Attitudes and Beliefs People with Head and Neck Cancer Hold Towards Food and Nutrition.

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Abstract

Background: Head and neck cancers (HNC) are devastating diseases that have significant impacts on a person's ability to achieve adequate nutrition. HNC treatments and subsequent side effects often cause nausea, taste changes, appetite loss, and most harmfully malnutrition. The severity of these side effects can leave people searching for ways to improve their condition and can lead to the development of strong attitudes and beliefs towards nutrition, some of which are evidence-based and others which are not. Dietary changes that are not evidence-based can lead to reduced recovery, and survival.

Objectives: Explore the attitudes and beliefs people with HNC hold towards food and nutrition in HNC prevention, causation, treatment, and recovery.

Methods: This study collected qualitative data using an online survey. Data was analysed manually using an inductive thematic analysis. All 39 participants were over 18 years of age, had been diagnosed with, and treated for, HNC in New Zealand (NZ), were currently living in NZ, and could independently complete the survey.

Results: The themes were participants' sources and perceptions of nutrition information, perceptions of food and nutrition, and participants' desire for additional support. The information sources people with HNC accessed the most and held in the highest regard were dietitians and survivors of HNC due to their relatable support and focus on evidence-based information. Alcohol, energy and protein were correctly identified to have significant roles in HNC. Additionally, very few participants believed the alternative dietary therapies mentioned were effective (ketogenic diet, high-dose vitamin C, prioritisation of fruits and vegetables), further indicating that participants valued evidence-based information and support. Finally, participants desired support for unintentional weight loss, involvement in treatment decision-making, receptivity to their opinions, and advice regarding long-term recovery recommendations. These findings highlighted the need for open communication between healthcare professionals and people with HNC.

Conclusion: The nutrition beliefs identified in this study highlighted the quality and range of dietary support available to people with HNC in NZ. The findings of this study provided insight into the areas of nutrition education and support that require improvement to ensure that people with HNC achieve the best possible health outcomes.

Keywords: head and neck cancer, survey, nutrition, attitudes, beliefs

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List of Abbreviations

DNA	Deoxyribonucleic acid
HNC	Head and Neck Cancer
HNCSA	Head & Neck Cancer Support Aotearoa
HPV	Human Papilloma Virus
IDDSI	International Dysphagia Diet Standardisation Initiative
NZ	New Zealand
NZE	New Zealand European
ONS	Oral Nutrition Supplement
PEG	Percutaneous Endoscopic Gastrostomy

Chapter 1: Introduction

Head and neck cancers (HNC) are rare but devastating diseases that have profound effects on a person's ability to achieve adequate nutrition. HNC are classified as malignancies of the oral cavity, pharynx (throat), larynx (voice box), paranasal sinuses, nasal cavity, salivary glands, and the skin of the head and neck (National Cancer Institute (NCI), 2023a). These malignancies represent approximately 3–5% of all cancer diagnoses in Aotearoa, New Zealand (NZ), and rank as the seventh most diagnosed type worldwide (Sung et al., 2021; Te Whatu Ora (Health NZ), 2020). Although HNC has a lower diagnosis rate than other cancers, its prevalence has been steadily increasing over the last 75 years, and in 2020, 547 New Zealanders registered with lip, oral cavity, and pharynx cancer (Health NZ, 2020). In addition to this increasing prevalence, HNC has been linked to several risk factors, including heavy alcohol consumption, smoking, and Human papillomavirus (HPV) exposure (Jethwa & Khariwala, 2017; Kobayashi et al., 2018; Koo et al., 2021).

HNC requires a variety of medical and dietary treatments depending on the location and severity of the cancer. Common treatments include surgery, chemo-radiation therapy, oral nutrition supplementation, and enteral feeding (Cancer Australia, 2023). HNC and its treatments can cause a range of debilitating side effects that significantly affect a person's ability to meet their nutrition requirements. These side effects can include mucositis, nausea, fatigue, taste changes, and frequently malnutrition (Willemsen et al., 2020).

Malnutrition is one of the most detrimental and debilitating outcomes of HNC. Characterised by weight loss, appetite reduction, inadequate oral intake, and increased nutrient requirements (caused by cancer), malnutrition significantly contributes to negative health outcomes (Lee et al., 2021). Malnutrition is exceptionally harmful in HNC as it depletes a person's energy and strength and increases their susceptibility to acute illness, consequently reducing the efficacy of treatment and contributing to impaired recovery and survival (Beirer, 2021).

Due to the extreme impact side effects that HNC have on a person's ability to obtain nutrition, it is likely that people with HNC desire advice on ways to improve their condition. Often, people who are unwell will search for nutrition information to support their treatment and recovery, and in their desperation, information of varying credibility and accuracy is accessed and utilised (Lee et al., 2023). This information may be evidence-based or less scientifically supported advice that could result in inappropriate dietary changes and adverse outcomes that exacerbate malnutrition risk. Furthermore, because all health treatments have varying levels of success and support, it is likely that strong attitudes and beliefs are developed towards nutrition information as people attempt to navigate their treatment and recovery journeys.

It is essential to understand the different perceptions people with HNC have toward nutrition because these perspectives enable health professionals to effectively tailor education interventions. Despite the importance of patient-centred interventions, there is limited research exploring the nutrition perceptions from the perspective of people with cancer, much less people with HNC.

A small number of qualitative studies have investigated the opinions people with a range of cancers have expressed towards their diets. These studies identified several strong beliefs among participants regarding the interaction between food and their cancers, their perception of weight loss, and their opinions of nutrition information sources (Beeken et al., 2016; Lee et al., 2023).

Some studies identified a belief that participants' diets were responsible for causing their cancers and that certain foods were imperative to achieving successful recovery (Beeken et al., 2016; Lee et al., 2023). One study noted that beliefs of this nature often resulted in participants enacting dramatic and sometimes unsupported dietary modifications (Beeken et al., 2016). Attitudes towards specific foods also featured in past research, particularly regarding the role of food in causing, treating, and recovering from cancer. Foods commonly attributed to cancer causation included sugar, processed foods, and additives (Lee et al., 2023). The foods participants believed would treat their cancers included specific vitamins and minerals such as selenium, magnesium, vitamin C, and red or green-coloured vegetables (Beeken et al., 2016). Additionally, some participants mentioned the importance of a balanced diet and consuming all foods in moderation (Beeken et al., 2016). Although some of the beliefs expressed in this research are evidence-based, a vast majority are alternative theories not supported by scientific literature.

Another concerning theme identified across existing qualitative research investigating people with cancer was a favourable opinion towards weight loss, where participants believed it was a positive outcome of their situation (Hiatt et al., 2022). This research noted that participants who celebrated weight loss had often not received any nutritional support.

Therefore, it was alarming to discover that multiple studies had reported that their participants felt they did not receive adequate dietary advice from their healthcare team (Lee et al., 2023).

Some studies reported that participants were forced to depend upon 'unreliable' information sources such as the media, the internet, friends and family, and unregulated health professionals (naturopaths, nutritionists) (Beeken et al., 2016; Lee et al., 2023). These sources offered a wide variety of nutrition information, some of which may have been evidence-based, and some which may have lacked the support of scientific literature, and could have led to inappropriate dietary changes. Additionally, the contradictory advice received from these sources led to increased distrust and dissatisfaction towards the media and participants' healthcare teams (Beeken et al., 2016).

