–1 = Well-Nourished, 2–3 = Mild/Suspected Malnutrition, 4–8 = Moderately Malnourished, and ≥9 = Severely Malnourished (Azevedo et al., 2024; Fu et al., 2022). Malnutrition was defined as a PG-SGA SF score between 2–8 (mild/suspected-moderate malnutrition) or ≥9 (severely malnourished). Abbreviations: PTP—Participant.

3.4.4 Energy and Macronutrient Status

Energy and macronutrient intakes varied among participants (Table 10). Inadequate EI was common among five participants (EI <EER), while PTP4 and PTP5 exceeded their EER by 1,488 kJ and 2,936 kJ, respectively. This could have been attributed to their dietary choices of energy-dense foods, respectively. For example, PTP4 stated, “I allow myself higher-fat foods like cream and nuts and chocolate sometimes as it helps to fill me up and keep my weight up.” Six participants had sufficient protein intakes. PTP7 was the only participant who presented with inadequate protein and EI, achieving 97% and 99% of their estimated requirements, respectively. Fat intake exceeded the upper range of the AMDR for all seven participants, while the AMDR for carbohydrates was suboptimal for six participants, failing to achieve the lower range of recommended AMDR.

3.4.5 Micronutrient Status

Micronutrient status varied for all seven participants (Table A3). The most notable finding was that calcium intake was inadequate in four female participants. Potassium intake was also inadequate in three participants. PTP3 and PTP4 both exceeded the set UL for niacin equivalents. PTP1 and PTP2 presented with the most nutrient deficiencies. PTP1, PTP2, and PTP7 were the only participants who had insufficient iron, selenium, magnesium and zinc intake, respectively.

Table 10. *Energy and Macronutrient Composition*

Participants	PTP1	PTP2	PTP3	PTP4	PTP5	PTP6	PTP7
TEI (kJ/day)	**7555**[*]	**6337**[*]	**8995**[*]	10,022	11,059	**6324**[*]	**11,377**[*]
EER (kJ/day)	8837	7993	11,344	8534	8123	8564	11,462
Protein (g/day)	67	92	88	87	98	74	**111**[c]
Range (1.2 – 1.5 g/day)	64 – 80	68 – 86	86 – 108	79 – 99	66 – 82	73 – 92	114 – 143
CHO (g/day)	199	151	185	258	236	137	305
CHO AMDR	**44%**[a]	**40%**[a]	**34%**[a]	**42%**[a]	**35%**[a]	**36%**[a]	45%
Total Fat (g/day)	76	54	107	109	146	69	107
Fat AMDR	37%	32%	44%	40%	49%	40%	35%
Dietary Fibre (g/day)	30	25	47	28	36	**23**[b]	46

Note. Energy requirements were calculated using the Henry Oxford equation (Henry, 2005) multiplied by a self-reported PAL factor.
Protein requirements are based on a range of 1.2-1.5 g/kg body weight per day.
Carbohydrate and total fat requirements are based on the AMDR of 45-65% and 20-35%, respectively (National Health and Medical Research Council et al., 2006).
Abbreviations: PTP—Participant; TEI—Total Energy Intake; kJ—Kilojoules; EER—Estimated Energy Requirements; CHO—Carbohydrate; AMDR—Acceptable Macronutrient Distribution Range; PAL—Physical Activity Level; AI—Adequate Intake.
[*]Inadequate energy intake, not meeting their EER.
[a] Inadequate CHO intake not meeting the recommended AMDR of 45-65% of TEI.
[b] Inadequate dietary fibre intake not meeting the recommended AI (25 g/day and 30 g/day for females and males, respectively).
[c] inadequate protein intake, not meeting estimated protein requirements.

3.4.6 Eating Adaptations and Coping Strategies

Participants reported a variety of eating adaptations and coping strategies, which are detailed in Table A4. Common adaptations included using water or other liquids to facilitate swallowing solid food, taking a cautious approach to mastication to avoid biting the tongue or cheek and using a topical numbing spray. For example, PTP1 stated, “I have ‘eating water,’ which is the water I have with a meal just to help me swallow things that are tricky (usually insoluble things like chopped parsley, nuts, or raw carrot). Without eating water, I don’t eat, as sometimes I choke, and that’s scary!” Additionally, dietary adaptations and food avoidances were noted by participants as a consequence of successive treatments. For example, PTP5 stated, “Food intake has narrowed with each successive operation and treatment.” Conversely, PTP3 positively reported, “I enjoy eating healthy foods and can eat as much as I want to," further stating, “I just eat slower.” Food fortification was used by PTP5 to increase calorie intake and alter food consistency, utilising high-energy-dense foods such as oil, milk, and cream. Notably, PTP2 would further fortify their diet by making eggnog with Ensure powder and Fortisip liquid, suggesting awareness and education around food fortification. Furthermore, PTP6 positively mentioned, “It is easier to have a timetable when eating certain foods, i.e., nuts at certain times of the day, always a biscuit with coffee, etc.”

3.4.7 Eating Experiences Post Head and Neck Cancer Treatment

Participants' restricted chewing apparatus, insufficient saliva, aversion to choking, and altered swallowing capabilities led to an increased time spent eating after treatment. Participants stated that they were often the last ones to finish a meal at the table, sometimes resulting in their food remaining uneaten. For example, PTP4 stated, “It takes time to eat, you can’t just grab a snack if you are running late. I use up my full 30-minute lunch break eating fairly small amounts.” Furthermore, food intake was reported to have narrowed as a consequence of successive treatments and meals were reported to be smaller in size. For example, PTP5 stated, “Meals take up to an hour to eat and often feel boring and sad.” Notably, treatment outcomes lead to difficulties managing food textures. For example, PTP2 reported being unable to move gluggy textures with her “thungue (thigh + tongue)," a reconstructed tongue using the anterolateral thigh flap after a radical operation: “I have very little control over my thungue; it just wants to sit there smugly and tell me it is a LEG and legs don’t help with eating.” A common challenge reported by participants two to three years post-treatment was the ingestion of food textures that were dry and crunchy, such as bread, crackers, biscuits, and bread rolls, which were often avoided without the presence of water. Eating in social situations was notably individualised, as depicted in Table A5.

3.5 Discussion

This case series highlights the complex interplay of physical, functional, and social impairments stemming from the prevalence of NIS. These impairments include malnutrition, inadequate protein and EI, micronutrient deficiencies, and social isolation. This section will discuss NIS, the nutritional impact and consequences thereof, and coping strategies used by participants.

3.5.1. Nutrition Impact Symptoms

Eating is simultaneously physiological in nature and symbolic (Ganzer et al., 2015b). The effects of HNC and its invasive treatments—radiation therapy, chemotherapy, and surgery—profoundly impact the "functional, psychological, social, and physical aspects of eating" (Cousins et al., 2013). Consequently, many HNC survivors endure long-term consequences of cancer treatment, specifically NIS. Despite advancements in treatment, eating problems and long-term consequences of NIS remain an ongoing challenge (McQuestion et al., 2011). Taylor et al. (2023) note that HNC survivors have not been extensively studied for their long-term challenges after treatment. In the present study, common NIS reported by participants included difficulty chewing, dry mouth, and, most commonly, difficulty swallowing, which significantly predicts dietary intake (Schmidt et al., 2013). Taylor et al. (2023) support these study findings, demonstrating that HNC survivors, five to ten years post-diagnosis, still experience difficulty swallowing, eating, and dry mouth. Similarly, Frowen et al. (2016) found a significant decline in swallowing function six months to five years post-treatment in HNC survivors. Payakachat et al. (2013) further identified that eating and swallowing problems persisted consistently five years after initial treatment. Collectively, these studies highlight that NIS remain a chronic health issue that can severely compromise the nutrition status and quality of life of HNC survivors. In compassion, Hammerlid et al. (1998) found that HNC survivors presented with fewer problems swallowing food ($p < .05$) at a two-year follow-up. Although a significant finding, fewer swallowing problems may have been attributed to the study's small sample size of 48 participants, which could have potentially affected the reliability of this finding. Furthermore, the heterogeneity of HNC location and treatment received in the cohort—whereby four participants had sinus cancer, one had skin cancer, and one had thyroid cancer, which is less likely to affect swallowing function due to their location and treatment area.

3.5.2 Physical and Functional Alterations

The oral cavity serves as a starting point for all food intake and digestive processes (Darwin et al., 2021). HNC and its treatments distinctly impact the specialised and intricate anatomical structures, organs, and tissues of the head and neck, which are essential for normal physiological functioning (Roesch & Tadi, 2024). Studies have demonstrated that muscle atrophy in the head and neck muscles affects the ability to ingest food and facilitate mastication and swallowing processes (Chiu et al., 2022; Gellrich et al., 2015). These functional impairments have been identified as underlying causes of malnutrition (Gellrich et al., 2015). This is particularly significant because disabling musculoskeletal functions of the head and neck disrupt conventional eating and drinking processes, thereby jeopardising nutrition status. Maintaining sufficient food intake can be challenging when such impairments exist.

The degree of altered physical and functional structures of the head and neck varies among survivors of HNC, depending on type of HNC and treatment received. Chewing and swallowing functional declines were prevalent in this case series. Some possible explanations for the high prevalence include the type of HNC treatment these participants underwent and their inability to maintain a positive energy balance necessary to sustain protein synthesis (McCurdy et al., 2019) in the intricate muscles of the head and neck region. This suggests that muscle loss may occur as a result of treatment side effects and inadequate EI, which impairs protein synthesis, prioritising body protein utilisation instead (Hayamizu, 2017). Disruptions in protein metabolism may stimulate muscle atrophy, compromising the physical structure of indispensable head and neck muscles and, in turn, manifesting as chewing and swallowing impairments.

PTP1, 3, 4, 6 and 7 all underwent neck dissections, and all seven participants received radiation therapy alone or in combination with chemotherapy to treat their HNC. Studies have documented neck muscle atrophy and soft tissue fibrosis following neck dissection and postoperative radiotherapy in HNC patients (Ghosh & Milone, 2015; Hirota et al., 2002). Diminished skeletal muscle function and reduced range of motion of nerves and muscles of the head and neck regions are also associated with complications after surgery (Hashida et al., 2021) and radiation-induced toxicity (Kim et al., 2015). These impairments significantly affect the mechanical ingestion of food and swallowing functions (Stubblefield, 2011). Furthermore, Pauloski (2008) reported that patients who underwent a partial glossectomy exhibited worsened swallowing function.