The findings of this study will provide healthcare professionals with information on the opinions people with HNC in NZ hold towards nutrition and if these ideas differ to or build on existing literature. Understanding the perceptions people with HNC have towards food and nutrition is important because following incorrect or non-evidence-based dietary advice can lead to malnutrition and other detrimental health outcomes. Therefore, this research provides an opportunity to collect information that could focus and strengthen evidence-based education and support programs for people with HNC in NZ. Improving these services could further encourage patient-centred care and improve health outcomes.

1.1 Research Aims

This research project aims to explore the attitudes and beliefs people with HNC in NZ hold towards food and nutrition in HNC causation, treatment, and recovery.

1.2 Research Objectives

a. Investigate the perceptions people with HNC in NZ have towards the sources of nutrition information they access.
b. Identify specific foods or nutrients people with HNC in NZ believe hold significance in HNC causation, treatment, and recovery
c. Determine the overarching perceptions people with HNC in NZ have towards food and nutrition in HNC causation, treatment, and recovery

1.3 Thesis Structure

This thesis is divided into six chapters. Chapter One provides an introduction to the background and purpose of this project, and includes the research aims and objectives. Chapter Two is a literature review of existing research surrounding the perceptions people with cancer hold toward food and nutrition. The review specifically highlights the treatments of HNC and provides an analysis of established qualitative research regarding the nutrition information sources people with cancer access and the attitudes they hold towards food and nutrition. Additionally, a summary of previously utilised research methods is included. Chapter Three provides a detailed description of, and rationale for, the methodology used in this thesis including the research and survey design, participant inclusion and exclusion criteria, data collection, storage, saturation, and analysis procedures, as well as the ethical considerations. Chapter Four presents participants' contextual demographics and provides an overview of participants' sources and perceptions of nutrition information, perceptions of food and nutrition, the social role of food, and participants' desire for additional support. Chapter Five presents an in-depth discussion of the research findings developed by this study. Finally, Chapter Six describes how the aim and objectives have been met, acknowledges the impact this project may have on people with HNC and their utilisation of nutrition information, and provides recommendations for future research.

1.4 Researcher Contributions

Table 1

Researcher contributions

Name	**Contribution**
Ruby Young MSc Nutrition and Dietetic Student	Second year dietetics student and primary author of the thesis. Involved in all aspects of this study: ethics application, survey development, participant recruitment, qualitative data analysis, interpretation of results and writing of the thesis.
Dr Maria Casale, NZ Registered Dietitian Primary Academic Supervisor	Conceptualised this study, assisted in ethics application, survey question development, and literature review direction. Provided review and feedback on all documentation in preparation for thesis submission.
Dr Rachel Batty Co-Supervisor	Assisted in ethics application, and survey question development. Provided review and feedback of documentation in preparation for thesis submission.
Emerita Pamela Von Hurst Co-Supervisor	Conceptualised this study. Provided review and feedback on all documentation in preparation for thesis submission.

Chapter 2: Review of the Literature

This chapter presents an overview of the literature, beginning with a broad summary of HNC, then a detailed review of the literature reporting attitudes and beliefs towards food and nutrition in people with cancer.

2.1 Head and Neck Cancer: An Overview

HNC is the seventh most common cancer globally, yet it is the cancer with some of the most devastating impacts on those who suffer from it (Sung et al., 2021). HNC includes cancers in the oral cavity, pharynx, larynx, paranasal sinuses, nasal cavity, salivary glands, and the skin of the head and neck (NCI, 2023b). In NZ, there is limited data detailing the prevalence of each subtype, however, oral cavity and oropharyngeal cancers, including those of the tongue, tonsils, gums, mouth, lips, and salivary glands were the most common HNC in America in early 2024 (American Cancer Society, 2024).

The three leading risk factors for HNC are human papillomavirus (HPV) infection and excessive tobacco and alcohol consumption. American and European studies have found tobacco smoking and chewing to be responsible for approximately 34% of HNC cases (Hashibe et al., 2009). Although there is currently no NZ specific data regarding risk factors, it is estimated to be similar to that of the above Western populations (Cancer Society, 2023). There is limited evidence regarding the effect of e-cigarettes or vaping on the risk of developing HNC despite the increased prevalence of use, perhaps due to the relatively recent uptake and popularisation of vaping (Nip et al., 2023; Szukalska et al., 2020; Health NZ, 2022). Additionally, studies across Europe and America have found heavy alcohol consumption to be responsible for approximately 5% of HNC cases (Hashibe et al., 2009). However, these studies have found the combination of alcohol and tobacco consumption contributes to approximately 75% of cases (not including HPV cases) (Hashibe et al., 2009).

HPV is a group of viral infections known for causing skin or mucous membrane growths (warts). HPV exposure is estimated to cause approximately 25% of HNC cases globally (de Martel et al., 2017; Ndiaye et al., 2014). The most common HNC-causing virus is HPV16, which contributes to approximately 70% of HPV HNC cases (Stein et al., 2015; Tumban, 2019). Globally, HPV HNC prevalence has increased compared to non HPV HNC, however, the HPV vaccine has been seen to reduce HPV infections and is hoped to reduce the incidence of HPV HNC (Menezes et al., 2021; Timbang et al., 2019).

In NZ, HNC (lip, oral cavity, and pharynx specifically) accounts for approximately 3–5% of all cancer cases and 547 New Zealander's cancers annually, according to 2020 Ministry of Health records (Health NZ, 2020). Whilst HNC has a smaller number of cases in NZ compared to other cancers, its prevalence has been rising steadily over the last 75 years, perhaps due to the increasing aging population and their high intake and duration of alcohol and tobacco consumption (Kanasi et al., 2016; Kleykamp & Heishman, 2011; Health NZ, 2020; Veerbeek et al., 2019).

Research has revealed HNC prevalence is inequitably spread across gender, ethnicity and socioeconomic status. For example, some studies have suggested a 3:1 ratio of males to females regarding HNC diagnoses, however, this differs by HNC type as in NZ lip, oral, and pharynx cancers are more common in females (Gaeta et al., 2023; Health NZ, 2020). Higher HNC (nasopharynx) incidences have been seen in the Pacific, Māori, and Asian populations (Minhinnick et al., 2022). However, ethnic differences have not been widely explored across all HNC types. Socioeconomic status is a similarly under-researched contributing factor to HNC. Emerging literature from America has suggested that lower socioeconomic status increases the risk of HNC (Guo et al., 2021).

2.2 Treatments

Treatments for HNC can include surgery, radiation therapy, chemotherapy, immunotherapy, or a combination of two or more of the above. The treatments used for each person depends on the location and stage of the cancer (Anderson et al., 2021). Unlike most other cancers, the treatments for HNC have profound long-term effects on many parts of a person's identity: talking, eating, self-confidence, and subsequently nutrition. Therefore, it is natural that people with HNC are highly motivated to seek out and understand their treatments.