These findings underscore the reliability that curative treatments aimed at preserving and restoring the structural integrity of affected head and neck structures (Pauloski et al., 2006) do not necessarily guarantee the restoration of full functionality. This is consistent with the existing literature and observations from this case series. For instance, PTP2, seven months post-partial glossectomy (reconstructed with anterolateral thigh flap), described restricted tongue movements and reliance on hyper-pureed foods. While PTP6, two years and five months post-partial glossectomy (reconstructed with radial forearm free flap), reported improved tongue mobility, stating, “Muscle improving!” These findings highlight that rehabilitation is not linear and emphasise the critical role of speech and language therapists (SLP) and physiotherapists in the recovery of these muscles and physiological functions.

3.5.3 Malnutrition in Head and Neck Cancer Survivors

Malnutrition development in HNC survivors is a complex and multifaceted issue (Einarsson et al., 2024). HNC and treatment-induced inflammation, combined with long-term NIS, contribute to reduced food intake. These concurrently accelerate the degradation of essential tissues, particularly muscular tissue. Insufficient EI transpires to the utilisation of free amino acids and body protein, making it a primary cause of malnutrition development (Gellrich et al., 2015). Malnutrition is frequently identified at the time of HNC diagnosis (Gorenc et al., 2015), prior to treatment (Susetyowati et al., 2024), as well as during and immediately following treatment (van den Berg et al., 2008). However, the prevalence of malnutrition and its screening among HNC survivors living in the community remains understudied and conceivably overlooked.

This is concerning, as sufficient food intake remains a significant challenge for HNC survivors, with detrimental effects on both physical health and quality of life. In this case series, six out of seven participants were classified as malnourished according to the PG-SGA SF criteria. Malnutrition was likely exacerbated by the interplay of multiple NIS, particularly difficulty chewing and swallowing, which were reported as the most impactful on oral intake. These NIS may have contributed to the observed insufficient energy and protein intakes, likely contributed to unintentional weight loss and increased protein metabolism due to insufficient carbohydrate intake. Additionally, participants underwent varying oral and oropharyngeal resections, which have been shown to result in decreased food consumption and inadequate nutrition over time (Barrios et al., 2014). These findings significantly contribute to the literature, foreshowing that HNC survivors living in the community are vulnerable to malnutrition, perpetuated by the vicious cycle of long-lasting NIS that impairs nutrition status, physical functioning, and quality of life. This is particularly concerning as malnourished HNC survivors may be

more susceptible to illness. Should they experience cancer reoccurrence or other serious conditions, their malnourished and deconditioned state would likely result in significantly worse health outcomes.

Although this study was unable to compare individual participants, it clearly identified the concerning prevalence of malnourishment and long-term NIS among HNC survivors. These findings draw attention to the importance of routine malnutrition screening and symptom management in this vulnerable population. Furthermore, healthcare professionals must employ appropriate methods to objectively assess the nutrition status of HNC survivors (Einarsson et al., 2024). This is imperative, as malnutrition and altered skeletal muscle mass can be masked by normal weight or obesity (Prado et al., 2022). This is further reinforced by our study findings, whereby participants classified as malnourished presented with body measures that were declared normal or overweight according to the WHO's BMI cut-offs. Moreover, studies suggest that implementing a multimodal approach, combining nutrition therapy and exercise as an early intervention to preserve muscle mass, could help prevent malnutrition rather than manage it after its onset (Einarsson et al., 2024). This highlights the critical roles of dietitians, SLTs, and physiotherapists, ensuring survivors have access to dietary guidance and strategies to address persisting physical and functional challenges (Ganzer et al., 2015b).

3.5.4 Energy and Macronutrient Status

This case series demonstrates that suboptimal EI can persist throughout the cancer trajectory pathway. A finding was further supported by Ferreira et al. (2020), who observed suboptimal EI in HNC patients actively receiving chemoradiation therapy, and Hammerlid et al. (1998), who observed inadequate EI in HNC survivors at two-year follow-up treated with radiation therapy in conjunction with chemotherapy and surgery, respectively. Conversely, Hammerlid et al. (1998) also observed a negative energy balance in both malnourished and well-nourished participants. This was a consistent finding, with PTP1 being the only well-nourished participant yet still presenting with insufficient EI. However, van den Berg et al. (2006) did not support this finding, observing an increase in energy consumption in HNC survivors at six-month follow-up. This discrepancy may stem from the prospective design of their study, which tracked HNC patients from diagnosis through active treatment and post-treatment, assessing EI at three different time points. Notably, they used an FFQ, which evaluated past intake rather than current intake, relying heavily on participants' memory.

Protein adequacy was achieved by six out of seven participants, likely due to a generous estimated intake of 1.2 – 1.5 g/kg/BW/day. Silander et al. (2013a) used the same protein range in a longitudinal study tracking HNC patients from diagnosis to 24 months post-treatment. Notably, the protein range used in this study is higher than the typical protein intake estimated for healthy adult subjects, 0.8

g/kg/BW/day, increasing to 1.0 g/kg/BW/day for those with increased need (Dekker et al., 2022). Despite protein intakes exceeding typical requirements, participants were still malnourished. Only one participant presented with inadequate energy and protein intake, which may have contributed to their mild/suspected diagnosis of malnutrition. This observation provoked further exploration into factors that may have contributed to insufficient EI, such as energy metabolism (Carbone et al., 2012), NIS (Kubrak et al., 2013), and social isolation (Roberts, 2000).

Carbone et al. (2012) validate the well-established link between insufficient EI and reduced skeletal muscle mass. When dietary intake, along with stored carbohydrates and fats, is inadequate to meet energy demands, the body will break down muscle proteins to obtain amino acids as a primary source of energy (Hayamizu, 2017). In this case series, six out of seven participants had insufficient carbohydrate intakes, failing to meet the AMDR of 45-65%, which aligns with findings from Ferreira et al. (2020). Inadequate carbohydrate intake supports the principle that when overall energy is suboptimal (due to insufficient carbohydrate intake), the body metabolises proteins or degrades body proteins to supply an energy source (Hayamizu, 2017). Additionally, factors contributing to reduced carbohydrate intake included dietary behaviours and food selection secondary to long-term NIS. Whereby difficulty chewing and swallowing, commonly experienced by participants, could have made it challenging to break down and ingest carbohydrate-rich foods. While a healthy diet requires vegetables, fruits, grains, dairy products and protein, participants six months to three years post-treatment exhibited NIS that can persist long after treatment. These factors likely contributed to the reduced carbohydrate intakes observed in this case series.

3.5.5 Micronutrient Status

The micronutrient status of all participants varied, with only two consistently deficient minerals: calcium and potassium. Insufficient calcium intake was observed in female participants (PTP 1, 2, 4, and 6). A potential reason for this could have been attributed to these female participants not consuming adequate calcium-rich sources in their diets or being unaware of higher requirements during menopause to support bone health. PTP 5 and 7 had adequate calcium intakes, exceeding the RDI for calcium. This was likely due to higher consumption of milk and dairy products—PTP 5 used creams, yoghurt, and milk to modify food textures to a consistency that was safe for consumption, while PTP 7 regularly consumed milky drinks. PTP3 met their RDI of calcium by consuming a diet varied in milk and dairy products. Other micronutrients found to be deficient in this group included iron, magnesium, zinc, thiamine, and vitamin A. Iron and zinc intake could have been insufficient because of the difficulty of chewing and swallowing tougher animal meat products that are rich sources of iron

and zinc. Vitamin A, magnesium, and potassium deficiencies could have been linked to difficulty consuming tough and crunchy fruits and vegetables.

3.5.6 Coping Strategies

Interestingly, some participants reported higher NIS presence scores compared to interference scores, suggesting the severity of NIS on oral intake may have been alleviated by coping strategies. This is an important finding, indicating that while HNC survivors suffer from NIS, some have adopted strategies to lessen the impact of the NIS on their oral intake. A common strategy was the use of water during mealtimes to lubricate the oral cavity and aid swallowing. PTP1, 3, 4, 5, and 7 all relied on water, particularly to wash down food and facilitate swallowing. This finding aligns with Einarsson et al. (2019), who identified this coping mechanism in HNC survivors two years post-treatment. From a symptom management perspective, participants found water helpful for eating, swallowing, and alleviating dry mouth. However, a particular concern is the displacement of nutrients, as participants may fill up on water, potentially reducing food intake.

3.5.7 Social Isolation

All participants expressed challenges associated with eating in social settings, a finding consistent with a comparable study on HNC survivors' eating experiences (Dornan et al., 2022). Participants frequently reported feelings of social separation, fear, and anxiety when eating and drinking in the company of others. Eating in social situations was sometimes avoided or described as challenging, characterised as "not easy," "off-putting," and "very difficult, sad, and isolated." Participants further described needing to be mindful and cautious of the foods they selected when eating out. Additional strategies reported were always ensuring water and utensils were available or eating before leaving the house. Some participants preferred to reframe or completely avoid eating in social situations. For many survivors of HNC, this realisation is an upsetting and distressing reality. Eating, a fundamental component of sustaining life, is also a means of social interaction. Crowder et al. (2019a) highlighted that social separation is a consequence of NIS, with long-lasting NIS depriving survivors of both the physical and social aspects of eating, thereby creating social barriers.

3.5.8 Strengths and Limitations

Among HNC survivors, malnutrition is underreported, and the effects of long-term NIS on dietary intake and nutrition status are devastating. This case series implemented validated tools to assess malnutrition risk and the presence and severity of NIS, which allowed us to identify long-term NIS and their significant impact on nutrition status. Furthermore, the use of a comprehensive dietary analysis (four-day food record) and multiple strategies to ensure accurate data (such as written food diaries, photographs of meals, and effective monitoring and data entry procedures) enabled us to assess energy, macronutrient, and micronutrient intakes.