2.2.1 Surgical Treatment: Types and Consequences

HNC surgeries typically involve the removal of tumours and any affected tissue, and the reconstruction of important structures in and around the head and neck (Cancer Australia, 2023). Surgical treatment is often a central component of HNC. However, morbidity associated with surgery is more common than any other treatment, and people with HNC often suffer with devastating and long-term consequences (Ronen et al., 2023). Base of tongue cancer is a common HNC subtype that demonstrates these effects. For example, in base of tongue cancer a partial or total glossectomy is typically required. Following a glossectomy, the tongue is often reconstructed using tissue from other parts of the body (for example, muscle from the thighs, arms, or back) (Vincent et al., 2019). Because these tissues are not accustomed to act as a tongue, recovering and relearning usual tongue functions can be a long and challenging process. Another example of a surgical treatment is a laryngectomy, the removal of the larynx (Chotipanich, 2021). The larynx is essential for talking, breathing, and swallowing. Therefore, Laryngectomees often require a lifelong voice prosthesis and extensive rehabilitation to regain these vital functions (Chotipanich, 2021). Many people who undergo surgical treatment are also required to complete radiation or chemotherapy, further compounding symptoms and adverse effects.

2.2.2 Radiation Therapy: Types and Consequences

Radiation therapy uses strong energy beams to target and kill tumours (Gao et al., 2019). Radiation beams damage cells' DNA, leaving them unable to replicate and survive (Gao et al., 2019). Beams are calculated to target and shrink tumours to slow their growth, increase accessibility for surgery, or treat remaining damaged cells post-surgery. The most common type of radiation used in HNC is an external beam radiation therapy called intensity-modulated radiation therapy—this therapy uses specialised technology to specifically target the tumour, limiting damage to healthy tissues (Alfouzan, 2021; Taylor & Powell, 2004).

Radiation therapy is used to treat a majority of HNC cases (Naghavi et al., 2018). Almost all people who undergo radiation therapy experience some of the following side effects: xerostomia, oral mucositis, difficulty and pain in mastication, speech and swallowing difficulties, trismus, periodontitis, fibrosis, and oral infections (Alfouzan, 2021).

Xerostomia is one of the most common radiation therapy side effects, it occurs when radiation damages salivary glands and reduces the amount of saliva produced (Aggarwal et al., 2021). Because of the essential lubricating and antibacterial functions of saliva within the oral cavity, hyposalivation can cause pain in the throat, impaired swallowing, altered taste, and dental decay (Pinna et al., 2015). All of these factors impact the ability people with HNC have to consume adequate nutrition and can lead to weight loss and poor health outcomes (Jin et al., 2021).

Oral mucositis is one of the most severe radiation therapy side effects. Radiation interferes with the replication of epithelial cells, leading to painful mucosal erythema, oedema, and debilitating oral ulcerations (Singh & Singh, 2020). The pain and functional deficit oral mucositis has in mastication and swallowing severely impacts the ability people with HNC have to consume nutrition orally, and sometimes means they are only able to gain nutrition through enteral methods. These debilitating side effects can occur throughout radiation treatment and last for several months or years after treatments have concluded.

2.2.3 Chemotherapy: Types and Consequences

Chemotherapy is a drug-based treatment used to destroy and slow the growth of cancerous cells (Cancer Australia, 2023). Common chemotherapy agents used in HNC include antibiotics, antineoplastics, and antimetabolites (NCI, 2023a). Chemotherapy however, also kills healthy cells that naturally divide and replicate quickly. Therefore, hair follicles and the lining of the mouth and intestines can become damaged, causing mucositis, diarrhoea, nausea, and alopecia (Gao et al., 2019). Nausea, fatigue, and vomiting are some of the more common side effects experienced by people with HNC, where certain chemotherapy agents can activate emesis receptors, triggering acute and delayed vomiting. Nausea and continual vomiting can deter people from eating and often causes appetite loss.

Chemotherapy is often used in conjunction with radiation therapy. Chemoradiation is a standard treatment for multiple HNC, often used for its intensity and positive clinical results. However, the combination of the treatments and subsequent build-up of toxic products within the body often exacerbates any side effects experienced (Akimoto, 2015).

2.2.4 Immunotherapy: Types and Consequences

Immunotherapy uses the immune system to kill cancer cells (Cancer Australia, 2023). Immunotherapy alters or synthetically mimics cells to activate or suppress the immune system into increased recognition of cancerous cells (Cancer Australia, 2023). Common types of immunotherapy used in HNC include vaccines, monoclonal antibodies, checkpoint inhibitors, and cytokines. As immunotherapy dampens the immune system, it increases the vulnerability people with cancer have to illness and infection and magnifies even the minor effects of viruses and bacteria during treatment (Morelli et al., 2022).

2.2.6 Long-term Effects of Treatment

HNC and the above treatments can cause various short and long-term side effects that affect people's ability to obtain optimal nutrition. Side effects can include dysphagia, dental issues, psychological and psychosocial symptoms, taste changes, appetite loss, and malnutrition.

Dysphagia is a more specific side effect of this cancer's location. Dysphagia can be caused by inflammation or sensory or neuromuscular damage to the swallow process from radiation and chemotherapies (Manikantan et al., 2009). Dysphagia means people are not able to consume solid foods and fluids orally without the risk of aspiration. Therefore, dysphagia significantly affects how a person obtains nutrients and places them at high risk of malnutrition.

Halitosis and dental issues are side effects that affect a person's ability to eat sometimes long after treatment. These side effects can be caused by tumour or treatment-related tissue necrosis, poor oral hygiene, or nasal obstructions (Albuquerque et al., 2010). More severe dental issues include treatment-related damage to the jaw or teeth and altered saliva production, which can cause complete tooth decay and edentulism weeks, months or years after treatments have concluded (Sroussi et al., 2017). These side effects have extensive effects on the mouth and when severe, can cause extreme pain and limit function to the point where oral intake is no longer feasible, and extraction and dentures are required.

Psychological and psychosocial symptoms are common in people with HNC, especially those who have undergone surgical treatments. Facial disfigurement is something people who have undergone surgical tumour removal or reconstruction may encounter. Because of their altered anatomy, these people often require different specialised foods such as supplements, enteral feeds, or texture modified foods. In the process of consuming these foods people with altered anatomy may sometimes eat differently to others, for instance, extended chewing time, spilling foods and fluids, and tube feeding (Ringash et al., 2018). These three aspects can cause feelings of anxiety and embarrassment for people with HNC and lead to an avoidance of social interactions to limit these feelings (Clarke et al., 2013). This becomes a nutritional concern when people with HNC limit or stop eating to avoid social judgement or negative self-feelings.

Long-term taste changes, a complete loss of taste, and lower sensitivity to certain foods, such as sweet, sour, salty, bitter, and umami flavours, are common side effects experienced across all treatment types (Mathlin et al., 2023). Taste changes can be caused by radiation damage, surgical removal of taste structures, and chemo or immunotherapy associated nausea and vomiting. Taste changes are often first experienced immediately after treatment in chemotherapy and one to four weeks after radiation therapy (Mathlin et al., 2023). These changes typically resolve within a few weeks of chemotherapy but up to one year after radiation therapy (Deshpande et al., 2018). Taste loss and taste changes are associated with reduced appetite, reduced intake, weight loss, and malnutrition (Mathlin et al., 2023).