The study's online approach allowed us to reach a broader geographical population of HNC survivors living in NZ. Data input was another strength of this case series, with SOP implemented and a limited number of researchers managing the data set. This facilitated extensive cross-checking and consistent data entry methods. However, the limitations of this case series included the self-selected and self-reported nature of the data, which may have led to over- or under-reporting, compromising the objective nature of this study.

Additionally, conducting the study in person would have allowed us to use the full version of the PG-SGA, enabling the assessment of participants' physical clinical presentation (muscle wasting and/or fat depletion), which are key diagnostic indicators of malnutrition. This limitation meant that body composition (muscle and fat) could not be assessed using the PG-SGA SF. Finally, within the bounds of this publication, the author acknowledges the limitation of not being able to report and describe each participant's personal survivorship journey in detail. This includes the restriction of fully conveying a comprehensive description of all seven participants' post-treatment experiences and capturing the personal impacts their cured disease continues to have on their lives today. This limitation restricts a comprehensive understanding of the treatment side effects endured and the social implications of life beyond treatment completion.

3.5.9 Conclusion

The prevalence of malnutrition in this case series was likely caused by a combination of NIS that resulted in undernourishment. This finding indicated that, despite HNC survivors no longer receiving treatment or having active cancer, they are still vulnerable to deconditioning tendencies due to the persistence of long-lasting NIS that affect dietary intake. The interconnected nature of NIS and their role in the aetiology of malnutrition highlights the potential for serious health concerns for HNC survivors living in the community who may be left to manage these symptoms alone. This emphasises the urgent need to understand the comorbidities and treatment side effects that HNC survivors experience throughout their survivorship trajectory (Nilsen et al., 2020). The findings of this case series highlight the importance of early detection and the ongoing need for surveillance and follow-up care by healthcare professionals (Granstrom et al., 2022). A multi-disciplinary strategy from dietitians, SLTs, and physiotherapists is necessary to prevent the development of malnutrition in HNC survivors, given the multitude of treatment implications. HNC survivors need routine screening for malnutrition risk by their general practitioner and adequate surveillance of all late and long-term effects (Nilsen et al., 2020). Chewing and swallowing difficulties were a particular burden for HNC survivors in this case series and are important predictors of nutrition status and weight (Gellrich et al., 2015). Given that the NIS burdens can significantly reduce dietary intake and quality of life, there is an urgent need for effective NIS prevention and intervention (Crowder et al., 2019b) in community-living HNC survivors.

Chapter 4 | Conclusion and Recommendations

"Head and neck cancer leaves far more visible and obvious daily challenges for the person than many other cancer sites that are covered by clothing and don't affect so much of everyday life and things we take for granted."(PTP5)

Chapter 4: Conclusion and Recommendations

4.1 Overview and Achievement of Study Aim and Objectives

This case series examined the prevalence of malnutrition, NIS, and dietary intake among community-living HNC survivors in NZ. Identifying malnutrition and long-term NIS are prevalent six months to three years post-treatment. Whereby six out of seven participants were identified as malnourished. Difficulty chewing, dry mouth, and difficulty swallowing were the highest-scored NIS that interfered with oral intake. Additionally, six out of seven participants exhibited inadequate carbohydrate intakes, and calcium and potassium intakes were found to be inadequate for PTP1, 2, 4, and 6 and PTP2, 3, and 6, respectively, highlighting a potential risk for key micronutrient deficiencies among HNC survivors. These results suggest that malnutrition and possible inadequate dietary intake may be underdiagnosed in community-living HNC survivors. These findings are consistent with existing literature, whereby Brown (2020) and Di Bella et al. (2020) demonstrate that malnutrition is frequently underdiagnosed and undertreated in oncology populations. Notably, to the authors' knowledge, there is limited research examining the long-term risk of malnutrition in HNC survivors despite evidence suggesting they are vulnerable and susceptible at any stage of their cancer trajectory. This highlights the need for further investigations to understand the true extent of malnutrition prevalence in treated HNC survivors.

Moreover, this case series showed that energy and protein intakes varied in terms of achieving estimated requirements or demonstrating suboptimal intakes. Inadequate EI was a common finding. While protein adequacy was common among participants. Notably, only one participant reported insufficient intake of energy and protein. Obtaining adequate intakes of dietary energy and protein is particularly important for HNC survivors, as a prolonged period of inadequate intake can aggravate deconditioning and increase malnutrition risk. Furthermore, six out of seven participants consumed insufficient dietary carbohydrates, which may have contributed to the development of malnutrition in this case series, as the body will utilise body protein for energy when carbohydrate intake is insufficient, particularly free amino acids and muscular structures. Ultimately, the malnutrition classifications, presence, and severity of NIS and the energy, macronutrient, and micronutrient intake presented in this case series provide unique insights into the nutrition status of each HNC survivor. This highlights that nutrition support needs to be tailored individually to the survivors, as it is evident each participant in this case series had their own particular combination of nutritional challenges that prevented them from achieving a nutritionally adequate diet. Thereby further reinforcing the importance of symptom assessment and management in the care of HNC survivors, given the well-researched effects long-term NIS have on nutrition, physical function, and quality of life. For this reason, there is a need for ongoing

surveillance from general practitioners and dietetic input during the survivorship period to treat and prevent malnutrition and provide support with long-term NIS.

4.1 Strengths

To the author's knowledge, this is the first observational study in NZ to describe and characterise the ongoing challenges that persist post-treatment and impact malnutrition risk and dietary intake among HNC survivors living in the community. The primary aim of this study was to assess malnutrition status, the presence and severity of NIS, and dietary intake through a case series approach.

The use of an online (non-conversational) design instead of an in-person format enabled the inclusion of individuals who might otherwise have been unreachable due to limited communication challenges resulting from treatment and associated embarrassment. Furthermore, this online approach allowed for a broader geographical reach of HNC survivors across NZ. Additionally, the use of validated tools to assess malnutrition risk presence and severity of NIS ensured accurate identification of the true extent of long-term NIS and its impact on nutrition status.

The use of a four-day food record provided detailed dietary data and a comprehensive assessment of participants' current dietary intake. Given the online nature of the data collection, this method offered the most robust and comprehensive dietary data available for this case series.

Finally, adopting a case series design instead of a pilot study enabled a deep and nuanced understanding of each participant's experiences. This approach yielded strong hypothesis-forming findings that will support future research in this important and overlooked area.

4.2 Limitations

Limitations are inevitable. The limitations in this case series highlight areas for improvement in future research. Firstly, the case series design of the study resulted in the inability to draw definitive conclusions, as we could not compare participants. Secondly, the data obtained in this case series was self-selected and self-described, increasing the potential for over- or under-reporting, which could compromise the objective nature of the study. Furthermore, self-reported data relies on the memory and recall of the participants, which can be influenced by various factors such as time, context, emotions, and motivation, potentially leading to selection bias.

Additionally, although we see the online non-conversational data collection method as a significant strength for this specific population, had we conducted this case series in person, it would have allowed for greater probing when needed, resulting in more in-depth data and understanding. Furthermore, had this study been in person, the full version of the PG-SGA could have been used, which is considered the gold standard in diagnosing malnutrition in oncology populations as it assesses the physical and clinical presentation of participants. However, the PG-SGA SF is validated and appropriate for diagnosing malnutrition in at-risk populations, encapsulating weight status, dietary intake, NIS, and functional capacity—all conceptual definitions of malnutrition established by the ESPEN and the American Society for Clinical Parenteral and Enteral Nutrition (Jager-Wittenaar & Ottery, 2017)—and can detect the risk and presence of malnutrition in oncology inpatients and outpatients with sensitivity, specificity, and accuracy (Abbott et al., 2016; Azevedo et al., 2024; Carrico et al., 2021; De Groot et al., 2020; Gabrielson et al., 2013; Jager-Wittenaar et al., 2020).

4.4 Recommendations and Future Directions for Research

The prevalence of malnutrition in this case series is hypothesis-forming: community-living HNC survivors post-treatment are susceptible to malnutrition and inadequate dietary intake secondary to the prevalence and severity of NIS. This is further supported by the prevalence of long-term NIS interfering with oral intake, which most commonly included difficulty chewing, dry mouth, and swallowing. These case-series findings highlight the importance of symptom assessment and management in community-living HNC survivors and the ongoing need for malnutrition screening and surveillance in this population.

Summarised Final Future Applications of this Research Are:

- Identify the extent of malnutrition in community-living HNC survivors post-treatment.
- Understanding and professional development needs of general practitioners to screen for and support the unique needs of HNC patients post-treatment.
- Longitudinal research that follows the patients from diagnosis and treatment to survivorship to identify key time points where intervention and support are needed.

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Appendix A: Patient-Generated Subjective Global Short Form Assessment

Scored Patient-Generated Subjective Global Assessment (PG-SGA)

History: Boxes 1 - 4 are designed to be completed by the patient.
[Boxes 1-4 are referred to as the PG-SGA Short Form (SF)]

Patient Identification Information

1. Weight *(See Worksheet 1)*

In summary of my current and recent weight:

I currently weigh about _____kg
I am about _____ cm tall

One month ago I weighed about _____ kg
Six months ago I weighed about _____ kg

During the past two weeks my weight has:

☐ decreased (1) ☐ not changed (0) ☐ increased (0)

Box 1 ☐

2. Food intake: As compared to my normal intake, I would rate my food intake during the past month as

- ☐ unchanged (0)
- ☐ more than usual (0)
- ☐ less than usual (1)

I am now taking

- ☐ *normal food* but less than normal amount (1)
- ☐ little solid food (2)
- ☐ only liquids (3)
- ☐ only nutritional supplements (3)
- ☐ very little of anything (4)
- ☐ only tube feedings or only nutrition by vein (0)

Box 2 ☐

3. Symptoms: I have had the following problems that have kept me from eating enough during the past two weeks (check all that apply)

- ☐ no problems eating (0)
- ☐ no appetite, just did not feel like eating (3)
- ☐ nausea (1)
- ☐ constipation (1)
- ☐ mouth sores (2)
- ☐ things taste funny or have no taste (1)
- ☐ problems swallowing (2)
- ☐ pain; where? (3) _____
- ☐ other (1)** _____
- ☐ vomiting (3)
- ☐ diarrhea (3)
- ☐ dry mouth (1)
- ☐ smells bother me (1)
- ☐ feel full quickly (1)
- ☐ fatigue (1)

**Examples: depression, money, or dental problems

Box 3 ☐

4. Activities and Function:
Over the past month, I would generally rate my activity as:

- ☐ normal with no limitations (0)
- ☐ not my normal self, but able to be up and about with fairly normal activities (1)
- ☐ not feeling up to most things, but in bed or chair less than half the day (2)
- ☐ able to do little activity and spend most of the day in bed or chair (3)
- ☐ pretty much bed ridden, rarely out of bed (3)

Box 4 ☐

The remainder of this form is to be completed by your doctor, nurse, dietitian, or therapist. Thank you.