Appetite loss is an extremely common symptom of cancer and the associated medical treatments. Appetite loss has a variety of causes, often including pain, nausea, and fatigue (Hacıömeroğlu & Çifci, 2024). Pain and nausea have profound effects on a person’s appetite. It is hypothesised that pain leads to appetite loss through dysregulated neural signalling (Malick et al., 2001). In contrast, nausea, any associated vomiting, and fatigue are thought to lead to appetite reduction or occur in conjunction with appetite loss because of their overwhelming and all-consuming unpleasant sensations (Wickham, 2020). Regardless of the aetiology of appetite loss, it has been linked to both partial and total suppression of nutrition intake, and subsequently, a high risk of malnutrition throughout HNC treatments.

Malnutrition is one of the most detrimental symptoms and side effects of HNC and its treatments. Malnutrition in HNC is characterised by (a) cancer cachexia, weight loss, and muscle wasting; (b) appetite loss; (c) decreased food intake; and (d) increased nutrient requirements caused by cancer (Lee et al., 2021; Willemsen et al., 2020). Malnutrition is detrimental for people with HNC as it decreases strength and energy, increases susceptibility to acute illness, and therefore, reduces the efficacy of treatments, leading to poor outcomes such as reduced recovery and survival.

The treatments and side effects described in the proceeding section demonstrate the profound impact that HNC has on all domains of a person’s life. These severe and life altering consequences and their subsequent trauma can push people with HNC to desperate points and provide some context for the strong opinions and attitudes developed towards food and nutrition.

2.3 Nutritional Treatment

Nutrition treatments in HNC are used to combat the side effects of cancer and treatments and avoid negative long-term consequences of weight loss, muscle wasting and malnutrition. Across the literature, unintentional weight loss is experienced by ~30–50% of people with HNC and up to 90% of people with HNC who undergo chemoradiation therapy (Ghadjar et al., 2015; Jin et al., 2021; Langius et al., 2016; Porter & Ukwas). Some Chinese, Malaysian, and Australian studies have reported an average of 7–8% total weight loss during treatments and up to a 60% prevalence of cachexia (Abu Zaid et al., 2022; Brown et al., 2018; Wang et al., 2021). This makes HNC one of the cancers with the most significant prevalence and rate of weight loss. Nutrition treatments used to combat these malnutrition symptoms include nutrition counselling, prophylactic feeding, oral nutrition support, texture modified diets, enteral feeding, blended feeds, and parenteral feeding (Ackerman et al., 2018).

2.3.1 Prophylactic Feeding Pre-treatment

In anticipation of malnutrition and treatment-related side effects that limit oral intake enteral feeding is often commenced prior to treatments beginning, to increase the time that optimal nutrition has to act (Fong et al., 2023). Often this prophylactic feeding is via a percutaneous endoscopic gastrostomy (PEG) in anticipation of long-term use and for the ease and comfort of the person (Qureshi et al., 2016). Prophylactic placement of a PEG in HNC is routinely completed in NZ (Fong et al., 2023). A study investigating people receiving radiation therapy showed a lower average weight loss, and less non-elective hospital admissions in people with a PEG, than people with HNC without a PEG, or enteral nutrition (Fong et al., 2023).

2.3.2 Oral Nutrition Support: The “Food First” Approach and Nutrition Counselling

Oral nutrition support includes three strategies to optimise nutrition: the encouragement of regular intake, food fortification, and the addition of nutritious drinks (Cawood, 2019). Regular intake means having meals and snacks at consistent intervals throughout the day to ensure nutrients are constantly being absorbed. Food fortification ensures that the foods eaten are nutrient-dense. Here, energy and protein-rich ingredients such as oils, butter, sugar, meats, or protein powders are added to foods. For a person with HNC, food fortification reduces the pressure of consuming large quantities of food to meet their requirements, as smaller amounts of nutrient-dense food have the same effect. Nutrition counselling is widespread support for patients around their dietary needs, and it has been seen to prevent weight loss in HNC patients (Krzywon et al., 2023). Nutrition counselling can include goal setting, problem solving, and coordination of care.

2.3.3 Second Line Oral Nutrition Support: Supplements

Oral nutrition supplements (ONS) are fortified fluids that increase nutrition intake when people are struggling to eat enough food. ONS are beneficial as drinking is easier and requires less energy than eating solid foods. The ONS used in clinical care include all of the essential macro and micronutrients. Therefore, if required ONS can be used as a sole source of nutrition. These supplements include powdered or ready-made drinks such as Ensure™, Sustagen™ or Fortisip™, as well as specialised formula for specific diseases and conditions (for example, Renilon and Nepro for renal disease). ONS come in a range flavours, and use milk-like and fruit juices bases. One study funded by Abbott, Nutricia, Nestle, Novartis, and Fresenius Kabi found that milky-based drinks with flavours such as vanilla, coffee, and berry were well-rated and reliable, whereas the fruity drinks were less tolerated. However, personal preference and trial and error were key in finding the best tolerated supplement for each person (Darmon et al., 2008). ONS are subsidised under the Pharmac community schedule for people who meet certain criteria (for example, malnutrition, tube feeding, malignancy, and glossectomies) (Pharmac, 2024). ONS can be prescribed by a dietitian or doctor, and depending on the criteria a person meets and the special authority that is applied for, it can be completely or partially funded.

As ONS are fortified with large amounts of nutrients, and sometimes large volumes are required, people often struggle with tolerance. The high concentration and osmolarity of ONS can cause gastrointestinal symptoms of diarrhoea, bloating, nausea, vomiting, and regurgitation (Abbott, 2018; Hébuterne et al., 2020). Each of these symptoms can discourage people from continuing to take them.

There are a few common controversies surrounding ONS. One of these is that they are not good for people with cancer because of their sugar content, suggesting a reference to the myth that sugar ‘feeds’ cancer. However, this myth has been debunked, and these supplements are carefully formulated to provide exactly what people with high requirements need. Furthermore, as ONS are used to treat malnutrition, their high fat and sugar content is less of a concern then a nutritionally perfect diet. Another controversy is that ONS are not ‘real food’. This idea is perpetuated by social media and others who differentiate supplements from food in posts and conversations.

2.3.4 Enteral and Parenteral Nutrition

Enteral nutrition and parenteral nutrition are more intensive dietary support prescribed by dietitians and doctors to treat more severe side effects of HNC. Enteral nutrition is a feeding method where fortified liquids are administered directly into the stomach or intestine through specialised tubes (Sheth et al., 2013). Enteral nutrition is used to treat a variety of HNC side effects, including low appetite, dysphagia, and commonly severe weight loss and malnutrition (Sheth et al., 2013). Enteral feeds are formulated from a range of essential nutrients. Therefore, if required, enteral feeds can be used as a sole source of nutrition. Generally, feeds contain dairy, soy, or pea proteins, glucose, dairy or fish derived fatty acids, and additional vitamins and minerals (Cámara-Martos & Iturbide-Casas, 2019).

Currently, there is only one plant-based enteral feed (Fortisip PlantBased 1.5kcal/ml), which has only recently become available in NZ (Nutricia, 2024). Because of its recent availability in NZ, it may not yet be available in all clinical environments. Therefore, this may require vegan people with strong beliefs to choose between their beliefs and treatments (Webb et al., 2016).