Additive Score of Boxes 1-4 ☐ **A**

email: faithotterymdphd@aol.com or info@pt-global.org

Note. PG-SGA SF screening form sourced from "Dietitians New Zealand Clinical Handbook", 2016 who received permission from Dr Faith Ottery. Copyright 2016 by Dietitians New Zealand Inc.

Appendix B: Phase One Online Survey

Nutrition Status and Dietary Intake in Head and Neck Cancer

Thank you for choosing to take part in our study. We are extremely grateful for your time, effort, and dedication. We highly value your commitment and involvement in our study, offering valuable insight and contribution to the expanding scope of head and neck cancer research.

This survey should take approximately **10 minutes** to complete.

This online survey is split into five sections:
Part A*:* Demographic Questions
Part B*:* Cancer Information
Part C*:* Self-Reported Body Measures
Part D: Symptoms and Dietary Intake
Part E: Activities and Function

Your answers will help us understand the nutrition status and dietary intake of individuals who have undergone treatment for head and neck cancer.

This online survey remains a partial fulfilment of this study. Once you have completed this online survey, you are required to complete a 4-day food record and final online survey.

If you have any questions, please contact:
Danielle Oakes via email: D.Oakes@massey.ac.nz or phone/text: **021 912 375**

All information in this survey will be kept confidential.

Low-risk ethics notification:
This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research. If you have any concerns about the ethical conduct of this research that you want to raise with someone other than the researcher(s), please contact Massey University Human Ethics by email: humanethics@massey.ac.nz.

I have read the study information sheet and understand what my participation involves. Please select "yes" below if you confirm your consent to take part in this study.	**Yes**
Part A: Demographic Questions	
Question	**Answer options**
What is your full name?	Text type
What is your full address?	Text type
What is your gender?	Text type

<table>
<tr><td>Which ethnic group do you belong to? Select all that apply to you.</td><td>Multichoice (Multiple answers)
<table>
<tr><td>1</td><td>New Zealand European</td></tr>
<tr><td>2</td><td>Māori</td></tr>
<tr><td>3</td><td>Samoan</td></tr>
<tr><td>4</td><td>Cook Island Māori</td></tr>
<tr><td>5</td><td>Tongan</td></tr>
<tr><td>6</td><td>Niuean</td></tr>
<tr><td>7</td><td>Chinese</td></tr>
<tr><td>8</td><td>Indian</td></tr>
<tr><td>9</td><td>Other, e.g., Dutch, Japanese, Tokelauan. Please state in the provided textbox.
[ ]</td></tr>
</table></td></tr>
<tr><td>Who lives with you at your usual address? Select as many options as you need to show all the people who live with you.</td><td>Multiple choice (Multiple answers allowed)
<table>
<tr><td>1</td><td>I live alone</td></tr>
<tr><td>2</td><td>My spouse / partner, e.g. husband</td></tr>
<tr><td>3</td><td>My parents(s), e.g. mother</td></tr>
<tr><td>4</td><td>My child(ren), e.g. daughter</td></tr>
<tr><td>5</td><td>My siblings(s), e.g. brother</td></tr>
<tr><td>6</td><td>My grandparent(s)</td></tr>
<tr><td>7</td><td>My grandchild(ren)</td></tr>
<tr><td>8</td><td>My flatmates(s)</td></tr>
<tr><td>9</td><td>Other, e.g., mother-in-law, step-child
[ ]</td></tr>
<tr><td>10</td><td>Please state who else lives at your usual address:
[ ]</td></tr>
</table></td></tr>
<tr><td>What is your highest level of education you have completed?</td><td>Multichoice (Allow one answer)
<table>
<tr><td>1</td><td>School</td></tr>
<tr><td>2</td><td>Polytechnic or similar</td></tr>
<tr><td>3</td><td>University</td></tr>
<tr><td>4</td><td>Other (please state in textbox)
[ ]</td></tr>
</table></td></tr>
<tr><td>Do you currently have paid employment?</td><td>Multichoice (Allow one answer)</td></tr>
</table>

	1 No 2 Yes – part-time 3 Yes – full-time 4 Other (please specify)
Part B: Cancer Information	
Question	**Answer options**
Which type of head and neck cancer were you diagnosed with?	Multichoice (Allow one answer) 1 Oral Cavity 2 Salivary glands 3 Paranasal sinuses 4 Nasopharynx 5 Oropharynx 6 Hypopharynx 7 Larynx 8 Other (please state here) 9 Not sure
What stage was your head and neck cancer when you were diagnosed?	Multichoice (Allow one answer) 1 Stage 1 2 Stage 2 3 Stage 3 4 Stage 4 5 Not sure
What option(s) below best describe the origin of your cancer diagnosis?	Multichoice (Allow one answer) 1 Tobacco related 2 Alcohol-related 3 HPV related 4 Other (please specify) 5 Not sure
What treatment did you receive for your head and neck cancer? Select as many options as necessary.	Multichoice (Allow multiple answers) 1 Radiation therapy 2 Surgery 3 Immunotherapy 4 Chemoradiation therapy 5 Chemotherapy 6 None 7 Other (please state here) 8 Not sure

Part C: Self-Reported Body Measures

The following questions are to help determine your nutrition status. If you are unsure of your weight or height, you can contact your GP practice, who will be able to advise you.

Question	**Answer options**
What is your current, or most recent, weight? *(Please feel free to note this in kgs, pounds, or stones)*	Text type
What date was this weight taken? If today, just enter "today."	Text type
What is your height? *(Please feel free to note this in cm, meters, or feet and inches)*	Text type
What was your usual weight before you were diagnosed with head and neck cancer? *(Please feel free to note this in kgs, pounds, or stones)*	Text type
One month ago I weighed about? *(Please feel free to note this in kgs, pounds, or stones)*	Text type
Six months ago I weighed about? *(Please feel free to note this in kgs, pounds, or stones)*	Text type
During the past two weeks my weight has:	Multichoice (Allow one answer) 1 Decreased 2 Not change 3 Increased

Part D: Symptoms and Dietary Intake

The following questions will help to determine symptoms that may be affecting your current dietary intake.

Question	**Answer options**
In the **last 3 days**, how often have you experienced symptom(s) 1–17 listed below? Please ensure you rank **all 17 of the listed symptoms** based on how often you have experienced the symptom(s) in the last 3 days. Please rank each symptom by selecting **one** of the following 5 options: **Not at all - A lot** for **all 17 symptoms**. *If you have experienced a symptom that is not listed in this table, please *specify in the box provided under other. Rank this symptom from the following 5 options: Not at all - a lot.*	Multiple choice (Allow one answer per symptom listed)

Symptom	**Not at all**	**A little bit**	**Some what**	**Quite a bit**	**A lot**
1. Pain					
2.Anxious					
3.Dry mouth					
4.Loss of appetite					
5.Constipation					
6.Feeling full					
7.Depressed					
8.Thick saliva					
9.Diarrhoea					
10.Sore mouth					
11.Lack of energy					

	12.Nausea					
	13.Difficulty chewing					
	14.Smells bother me					
	15.Vomiting					
	16.Difficulty swallowing					
	17.Taste changes					
	Other: Specify					

In the last **3 days**, has the symptom(s) listed (1–17) interfered with your eating? Please ensure you rank **all 17 of the listed symptoms** based on how often they have interfered with your eating in the last 3 days. Please rank each symptom by selecting **one** of the following 5 options: **Not at all - A lot** for **all 17 symptoms**.

*If you have experienced a symptom that is not listed in this table, please *specify in the box provided under other. Rank this symptom from the following 5 options: Not at all - a lot.*

Multiple choice (Allow one answer per symptom listed)

Symptom	**Not at all**	**A little bit**	**Some what**	**Quite a bit**	**A lot**
1.Pain					
2.Anxious					
3.Dry mouth					
4.Loss of appetite					
5.Constipation					
6.Feeling full					
7.Depressed					
8.Thick saliva					
9.Diarrhoea					
10.Sore mouth					
11.Lack of energy					
12.Nausea					
13.Difficulty chewing					
14.Smells bother me					
15.Vomiting					
16.Difficulty swallowing					
17.Taste changes					
Other: Specify					

Food intake: As compared to my normal intake, I would rate my food intake during the past month as...

Multichoice (Allow one answer)

1	Unchanged
2	More than usual
3	Less than usual

Food intake: How would you best describe your current food intake? Please select a suitable answer listed below. I am now taking...