Blended feeds are an increasingly popular alternative enteral feed. Blended feeds are standard meals that are blended into smooth liquids and inserted into feeding tubes by people at home (McCormack et al., 2023). However, blended feeds are controversial due to the risks associated with their homemade nature. Blended feeds can cause tube blockages, bacterial illness, and inadequate nutrient intake (AuSPEN, 2021). For instance, blended feeds have a higher risk of blocking feeding tubes as they may not be fully liquidised and could contain fibrous chunks (AuSPEN, 2021). Blended feeds are at a higher risk of bacterial contamination due to unsterile home environments, unregulated constituents, and a potential lack of food safety in the preparation, use, and storage of the feed (AuSPEN, 2021). The largest risk blended feeds hold for people with HNC is that they may not be nutritionally adequate (AuSPEN, 2021). Because blended feeds are home-made, the nutritional makeup of the feeds will vary across batches, meaning the adequacy of people’s intake is reliant on the education provided and people’s ability to condense nutrients into meals.

Parenteral nutrition is an intensive feeding method, it bypasses the digestive system, and nutrients enter the body directly through the bloodstream (ASPEN, 2017). Parenteral feeds are composed of the simplest form of nutrients, including glucose, fatty acids, amino acids, vitamins and minerals (ASPEN, 2017). Parenteral nutrition can supplement enteral feeding or provide a sole source of nutrition in very specific circumstances. Parenteral nutrition is not often prescribed for HNC due to its specific indications. Generally, parenteral nutrition is indicated for intestinal ileus, short bowel syndrome, high-output fistulas, or bowel obstructions and in most HNC cases the lower gastrointestinal tract is functional (Martinovic et al., 2023).

2.3.5 Texture Modified Diets

Texture modified diets facilitate safe oral intake in people with dysphagia and high aspiration risk. Texture modified diets range in their consistencies from thickened fluids to minced and moist textures, depending on the severity of a person's dysphagia. People can purchase thickeners that modify the texture of their foods or opt for ready-made texture modified meals.

Each and often multiple of these nutrition strategies are used to support people with HNC through their HNC treatments and bring about the best possible health outcomes.

2.4 Attitudes and Beliefs Towards Food and Nutrition in Head and Neck Cancer

Understanding the perceptions people with HNC hold towards nutrition is important as health professionals, including dietitians, nurses, and speech-language therapists need to be aware of prevalent attitudes and beliefs towards food and nutrition to best tailor interventions and treatments. The location of HNCs and their extreme effects on eating and obtaining nutrition would likely lead to people feeling desperate for information and advice on how to better their situations. Hence, there are likely strong attitudes and beliefs towards nutrition in this population as people search for and trial diets and advice. Existing research examining this is detailed in Section 2.4.1 of this review.

Today, people with HNC have unrestricted and endless access to a wide array of nutrition information, which may be evidence-based, health professional-endorsed advice, or alternative information and services that are not as supported by scientific literature (Walsh et al., 2010; Warner et al., 2022). This may lead to people accessing misinformation and following ineffective or even harmful nutrition advice, which in turn may result in negative treatment outcomes, such as malnutrition and false hope for certain outcomes (Ayoob et al., 2002; Ernst & Cassileth, 1996; Fillon, 2022).

Malnutrition and poor nutrition are the largest risks people with HNC face when they are presented with misinformation and ineffective nutrition treatments (Ernst & Cassileth, 1996). For instance, people may not consume enough energy and protein or exclude certain foods, meaning the diet cannot provide adequate nutrients in a time when there are increased requirements.

False hope for certain outcomes is another risk people with HNC face when interacting with misinformation. People may be drawn into baseless treatments that offer a 'magic' cure or an answer to their symptoms and cancer. This is detrimental to people with HNC and health professionals alike as it devalues and pushes people away from evidence-based services (Ernst & Cassileth, 1996).

The benefit of understanding the attitudes and beliefs people with HNC hold is that health professionals can provide patient-centred nutrition treatments incorporating the information people have expressed they want to learn about. Patient-centred treatments themselves have a range of benefits, as they lead to increased treatment compliance and positive outcomes, as well as a higher likelihood of people continuing to use evidence-based services (Ardoin et al., 2022; Jones et al., 2021). Compliance to nutrition treatments is influenced by the way that people perceive treatments. If people understand why they need treatment and how to incorporate treatments into their lifestyles, they are more likely to implement nutrition interventions successfully (Jin et al., 2008). Ensuring that dietitians provide comprehensive nutrition education that is tailored to each persons' personal, cultural, and social situations will help them to feel supported and listened to, building the knowledge, rapport, and trust between them and the clinician. Improving this relationship and the knowledge shared between people and healthcare professionals will help to increase access to nutrition care, encourage people to continue their treatments, and ultimately improve the likelihood of positive health outcomes.

This clearly demonstrates the importance of understanding the perspectives of people with HNC regarding nutrition, as the potential consequences can be a distraction from evidence-based services and a waste of the person's money at best and cause irreparable harm to their health at worst.

2.4.1 Key Themes Identified From Past Research

The following section details the current evidence in the literature and aims to encompass the key attitudes and beliefs people with cancer hold towards nutrition.

2.4.2 Information Sources Forming Attitudes Towards Nutrition

Existing research has acknowledged that people with cancer interact with and are influenced by a range of sources when gathering nutrition information (Lee et al., 2023). For example, Beeken et al. (2016), Lee et al. (2023), and Mullee et al. (2020) found the greatest influences were the media and the internet, as well as people's family and friends, healthcare professionals, and private persons giving nutrition advice. Hiatt et al. (2022) found that cancer survivors had a strong influence on people, especially if they claimed to have cured their symptoms or cancers with their diets, despite the idea of curing cancer with food is misleading.

Internet

Lee et al. (2023) found that while 35% of people with cancer went to their oncologist for nutrition information, up to 50% used the Internet. Information from the media and internet should not be inherently trusted. For example, Cooper et al. (2012) found that over two-thirds of dietary 'facts' shown in UK tabloids had insufficient evidence to back their claims. These studies highlight an alarming direction of nutrition advice, where people with cancer are choosing to access potentially unregulated and incorrect information over the advice of qualified health professionals. Additionally, Bell et al. (2009) and Sullivan et al. (2021) observed that people with cancer received huge amounts of nutrition advice from different sources, and this information overload often led to contradictions and confusion.

Culture

Culture is another aspect that significantly influences the perceptions people with HNC have towards nutrition. Bell et al. (2009), an ethnographic study that explored the way Chinese

Canadian people with cancer talked about their diets, found that nutrition recommendations between these Chinese and Canadian culture contradicted. These differences created confusion in non-Western people, as Western treatments dominated the medical space. Contradictions between the cultures ultimately led to excessive amounts of foods being excluded. These discrepancies are problematic for people's health and cultural identity, as these messages can cause internal conflict in those who value both their cultural traditional views and Western medicine. Although Bell et al. (2009) investigated the perceptions of Canadian and Chinese individuals, their findings could be applied to other individuals living amongst multiple cultures, such as Māori or Pacific in NZ. This study reflects the major position Western countries have in health care and how traditional therapies are often lost because of this large influence. In short, people with cancer receive nutrition advice from a vast range of sources, and it can be difficult for them to discern which are correct and appropriate and which are providing incorrect information that will affect their treatments.

2.4.3 Identified Attitudes and Beliefs Towards Nutrition

Weight changes

The perception of weight changes in cancer is an important attitude expressed across the literature. People with cancer often experience weight changes during and long after their treatments. However, Lee et al. (2023), Sullivan et al. (2021), and Hiatt et al. (2022) each identified people with cancer that had skewed attitudes towards this change. All three studies found people with cancer who reported weight loss, and that approximately a third of these people celebrated this change. Lee et al. (2023) even found that 80% of the people they interviewed wanted and aimed to lose weight during their treatments.

People with cancer are not exempt from weight stigma (Hawley et al., 2024). The shame framing and social judgement of larger bodies is still experienced by people with cancer and other people around them, and could contribute to the positive views of weight loss that were observed (Hawley et al., 2024; Talumaa et al., 2022). Lee et al. (2023) implied that a lack of knowledge or support in understanding the effects of weight loss in cancer treatments was another factor in these positive feelings towards weight loss. This theory is supported by Sullivan et al. (2021), who found that people with cancer who were happy about their weight loss were less likely to have seen a dietitian or any healthcare professional to support their nutrition knowledge. This idea is then reinforced again by Hiatt et al. (2022), who suggested that after receiving nutrition education and going through treatment, the perceptions people with cancer had towards weight flipped, and weight gain was seen to be a positive thing.

Weight loss is often expected in people with HNC due to increased energy requirements and the difficulty people have meeting these when symptoms arise (Yuen et al., 2020). However, a positive attitude towards weight loss may lead to larger reductions in weight, perhaps because people are not participating with as much effort in compensatory interventions. Weight loss, regardless of the intentions behind it, is detrimental to HNC treatment and recovery. For example, there are negative effects on radiation therapy accuracy, where weight loss can change the carefully calculated borders and result in excess healthy tissue damage (Bomford et al., 2003).

Diet

People with cancer often have strong and polarising opinions about their diet's potential to have caused their cancers and its importance in their treatments. Beeken et al. (2016) found that the majority of people attributed their cancers to their diets, reporting that their poor or even normal diets were the only possible explanation for their illness. Beeken et al. (2016) however, recruited people with all cancers, some of which have clear causation connections to nutrition, including some HNC (Ryan-Harshman & Aldoori, 2007; Testino, 2011). Adams and Glanville (2005) supported this sentiment noting that this belief gave people control and a means of coping with treatment. However, Adams and Glanville (2005) interviewed people with breast cancer, for which no correlation between food and causation has been proven (Mourouti et al., 2015). Lee et al. (2023) found that most people were not worried about their diets, and up to 70% did not think their diets contributed to their cancers. Despite that Lee et al. (2023) focused on a range of cancers, the participants were Australian, and due to similarities in Australian and NZ culture, this belief could resonate with New Zealanders with cancer.

Similarly, in NZ, Peniamina et al. (2021) found that survivors of cancer had limited nutrition awareness about their cancers. Some participants believed their diets were already 'healthy' enough and did not need any changes. However, others were unsure and experienced a lack of support in understanding any potential correlations. Despite the small sample size of Peniamina et al. (2021) (n=25), this study interviewed cancer survivors of NZ European, Māori, and Pacific ethnicities, giving some insight into the different cultural opinions across NZ. The indifferent or confused attitude was similarly identified by Anderson et al. (2013), who found that only a small amount of people from the United Kingdom expressed any connections between their diets and cancers, despite these people having colorectal cancer and a clearer correlation than most other cancers.

These studies draw attention to the differing views people with cancer have towards the role of nutrition in cancer causation, and therefore, how open people may be to changing their diets as a cancer prevention tactic. These studies each looked at a range of cancers, which have various proven and unproven causes and risk factors. In contrast, there is an established association between HNC and alcohol intake (Hashibe et al., 2009). Therefore, people with HNC may have stronger attitudes regarding the potential dietary causes of their cancers. However, there is insufficient evidence to support this.

The importance of the diet during cancer treatments was another key attitude identified by people with cancer. Sullivan et al. (2021), Hiatt et al. (2022), and Lee et al. (2023) each reported a majority of people believed nutrition was extremely important in their cancer care. These studies described the value people with cancer placed on both traditional healthy eating and ‘unhealthy’ foods when treatment success and weight gain were priorities. The research designs of Sullivan et al. (2021), Lee et al. (2023), and Hiatt et al. (2022) (cross-sectional and longitudinal designs) support the credibility of this evidence, as they show that this opinion stayed prevalent over the duration people were assessed. The importance of healthy eating was supported by Beeken et al. (2016), who found people with cancer reported similar positive opinions towards healthy dietary patterns.

Alternative dietary therapies

Beeken et al. (2016) also identified more polarising opinions around the use of alternative dietary supplements in cancer. For example, vitamins A, B, C, D, and E, selenium, and magnesium. Beeken et al. (2016) found that most people taking these supplements could not say why they were using them, suggesting an indifferent attitude. However, strong attitudes may exist, as many people take supplements despite concern from healthcare professionals regarding their efficacy or medication interactions (Redd et al., 2023).

Vitamin C is a prime example of an anecdotally common but unsupported supplement used during cancer treatments. The general belief behind taking high-doses of an anti-oxidant such as vitamin C is that it increases chemosensitivity and reduces chemo-related toxicities and fatigue (Zasowska-Nowak et al., 2021). However, researchers and health professionals have debated this theory for decades, citing that an anti-oxidant directly defeats the purpose and reduces the effects of medical treatments such as chemotherapy that aim to oxidise cancer cells and dampen the immune system (Lawenda et al., 2008). Despite passionate debates for both sides of this argument, there is little evidence-based literature investigating the prevalence of people with cancer acting upon it.

Some other studies have investigated the attitudes that people with cancer have regarding the importance of alternative dietary therapies. Sullivan et al. (2021) found that 37% of people with cancer were following alternative diets. Sullivan et al. (2021) and Lee et al. (2023) both had participants that reported the importance of alternative diets such as detoxes, sugar-free, and restrictive diets held to participants.

The sugar-free diet and the idea that sugar ‘feeds’ cancer is another long-standing belief and debate. This theory began in the 1920s with German scientist Otto Warburg, who observed that cancer cells consumed and utilised glucose at a faster rate than healthy cells as they rapidly divided (Warburg et al., 1927). This observation led to the idea that glucose was ‘feeding’ the cancerous cells and causing increased growth (Warburg et al., 1927). Based on this theory, sugar-free cancer treatments such as the ketogenic diet were created to eliminate the energy source of cancerous cells. However, it is now known that cancerous cells utilise large amounts of nutrients to fuel their rapid growth, and if required, they will harvest nutrients from neighbouring cells to continue this growth (NCI, 2021). Because glucose is used by all cells, depriving the body of sugar to destroy cancer cells also deprives healthy cells too of an energy source. To combat this lack of energy and glucose, the body must synthesise it from stored fats and proteins, accelerating weight and muscle loss and increasing the risk of malnutrition (Olson et al., 2020).