Multichoice (Allow one answer)

	<table><tr><td>1</td><td>Normal food, but less than normal amount</td></tr><tr><td>2</td><td>Little solid food</td></tr><tr><td>3</td><td>Only liquids</td></tr><tr><td>4</td><td>Only nutritional supplements</td></tr><tr><td>5</td><td>Very little or anything</td></tr><tr><td>6</td><td>Only tube feeding or only nutrition by vein</td></tr><tr><td>7</td><td>None of these apply to me</td></tr></table> If answers 4 or 6 were selected by respondents, they were required to complete the additional questions outline in blue and purple.
Please state what type of nutritional supplement(s) you are currently taking.	Text type
Please state the type of tube you have. *(For example " I have a PEG or an NGT In-Stui.")*	Text type
What type of nutrition feed goes through your feeding tube? (*For Example: Ensure Two Cal, Fortisip).*	Text type
Symptoms: I have had the following problems that have kept me from eating enough during the past two weeks (select all that apply).	Multichoice (Allow multiple answers) <table><tr><td>1</td><td>No problems eating</td></tr><tr><td>2</td><td>No appetite, just did not feel like eating</td></tr><tr><td>3</td><td>Nausea</td></tr><tr><td>4</td><td>Constipation</td></tr><tr><td>5</td><td>Mouth sores</td></tr><tr><td>6</td><td>Things taste funny or have no taste</td></tr><tr><td>7</td><td>Problems swallowing</td></tr><tr><td>8</td><td>Vomiting</td></tr><tr><td>9</td><td>Diarrhoea</td></tr><tr><td>10</td><td>Dry mouth</td></tr><tr><td>11</td><td>Smells bother me</td></tr><tr><td>12</td><td>Feel full quickly</td></tr><tr><td>13</td><td>Fatigue</td></tr><tr><td>14</td><td>Pain; where?</td></tr><tr><td>15</td><td>Other** Examples: ** depression, money, or dental problems</td></tr></table>
Part E: Activities and function	
Question	**Answer options**
Over the past month, I would generally rate my activity as:	Multichoice question (Allow one answer)

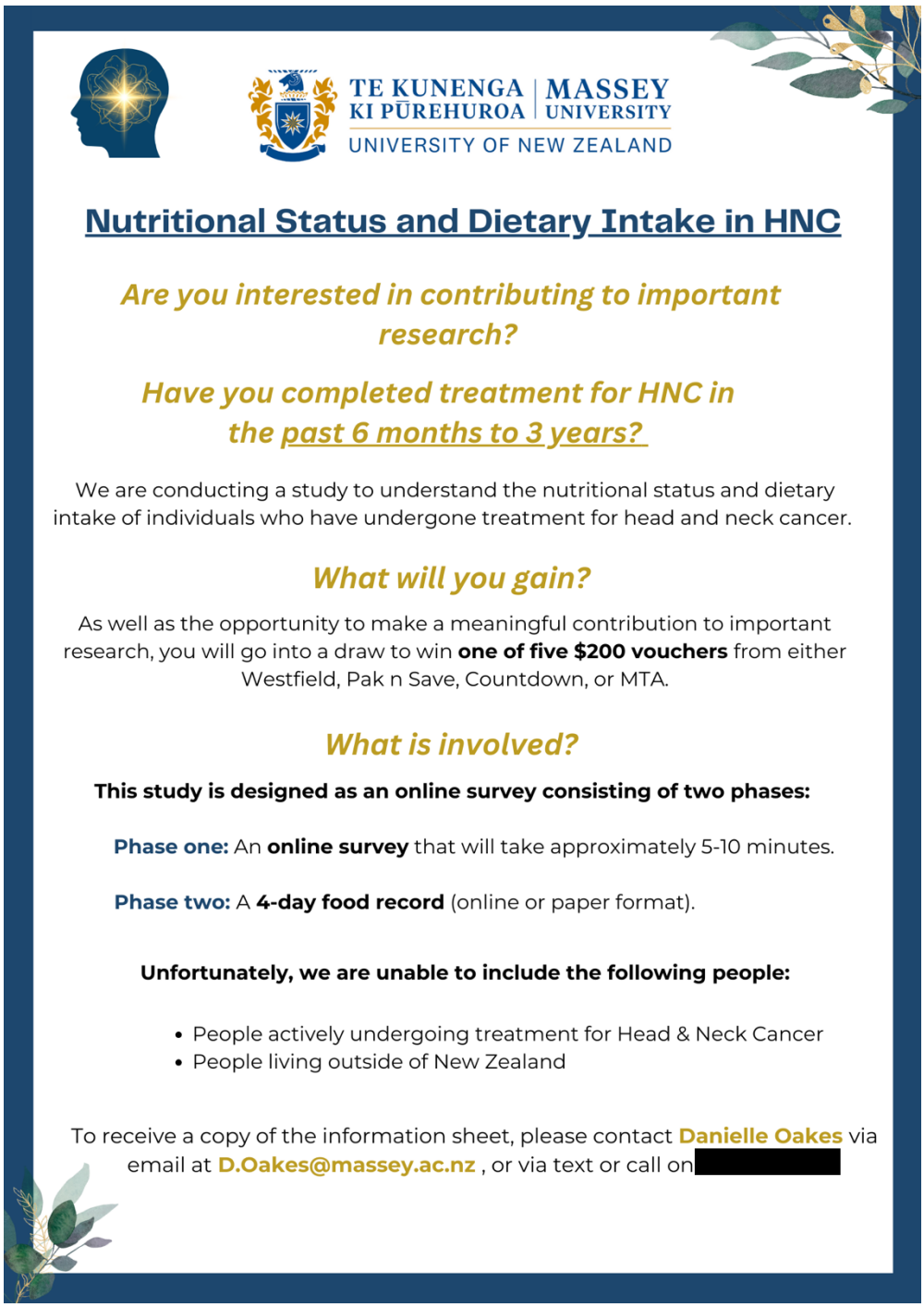
1	Normal with no limitations
2	Not my normal self, but able to be up and about with fairly normal activities
3	Not feeling up to most things, but in bed or chair less than half the day
4	Able to do little activity and spend most of the day in bed or chair
5	Pretty much bedridden, rarely out of bed

Appendix C: Head and Neck Cancer Symptom Checklist

During the past 3 days:	How often did you have this symptom?					Has this symptom interferred with eating?				
Symptom	Not at all	A little bit	Some what	Quite a bit	A lot	Not at all	A little bit	Some what	Quite a bit	A lot
Pain	1	2	3	4	5	1	2	3	4	5
Anxious	1	2	3	4	5	1	2	3	4	5
Dry mouth	1	2	3	4	5	1	2	3	4	5
Loss of appetite	1	2	3	4	5	1	2	3	4	5
Constipation	1	2	3	4	5	1	2	3	4	5
Feeling full	1	2	3	4	5	1	2	3	4	5
Depressed	1	2	3	4	5	1	2	3	4	5
Thick saliva	1	2	3	4	5	1	2	3	4	5
Diarrhea	1	2	3	4	5	1	2	3	4	5
Sore mouth	1	2	3	4	5	1	2	3	4	5
Lack of energy	1	2	3	4	5	1	2	3	4	5
Nausea	1	2	3	4	5	1	2	3	4	5
Difficulty chewing	1	2	3	4	5	1	2	3	4	5
Smells bother me	1	2	3	4	5	1	2	3	4	5
Vomiting	1	2	3	4	5	1	2	3	4	5
Difficulty swallowing	1	2	3	4	5	1	2	3	4	5
Taste changes	1	2	3	4	5	1	2	3	4	5
Other: Specify	1	2	3	4	5	1	2	3	4	5

Note. The Head and Neck Cancer Symptom Checklist retrieved from "The Head and Neck Symptom Checklist©: An Instrument to Evaluate Nutrition Impact Symptoms Effect on Energy Intake and Weight Loss," by C. Kubrak, K. Olson, V.E. Baracos, 2013, *Official Journal of the Multinational Association of Supportive Care in Cancer*, *21*(11), 3127–3136 (https://doi.org/10.1007/s00520-013-1870-z). Copyright 2024 by Springer Nature Limited.

Appendix D: Study Recruitment Poster



Appendix E:

Participant Information Sheet

Nutrition Status and Dietary Intake in Head & Neck Cancer

An Observational Study.

Lead Researcher: Dr Maria Casale

Study Mode: The study and all communication will be completed online or via posted paper forms, but you have the option of speaking to a researcher over the phone or via text if you have questions.

Research Contact: Danielle Oakes
Contact Phone Number: [redacted]
Email: D.Oakes@massey.ac.nz

You are invited to take part in a study investigating nutrition status, nutrition impact symptoms, and dietary intake**.** Whether or not you take part is your choice. If you want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits to you might be, and what would happen after the study ends.

You do not have to decide today whether or not you will participate in this study. Before you decide, you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

This form is **3 pages long**. Please make sure you have read and understood all the information provided to you.

Voluntary Participation and Withdrawal from this Study

Participation in this study is completely voluntary. You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular questions.
- Withdraw from the study at any time.
- Ask any questions about the study at any time during participation.
- Provide information on the understanding that your name will not be used.
- Be given access to a summary of the study findings when it is concluded.

Withdrawing from the study, should you choose to, will not result in any disadvantage to you.

What is the Purpose of the Study?

People with head & neck cancer are nutritionally vulnerable, often long after treatment has concluded. More information is needed to help guide support services and improve healthcare professional's understanding of nutrition challenges in this group. The findings will also help enable better and more effective nutrition support and, foster greater understanding of the unique challenges faced by people who have had head and neck cancer.

This study aims to investigate nutrition status, nutrition impact symptoms (symptoms that prevent people with head & neck cancer from eating as they wish), and dietary intake.

How is the Study Designed?

This study will involve people over the age of 18 who have completed treatment for head and neck cancer in the past six months to three years. Participants will complete an online screening questionnaire to check eligibility. If eligible, they will complete one more short online survey and keep a four-day food and drink record.

You may choose to complete your four-day diet record electronically, or we will post you a paper template that you can use.

Who can Take Part in the Study?

Men and women aged 18 years or older, who completed treatment for head & neck cancer between 6 months and 3 years ago, who were diagnosed and treated in New Zealand, and currently living in New Zealand. Participants will complete a short screening questionnaire to ensure they meet inclusion criteria.

What will my Participation in the Study Involve?

If you decide to take part in the study, after you have read and had time to consider the information in this information sheet, you will be asked to complete the screening questionnaire. This will be done via an online form and takes approximately three minutes. Your answers will help us see if you are eligible to take part in this study or not.

If you are eligible, we will ask you to complete the following:

- An online survey, which will take approximately ten minutes.
- A four-day diet record (a record of everything you eat and drink for four days).

For the diet record, we request that for four days you record everything that you eat and drink. Instructions will be provided in more detail after you complete the screening questionnaire.

What are the Possible Benefits of this Study?

- You will be contributing to a greater understanding of the nutritional challenges people with head and neck cancer face in the longer term after treatment finishes.
- You will receive a summary of the study results.

Will I Receive Anything for Taking Part in this Study?

Everyone who completes the study will go into the draw to win **one of five $200 gift vouchers** from either *Westfield, Pak N Save, Countdown, or MTA.*

What will happen to my Information?

During this study, the researchers will record information about you and your study participation. This includes your diet record. Only the research staff will have access to any of your identifiable information, and all other data will be de-identified.