There is a range of other alternative beliefs towards nutrition and cancer that have been anecdotally reported. For example, dairy, spicy foods, and soy cause cancer, and organic, unprocessed foods protect against cancer (Beeken et al., 2016). However, again, most of these beliefs are unsubstantiated, and if anything result in over-restriction and extra expenses for people with cancer (Bradbury et al., 2014; Chan et al., 2021; Fan et al., 2022;

NCI, 2024; Nilsson et al., 2020). This list of anecdotal beliefs is non-exhaustive, they have only briefly been acknowledged to ensure this review remains focused on the nutrition beliefs in the literature. Overall, there is vast clinical anecdotal evidence of people holding these and other alternative beliefs however, there is very little evidence to show the prevalence or effects of such ideas. This research further highlights the idea that people crave control during their treatments. Having something to blame and a way people can personally act, such as changing the diet, can be one of the only ways that people can obtain a sense of control in an otherwise uncontrollable situation. In this sense, the diet and dietary information, both evidenced-based and unsubstantiated, can provide hope, sometimes falsely for positive outcomes.

Response bias was a widely recognised weakness in the studies discussed above. These studies estimated that people who were health and nutrition-conscious would participate in research due to increased interest. This weakness presents an opportunity to investigate the nutrition perceptions of the entire population, including those of health-indifferent individuals, to understand if and how views differ from the current opinion and the literature.

The literature review search strategy is described and included in Appendix A.

2.6 Chapter Summary

An analysis of key literature regarding the opinions people with cancer have towards nutrition has identified a lack of focus on the perceptions of people with HNC and how these may differ and match those of other people with cancer. The notable key gaps identified in this review included attitudes towards specific foods (e.g., alcohol, sugar, vitamin C) as causes, exacerbators, or cures of their disease, along with NZ specific perceptions, including those of Māori and Pacific people with HNC, to understand how culture affects such beliefs. Most importantly, this review has emphasised the value of exploring the views of people with HNC specifically, due to the proximity of HNC to eating anatomy, the direct effect of treatment on eating functions, and the negative consequences ineffective and inadequate nutrition treatments have on patient health outcomes and survival. These gaps in the literature are important to investigate because if healthcare professionals do not know what people with HNC value, the information they wish to learn, and their current nutrition attitudes, they cannot effectively provide patient-centred treatments that reinforce evidence-based nutrition therapies.

Chapter 3: Methodology

This chapter details and justifies the methodological approach of this study. This chapter begins by justifying the methodology used and describing the survey design. The focus of the chapter then turns to reporting the participant criteria, data collection, and data handling strategies used. Following this, ethical considerations and their consequences are detailed. Lastly, the qualitative data analysis process is described, detailing how the results were generated.

3.1 Ethical Approval and Considerations

A Low-Risk Notification was submitted to the Massey University Research Ethics Committee (Application 4000028476) in February 2024. Ethical considerations discussed in the application included anonymity, risk of dietary change, and exclusion criteria. Risks pertaining to participants' personal information and privacy were minimised as all information collected by the survey was anonymous. Survey questions were carefully designed not to be leading, including the purposeful exclusion of keywords such as "lunch" because using words to label mealtimes can create response bias. This study excluded people with cognitive impairments that could have affected their ability to participate and complete the surveys, as well as people who were end of life. It was decided to exclude these people as it would be an inappropriate and unnecessary burden. Participants were reminded of their rights at the onset of the survey and could decline to answer any question or withdraw at any time.

The primary supervisor consulted Māori and Pacific academic leaders in the planning stages of this project to determine how this research could best support these groups of people. It was suggested that this research should have general focus on the NZ population, as research focusing on Māori and Pacific populations should ideally be conducted by Māori and Pacific researchers.

3.2 Research Design

Qualitative research methods are accepted as the best way to understand complex human behaviour and explore novel concepts from the perspective of participants (Maxwell, 2012; Merriam & Tisdell, 2015). Qualitative research with an exploratory focus investigates new and under-researched ideas, clarifies concepts, and develops theory around a topic (Hunter et al., 2019). Additionally, exploratory research identifies topics of interest for future studies to further investigate (Hunter et al., 2019). A qualitative research method aims to investigate the ‘how’ and ‘why’ of decision-making and gather information in great depth and detail (Maxwell, 2012; Patton, 2014; Renjith et al., 2021). This approach allows participants to provide detailed descriptions of the meanings they assign to behaviour, events, or objects, which cannot be captured using quantitative methods that use surface level ‘what’ and ‘where’ type questions (Hennink et al., 2020; Maxwell, 2012; Merriam & Tisdell, 2015; Sutton & Austin, 2015). This research project aimed to explore the attitudes and beliefs people with HNC hold towards food and nutrition. It endeavoured to investigate the rationale behind individuals’ decision-making in an area of research that has been largely unexplored in NZ. Therefore, a qualitative method was considered the most appropriate approach for this research project.

Semi-structured qualitative interviews are a standard data collection tool for qualitative research (Merriam & Tisdell, 2015). However, it was acknowledged by the researcher that people with HNC often experience communication difficulties such as a loss of speech, voice changes, and excessive drooling, which can make social interactions such as interviews embarrassing and off-putting (Kroll, 2011; McGrory, 2011; Nind, 2008). Lengthy interviews would also require long periods of talking, which may cause unnecessary fatigue, discomfort, and pain (Kroll, 2011). Consequently, it was determined that the most appropriate method to collect data for this study would be an online qualitative survey. There are multiple advantages of online surveys in this unique qualitative context, particularly that they allow participants to type responses, choose when to complete them, and take as much time as needed to avoid the difficulty, fatigue, and/or embarrassment of verbal communication (Braun et al., 2021; Hickey et al., 2024; Wilson et al., 2013).

3.3 Survey Design

The survey contained exploratory questions, that were designed to gather data to answer the research question and explore the attitudes and beliefs people with HNC held towards food and nutrition. The full survey is displayed in Appendix B. Questions were developed based on gaps in research that were identified in a literature review. Areas for inquiry included the opinions people with HNC have toward the sources of nutrition information they access, the perceived role of food, nutrition, and alternative dietary theories in HNC, and participants' level of involvement in their healthcare.

The structure of these questions incorporated an open-ended format, clear language, a Likert scale, and a final summary question (Bhattacharya, 2017; Hennink et al., 2020; Patton, 2014). Open-ended questions were worded to avoid 'yes' or 'no' answers, they are thought provoking, and aim to elicit in-depth responses from participants without directing them to a specific answer (Bhattacharya, 2017; Hennink et al., 2020; Patton, 2014). Additionally, it was important that questions were clear and focused on one topic to reduce confusion and wayward interpretations (Hennink et al., 2020; Patton, 2014). A Likert scale question was used to guide participants answers, and ensure each topic of interest was commented on (Joshi et al., 2015). Lastly, a final question was used to give participants the feeling of having the last say and allow them to provide any additional insight after reflecting on the previous questions (Hennink et al., 2020).

The survey questions were developed by the researcher and distributed to participants using Qualtrics software (Qualtrics, 2020). The questions were designed over several meetings with the support of supervisors and a leader from the Head & Neck Cancer Support Aotearoa (HNCSA) group to ensure the question design, formatting, and content were appropriate and respectful for use with people with HNC. The survey was designed to be anonymous. Participants were asked to create a code using the first initial of the first name, the last initial of the last name, and a two-digit number of their choice (e.g., RG21). This code enabled the researcher to align participants' responses and quotes to their demographic data and clearly compare the responses of different participants.