Information that identifies you will not be included in any report generated by the researcher – instead, you will be identified by a code. The researcher will keep a list linking your code with your name, so that you can be identified by your coded data if necessary.

The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

Study Ethics

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.
If you have any concerns about the ethical conduct of this research that you want to raise with someone other than the researcher(s), please contact Massey University Human Ethics by email: humanethics@massey.ac.nz.

Appendix F: Eligibility Screening Questionnaire

Question	Answer options
What is your date of birth? *(Please provide the date, month, and year.)*	Text type
Are you currently undergoing active treatment for head and neck cancer?	Multiple choice (Allow one answer) 1 Yes 2 No
Are you currently under the care of a dietitian?	Multiple choice (Allow one answer) 1 Yes 2 No
Did you live in New Zealand when you were diagnosed with head and neck cancer?	Multiple choice (Allow one answer) 1 Yes 2 No
Was your treatment for head and neck cancer in New Zealand?	Multiple choice (Allow one answer) 1 Yes 2 No
Do you currently live in New Zealand?	Multiple choice (Allow one answer) 1 Yes 2 No
Have you completed any form of head and neck cancer treatment in the past 6 months – 3 years? *(Head and neck cancer treatment includes: radiotherapy, surgery, chemoradiation, immunotherapy, or chemotherapy.)*	Multiple choice (Allow one answer) 1 Yes 2 No
What month and year were you diagnosed with head and neck cancer?	Text type (Will confirm respondent has completed HNC treatment in the past 6 months – 3 years)
Please provide your full name. *(For the purpose of contacting you.)*	Text type
Please enter your preferred form of contact. *e.g., phone number, WhatsApp Messenger (please provide a mobile number), or email address*	Text type

Note. Respondents were eligible to participate in the study if the following blue answers were selected.

Appendix G: Phase 3 Online Survey

Participants Study ID
Phase 3: Online Survey

Treatment Side Effects, Eating Experiences, and Dietary Preferences after Head and Neck Cancer Treatment

Thank you for your ongoing commitment and efforts to participate in our study. We are truly grateful for all your hard work, dedication, and time spent completing phases one and two of our study. We highly value your commitment and involvement in our study, offering valuable insight and contribution to the expanding scope of head and neck cancer research.

This survey is the final phase for the fulfilment of our study, and should take approximately **10 minutes** to complete.

This online survey is split into **three sections**.
Section A: Side Effects of Head and Neck Cancer Treatment
Section B: Eating Experiences after Head and Neck Cancer Treatment
Section C: Dietary Preferences

Your answers to sections (A-C) will help us better understand the lived experience of side effects, eating experiences, and dietary preferences after Head and Neck Cancer Treatment.

After the competition of phase 3 (our final online survey), you will receive a voucher of your choosing, **valued at $140**.

If you have any questions, please contact:

Danielle Oakes

via email: D.Oakes@massey.ac.nz or phone/text: **021 912 375**

All information in this survey will be kept confidential.

Low-risk ethics notification:
This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research. If you have any concerns about the ethical conduct of this research that you want to raise with someone other than the researcher(s), please contact Massey University Human Ethics by email: humanethics@massey.ac.nz.

Additional questions asked	
Question	**Answer options**
Question 1: In our first survey, you told us you were diagnosed with stage (Individualised based on participant) HNC in the (Individualised based on participant), and that you received (radio or chemo) therapy and surgery. Can you please describe the **surgery** you received? Please include as many details as you like.	*Essay text type*

<table>
<tr><td>Question 2: Please select which type of cancer you were diagnosed with, if known.</td><td>Multichoice (Multiple answers)
<table><tr><td>1</td><td>Squamous cell carcinoma</td></tr><tr><td>2</td><td>Lymphoma</td></tr><tr><td>3</td><td>Melanoma</td></tr><tr><td>4</td><td>Adenocarcinoma</td></tr><tr><td>5</td><td>Sarcoma</td></tr><tr><td>6</td><td>Niuean</td></tr><tr><td>7</td><td>Other</td></tr><tr><td>8</td><td>I don’t know</td></tr></table></td></tr>
<tr><td colspan="2">Part A : Head and neck cancer treatment side effects</td></tr>
<tr><td>Question</td><td>Answer options</td></tr>
<tr><td>Question 3: Thinking back to before your head and neck cancer treatment started, please describe what your expectations were on how it might impact your eating and drinking.</td><td>Essay text type</td></tr>
<tr><td>Question 4: How would you describe the support provided to you by your medical team around managing your eating and drinking after your treatment finished?</td><td>Essay text type</td></tr>
<tr><td>Question 4A: What would you want your medical team (dietitians, speech language therapists, nurses, doctors) to know about what it is like to live with symptoms that affect your eating and drinking?</td><td>Essay text type</td></tr>
<tr><td>Question 5: In the first survey, you indicated that you had the following symptoms:

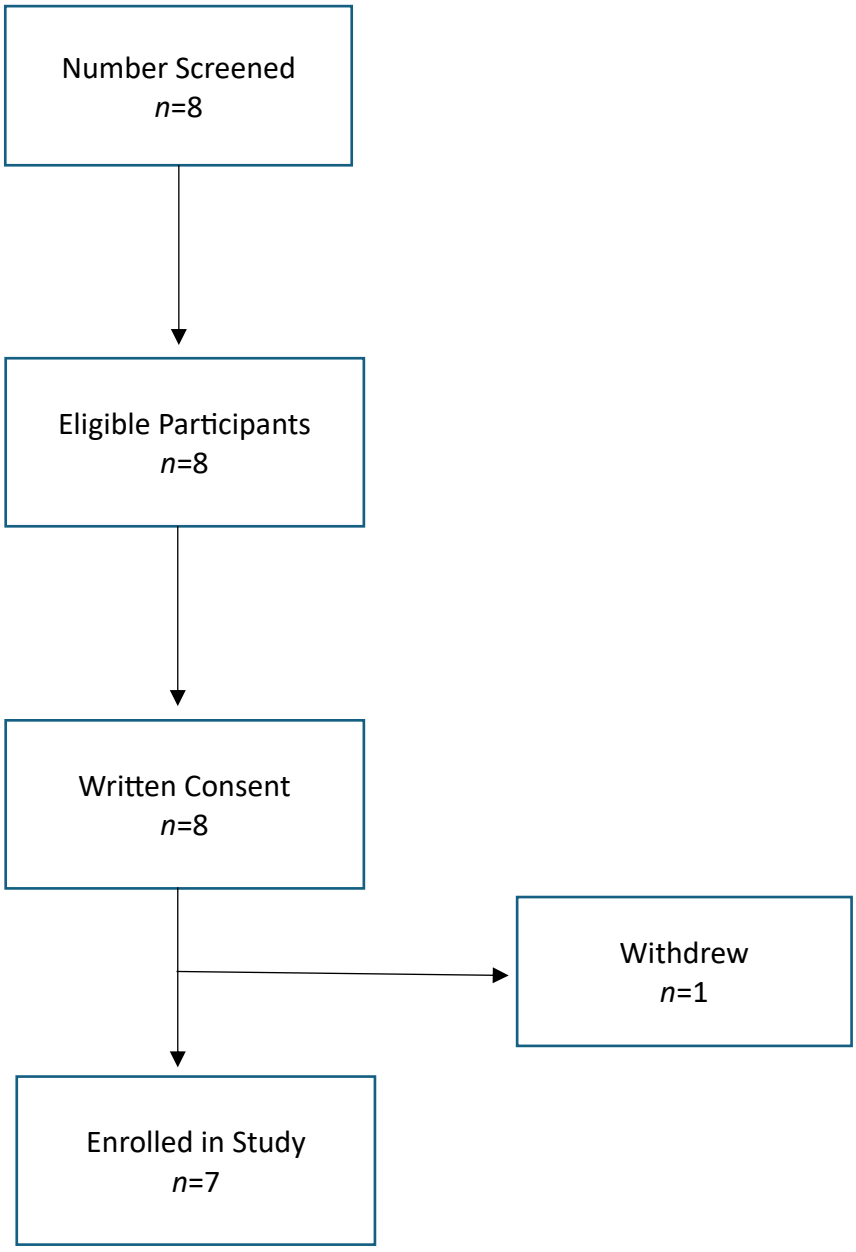
Participants individualised symptoms based on responses to first survey (phase one).

Please describe what, if any, coping strategies you have developed to help manage these symptoms?</td><td>Essay text type</td></tr>
<tr><td>Question 5A: Other than the strategies you’ve described above, do you have any external support with eating and drinking, for example, someone helping you with food preparation.</td><td>Essay text type</td></tr>
<tr><td colspan="2">Part B: Eating experiences after head and neck cancer treatment</td></tr>
<tr><td>Question</td><td>Answer options</td></tr>
<tr><td>Question 6: People with head and neck cancer often experience changes to their eating experience during mealtimes.

Please describe how your eating experience has changed since finishing treatment.</td><td>Essay text type</td></tr>
</table>

Question 6A: Please **describe** how this has impacted **how much** you eat.	*Essay text type*
Question 7: Can you please **describe** how you find eating in social situations, and how you **cope with this**?	*Essay text type*
Part C: Dietary Preferences	
Question	**Answer options**
Question 8: Are there any foods that you have chosen to avoid post-head and neck cancer treatment? Please **describe** the **types** of food and **why** you have avoided them.	*Essay text type*
Question 9: Are there any types of foods or textures that you find that are easier to manage since completing treatment? **Please describe**. Please **include why you think this is.**	*Essay text type*
Question 9A: Are there any types of foods or textures that you can no longer manage since completing treatment? **Please describe**. Please **include why you think this is.**	*Essay text type*
Question 10: Please **describe** what your appetite (**hunger and fullness signals**) is like currently?	*Essay text type*
Question 10A: Is this different to pre-treatment? **Please describe**.	*Essay text type*
Question 11: What dietary supplement(s) do you currently take? Please **give brand** name and how **often you take these**.	*Essay text type*
Question 11A: For each supplement listed above, can you **please explain** your **reasoning for taking this?**	*Essay text type*
Question 12: Finally, is there anything else about **your experience overall** (your personal journey) that you would like to share with us?	*Essay text type*

Appendix H: Outlined Study Recruitment, Screening, and Enrolment



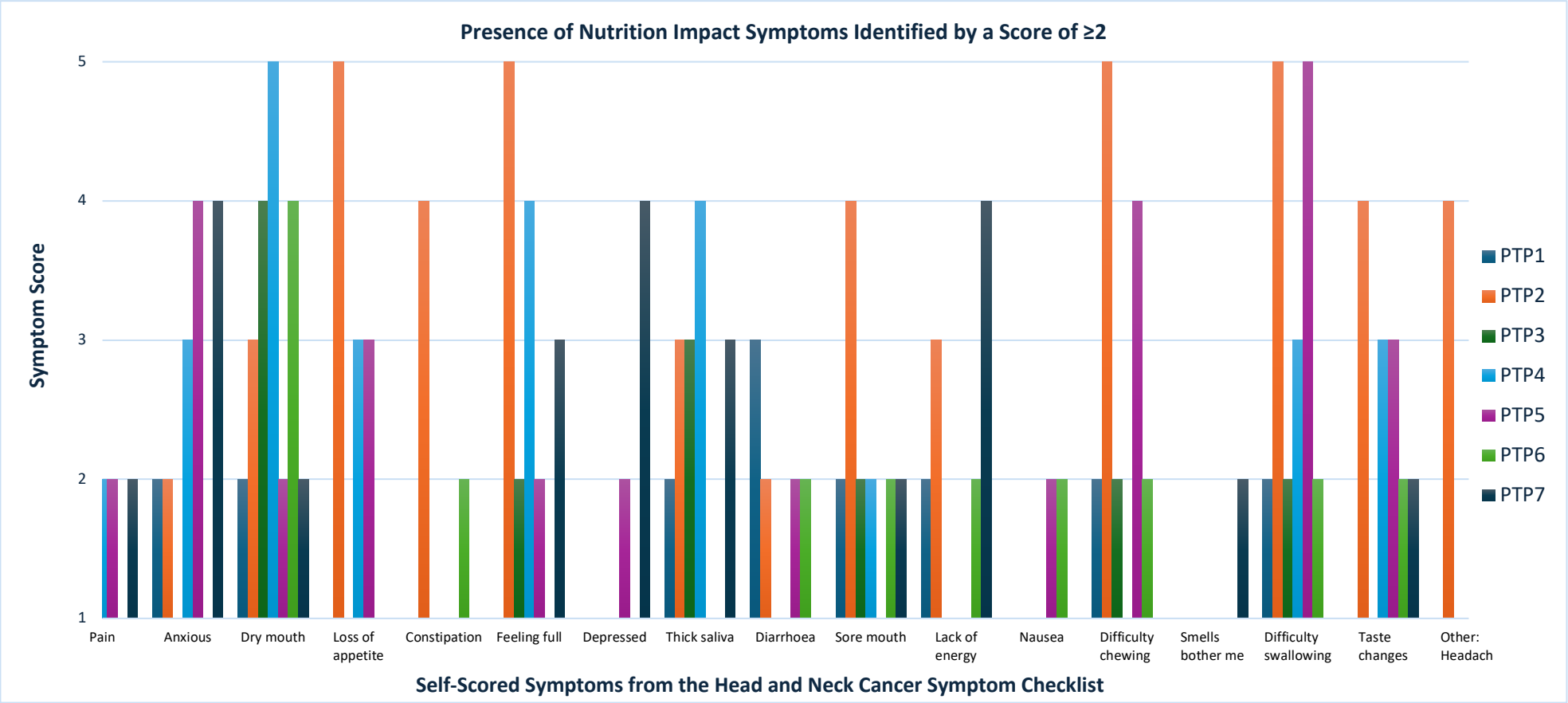
Appendix I: *Participants' Use of Over the Counter and Prescribed Supplements*

Participants	Supplement Used
PTP1	NutraLife Fish Oil: 1500 mg capsule OD, consumed 4/4 days
	Thompson Immunofort: 1 capsule OD, consumed 4/4 days
PTP2	Fortisip multifibre: 200 ml bottle BD, consumed 4/4 days
	Ensure powder: 6 scoops (53.8 g) OD, consumed 4/4 days
	Ensure powder: 3 scoops (26.9 g) every second day with homemade eggnog
	Benefibre: 3.5 g OD, consumed 4/4 days
PTP3	Multivitamin BPC (MVI BOM): 2 tablets OD, consumed 4/4 days
	Good health vitamin C plus: OD, consumed 4/4 days
	Now Niacinamide: OD, consumed 4/4 days
	Whey powder (Reactive Pure NZ Isolate): 1 x heaped teaspoon, consumed 3/4 days
PTP5	Sustagen Powder: Consumed 2/4 days. Day 1, 2 scoops (40g), and Day 2, 3 scoops (60g)
	Centrum for women multivitamin: 1 dissolvable, taken 1/4 days
PTP6	Vitamin B + C (1 dissolvable tablet), consumed 1/4 days
	Apple Pectin: 2 tablets OD, consumed 4/4 days
PTP7	Picking rock women's multivitamin: 1 capsule OD, consumed 4/4 days
	Berocca energy 1 x dissolvable tablets: Consumed 2/4 days
	Konsyl D Psyllium Husk Powder ½ dessert spoon OD consumed 4/4 days

Note. PTP4 did not use prescribed or over the counter supplements during the food intake recording period. Abbreviations: OD—Once Daily; BD—Twice Daily.

Appendix 1

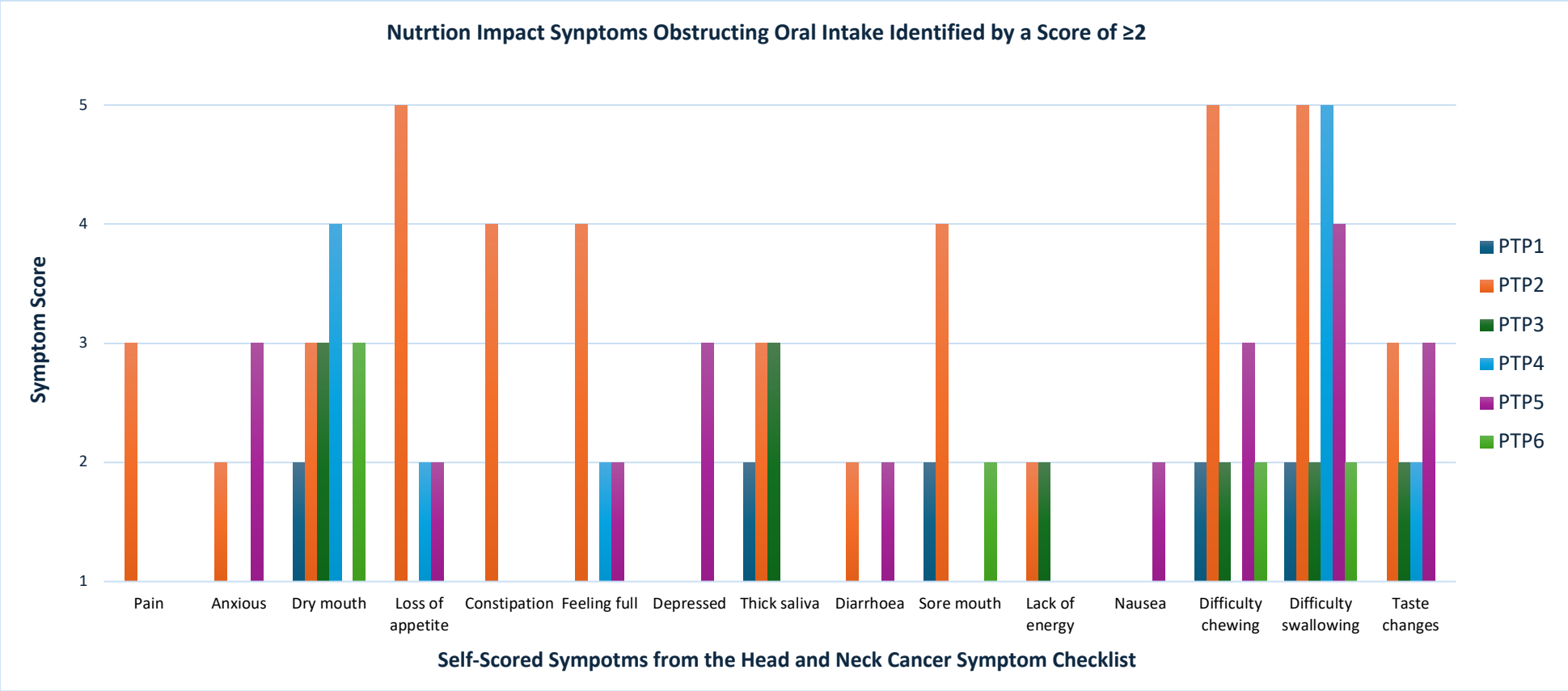
Figure 1. *Self-Reported Nutrition Impact Symptoms During the Past 3 Days*



Note. NIS were classed present if a participant self-scored the symptom(s) with a corresponding score of ≥2. Presence scores on the HNSC: 1 = Not at all, 2 = A little bit, 3 = Somewhat, 4 = Quite a bit, and 5 = A lot. Self-reported frequency scores of ≥2 classified presence. NIS that scored a one are not presented in this figure. Abbreviations: NIS—Nutrition Impact Symptoms; HNSC—Head and Neck Cancer Symptom Checklist.

Appendix 2

Figure 2. *Self-Reported Nutritional Impact Symptoms Interfering with Oral Intake During the Past 3 Days*



Note. PTP7 reported all 17 symptoms of the HNSC with a score of 1 (not at all); therefore, PTP7 is not presented in this figure. Interference scores on the HNSC: 1 = Not at all, 2 = A little bit, 3 = Somewhat, 4 = Quite a bit, and 5 = A lot. Self-reported interference scores of ≥2 classified a NIS obstructing oral intake. Self-reported NIS that scored a one are not presented in this figure. Abbreviations: NIS—Nutrition Impact Symptoms; HNSC—Head and Neck Cancer Symptom Checklist.

Appendix 3

Table 1. *Participants Micronutrient Status*

Participants	**PTP1**	**PTP2**	**PTP3**	**PTP4**	**PTP5**	**PTP6**	**PTP7**
Vitamins (Unit)							
Vitamin A (µg)	1,619.5	1,061.7	508.5	**515.7***	1,644.6	926.4	1,532.4
Thiamin (mg)	1.5	2.9	1.5	1.6	1.6	1.1	1.6
Riboflavin (mg)	2.4	2.3	1.5	2.0	3.9	1.4	2.6
Niacin equivalents (mg)	27.9	34.3	43.3*	33.8	30.6	21.8	37.5*
Folate (µg)	701.6	577.9	488.4	575.1	525.6	533.3	795.3
Vitamin B6 (mg)	3.5	2.1	1.9	1.3	1.4	1.3	2.1
Vitamin B12 (µg)	3.3	5.0	**2.1***	3.0	4.6	4.4	3.2
Vitamin C (mg)	137.5	100.3	95.0	116.9	**42.8***	56.7	167.6
Vitamin E (mg)	17.2	7.8	13.5	15.3	12.3	7.9	11.8
Minerals and Trace Elements (Unit)							
Calcium (mg)	**737.8***	**951.5***	1,005.2	**942.3***	1,674.6	**709.0***	1,357.4
Iron (mg)	**12.9***	16.8	20.5	13.4	12.3	10.9	19.2

Participants	**PTP1**	**PTP2**	**PTP3**	**PTP4**	**PTP5**	**PTP6**	**PTP7**
Minerals and Trace Elements (Unit)							
Zinc (mg)	8.2	18.9	11.5	10.1	13.7	11.8	**13.4***
Sodium (mg)	2,309.6	1,744	1,112.8	2045.7	1,869.6	1,519.1	3,646.7
Potassium (mg)	3,134.9	**2458.6***	**3,445.8***	3,382.2	4,303.3	**2,535.8***	4,241.3
Magnesium (mg)	385.1	**287.9***	531.1	499.3	550.7	318.1	555.9
Phosphorus	1059.4	1173.4	1666.0	1560.9	2380.5	1093.2	2111.6
Selenium (mg)	**37.8***	70.8	102.3	91.1	59.8	64.4	74.7

Note. Each participant's intake of the listed micronutrients is summarised in the above table according to the recommended (RDI and AI) set for Australia and New Zealand population with references to demographic and life stage characteristics (National Health and Medical Research Council et al., 2006).
Iodine was excluded from the dietary analysis, as we did not specifically ask participants about the consumption of iodised salt or fortified bread. Vitamin E is represented as Alpha-tocopherol equivalents, Vitamin A as Retinol equivalents and Folate as dietary folate equivalents. Sufficient nutrient intakes meet their recommended NRVS (RDI or AI) if the nutrient is ≥ 100% of the NRV but not exceeding the set UL. Inadequate nutrient intakes are blooded, meaning they are below the set recommended requirements. Recorded nutrient values in this table exclude nutrients from purchased over-the-counter supplements.

Abbreviations: PTP—Participant; mg—Milligrams; µg—Micrograms; AI—Adequate Intake; RDI—Recommended Dietary Intake; UL—Upper Limit; NRV—Nutrient Reference Values.

*Signifies a micronutrient is below the recommended AI and RDI for age and gender.

* signifies a micronutrient is above the recommended UL for age and gender.

Appendix 4

Table 2. *Participants Coping Strategies*

Participants	Identified Symptoms and Developed Coping Strategies to Manage These
PTP1	***Sore mouth:*** "Difflam Gel - antiseptic and numbing to improve comfort and help heal ulcers quickly." ***Thick saliva:*** "Lots of water and mouth washes - I also use a soft toothbrush to clean pockets inside my mouth where thick saliva tends to accumulate." ***Dry mouth:*** "As above plus occasional use of mouth gels (I used these frequently after radiation including overnight). I also sleep with the irradiated side down, and my 'good side' helps keep my dry side moist due to gravity." ***Difficulty chewing:*** "Practice, practice practice … it's gotten easier and I bite my tongue less frequently now. I have surgery scheduled for later this year where I will get tooth implants (three years post treatment after lots of chasing!) and this will require some more practice to get used to the new teeth I'm sure." ***Difficulty swallowing*** : "I have "eating water" which is the water I have with a meal just to help me swallow things that are tricky (usually insoluble things like chopped parsley, nuts, raw carrot). Without eating water, I don't eat, as sometimes I choke and that's scary!" ***Pain:*** "Difflam usually helps with the pain, occasionally ibuprofen but not required often." ***Diarrhoea:*** "Experimenting with eating to see whether there are foods that aren't working for me … still working on that!" ***Anxiousness:*** "Mindfulness, good support from friends, audiobooks." ***Lack of energy:*** "Working on that - have taken the past 7 months off work and have been focusing on eating well and exercising and doing things I enjoy. My lymphocytes are low."
PTP4	**Difficulty swallowing**: "Sip water with each mouthful as its usually needed to swallow." ***Taste changes***: " I add sauces to meals and probably too much salt to make them tasty. I am not too worried about taste." **Extra Mucus:** "I use an electric toothbrush and brush my gums and teeth for at least 3 mins, then floss once per day. I also use a plastic tongue scraper as I find there is often mucus or remnants of my last mouthful left on the back of my tongue." ***Dry mouth:*** "I have used dry mouth saliva substitutes but don't really like them." ***Time available for lunch:*** "I always have a reasonable sized breakfast before I leave the house in the morning, so if I struggle to sit and eat later, then at least I have a good start." ***Pain:*** "For pain - use paracetamol."

Participants	Identified Symptoms and Developed Coping Strategies to Manage These
PTP5	***Difficulty swallowing:*** "I have a glass of water beside me when eating to help swallowing. I've learnt how to sense when pieces of food are stuck and can cough them up to avoid choking. I've had 3 serious choking incidents that were scary." ***Nausea:*** "I find de-gas capsules work well to deal with the extra air I ingest with eating which causes a lot of discomfort and nausea. Omeprazole daily also helps."
PTP6	***Dry mouth:*** "Worse when lying down so use xylitol lozenges and oral gel." ***Sore mouth:*** "Comes and goes so careful what foods I eat avoiding acidic, spices, crunchy, bones." ***Difficulty chewing:*** "Need to really concentrate on where food is in my mouth and definitely no talking! Can easily bite tongue and side of mouth." **Difficulty swallowing:** "Is getting progressively better with practice." ***Taste changes:*** "still ongoing but improving." ***Anxiousness:*** '"when follow-up appointments/scans are due. Need to remind myself not to worry over something which may never happen." ***Constipation***: "Rarely mainly due to diverticulosis but under control with high fibre diet." **Diarrhoea**: "Rarely now." ***Nausea***: "Can be a problem most mornings but not severe enough for meds. Usually don't eat breakfasts but ok by midday." ***Lack of energy:*** "Rarely now. Tried cannabis oil for sleep issues which helped."
PTP7	***Lack of energy and sore-mouth:*** "Chewing is something I have to engage with and even recently this has been a consideration without solution other than avoidance." ***Dry mouth and Thick saliva:*** "These features are probably the hardest to deal with as enunciation is affected with dry mouth while thick saliva is something I have stretched to sinus congestion dropping into my mouth or lifting up from my lungs. Coping is more about my irritation than managing the changes. I mean my dry mouth is problematic if I am using it. If static and unengaged I have plenty of moisture but when active or in a social situation coping is required and again soda water seems effective although I have been dialing that back due to the impact it has on tooth enamel and price so mainly just drink water if out anywhere."

Note. The table presents coping strategies shared by participants who addressed this question in the final survey. Direct quotes for participants are included in this table.

Appendix 5

Table 3. *Eating Experiences in Social Settings Described*

Participants	Participants Eating Experiences Described
PTP1	PTP1 described eating in a social situation as "not easy!" "Sometimes I don't eat, other times I just have to be careful about what I eat and it's a bit risky. Eating with friends at home is fine, they understand."
PTP2	PTP2 reported avoidance of eating in social situations, stating "I don't."
PTP3	PTP3 reported food selectivity in social settings, stating, "I am selective with what I eat and only eat small portions. Ensure knife and fork is available to cut up food. Am mindful that I don't have full feeling in my face so careful that I am not inadvertently spilling."
PTP4	PTP4 reported if she is eating out: "I will tend to only eat half the meal unless, I am with family who knows to give me lots of time." Notably, PTP4 expressed that eating in social situations can be off-putting: "It puts me off eating out, but I do try not to let it. Dinner at friends is usually OK. I will let them know if I can't eat something, or just hand the remainders to my husband(!)."
PTP5	PTP5 expressed being immobilized in their speech and eating, reporting: "These create isolation from family, friends, and make it nearly impossible to take part in social events." Further, expressing "Eating in social situations can be "very difficult, sad, and isolated." PTP5 also experienced "fair & anxiety about chocking on food especially when eating with others – even close family." PTP5 expressed how they feel "very self-conscious about disability" and how different their plate of food looks to others: "Its baby food essentially and it takes me so much longer to eat even a smaller portion– everyone else is done and I'm still slogging it out." PTP5 mentioned: "I can't eat and talk–that is something we take for granted and people find it very challenging to have a silent person during social events." PTP5 further stated, "We do not get invited to dinner with friends now and eating out at restaurants is not always easy as they can be quite inflexible about the menu items they will provide you or even blend."
PTP6	PTP6 reported typically refraining from eating in social situations. PTP6 remarked they tend not to eat out: "As it is hard to find bland foods and the need to constantly wipe mouth can be off putting, and coughing fits too." PTP6 further stated, "It's impossible to carry a conversation, but people who know me understand this." In the circumstance that PTP6 did eat out, they would select soft foods and preserve water nearby. Notably, PTP6 mentioned alcohol irritated their tongue, however, incorporating soda water in alcoholic beverages assisted PTP6 when celebrating."

Participants	Participants Eating Experiences Described
PTP7	PTPT 7 stated: “Social situations are not too much of a problem” as they don't experience many. “The closest I get is eating nibbles at board gaming or a funeral.” PTP7 further states, “My scar is underneath my jaw and doesn't really cause me trouble other than with saliva and chewing so if I did go out anywhere to eat anything other than roast/fried meat or crackers would be fine.”

Note. The table includes direct quotes from participants describing their eating experiences in social settings.