In addition, the survey included an initial section that collected participants' demographic information, along with information that provided context to the participant's condition. This data identifies the characteristics that are and are not represented in this study sample, and allows the researcher to determine factors that may influence responses (Dobosh, 2017; Henrich et al., 2010; Ray & Fellow, 2020).

3.4 Participant Criteria

This study utilised criterion sampling. This sampling method requires participants to be recruited based on a set of predefined criteria (Patton, 2014). Criterion sampling was used to ensure all participants met the inclusion criteria (Patton, 2014). Table 2 details the inclusion criteria established for this study.

Table 2

Inclusion Criteria

Inclusion criteria	**Justification**
Age above 18 years	This study aimed to explore the perceptions of adults with HNC.
Diagnosis with and treatment for HNC	HNC was defined according to internationally recognised HNC classifications, that include cancers of the oral cavity, pharynx, larynx, paranasal sinuses, nasal cavity, salivary glands, and the skin of the head and neck (NCI, 2023b). The time since diagnosis was not limited due to the significant side effects that can extend long after recovery (NCI, 2023b).
Current residence in NZ, as well as residence in NZ for both diagnosis and treatment	This research aimed to explore the perceptions of people with HNC in NZ. Therefore, to investigate New Zealanders and apply the results of this study in NZ, participants must have been diagnosed and treated within the NZ health system.
Ability to independently answer the survey questions	To respectfully exclude people who were end of life, this criterion was included. End of life refers to the time just before death and is often synonymously presented with actively dying (Cambridge Dictionary, 2024). It is defined as an expected survival of months, days, or hours (Hui et al., 2014). This wording was not included due to its sensitive nature. Instead, criterion four was included, as these people would unlikely be able to independently complete a survey.

In this study, the terminology ‘people with head and neck cancer’ or ‘people with HNC’ is used to describe people who have been diagnosed with or have recovered from head and neck cancer. This terminology reiterates that a diagnosis does not define a person and is considered best practice in person-centred literature (Wooldridge, 2023).

3.5 Recruitment and Data Collection

Recruitment took place via closed Facebook support groups for HNC survivors in NZ. The networks used to recruit participants for this study were the HNCSA and the NZ Head and Neck Cancer Support Group – The Explorers Facebook pages. The primary supervisor emailed a moderator from each group outlining the research and requesting permission to publish a post seeking participants. Support networks are an effective way to find and contact large amounts of people with similar characteristics (Hennink et al., 2020). Additionally, association with the support network provides an implicit endorsement towards the research, further encouraging participation (Hennink et al., 2020).

A recruitment poster detailed the objectives of this study, inclusion criteria, the survey link, and the contact email of the researcher and primary supervisor. The poster is included in Appendix C. The voluntary nature of this study was also stated. The recruitment poster was published and reposted three to five times over the 23 days it was active on the HNCSA Facebook group, and 13 days it was active on the Explorers Facebook group by the researcher, primary supervisor, and the HNCSA moderator.

Individuals were invited to directly access the Qualtrics survey via the poster link or contact the researcher via email or Facebook Messenger if they wished to confirm their eligibility. Once a message to the researcher was received, the participant's eligibility was confirmed against the inclusion criteria. Participants who met the criteria were then emailed a link to the survey. For participants who went directly to the survey link, their eligibility was confirmed by comparing the demographic data collected from questions two to seven of the survey (included in Appendix B) with the inclusion criteria.

3.6 Credibility and Reliability

In this research project, the goal of data collection was to reach data saturation. Saturation was considered achieved in this study when the themes encapsulated all the relevant collected data, and it was assessed that no new information was emerging that would alter or expand their meaning. Data saturation was sought to ensure the patterns and themes were representative of participants responses and comprehensive enough to confidently address the research question (Merriam & Tisdell, 2015; Renjith et al., 2021)

In this project, credibility was increased by including reflexivity and searching for inconsistencies. Reflexivity was acknowledged when the researcher continually reflected upon their potential biases throughout the data analysis (Maxwell, 2012). The bias recognised included anchoring bias formed by the researcher's formal nutrition and dietetic education, and unconscious bias related to their NZ European ethnicity and female gender. Additionally, the researcher purposely sought any discrepant data that could have modified the themes (Sutton & Austin, 2015). Credibility was considered because it is the component that refers to the extent to which research findings reflect participants' actual perspectives (Merriam & Tisdell, 2015; Rose & Johnson, 2020).

Reliability was assured in this project when research decisions were rigorously justified, and enough detail was provided to ensure other researchers could accurately replicate the methodology (Creswell & Poth, 2016; Rose & Johnson, 2020). Additionally, the standardised inclusion criteria, recruitment instructions, and an audit trail of data analysis decisions were included (Merriam & Tisdell, 2015; Rose & Johnson, 2020). To increase reliability within data analysis, the data was reviewed three to four times at each level of coding (Maxwell, 2012). This ensured that at each step of coding, mistakes could be identified and ensured the data combinations and summaries were the most fitting (Maxwell, 2012; Merriam & Tisdell, 2015). Reliability, thorough justification, and inclusion of descriptive components are important in confirming the stability and consistency of the qualitative research process, maintaining transparency, and enabling other researchers to scrutinise research decisions (Merriam & Tisdell, 2015). A reliable methodology implies that a study's results can be reproduced and enables future research to appropriately utilise and build on its findings (Merriam & Tisdell, 2015; Renjith et al., 2021; Rose & Johnson, 2020).

3.7 Data Storage

All data collected was initially stored in Qualtrics, a secure password protected software. Once the data was downloaded to Excel spreadsheets for analysis it was stored on a password protected university based OneDrive. None of the data collected in this study could have identified the individuals who participated. All the collected data and information pertaining to this study will be stored securely for five years after the completion of this study. After five years all raw data will be deleted.

3.8 Data Analysis

The qualitative data was manually analysed using an inductive approach to thematic analysis. A manual process was chosen to encourage thorough and more meaningful engagement with data and give the researcher control over the comparisons and interpretations developed (Maher et al., 2018). A thematic analysis aims to deconstruct, organise, and summarise the data to create a series of themes that represent the ideas participants express (Hennink et al., 2020; Maxwell, 2012; Sutton & Austin, 2015). Thematic analysis was chosen as it produces detailed descriptions of data, allowing an in-depth understanding of participants' responses

(Creswell & Poth, 2016). The inductive approach allows patterns, codes, and themes to emerge naturally without the influence of any hypotheses or pre-established ideas (Bhattacharya, 2017; Patton, 2014). The inductive approach to the thematic analysis was chosen as there is almost no current theory or literature on this topic. Therefore, it let the researcher explore all of the ideas held and expressed by participants, including any unexpected views (Merriam & Tisdell, 2015; Patton, 2014).

Firstly, the researcher completed open coding for each response across the data set to separate it into manageable chunks of information (Bhattacharya, 2017; Hennink et al., 2020). This initially involved a line-by-line breakdown of responses into basic descriptions (Hennink et al., 2020). The descriptions were collated, and a list of frequently occurring words or phrases was generated, creating the open codes (Bhattacharya, 2017; Renjith et al., 2021). Throughout this process, data was continuously compared to previously created codes to ensure that each piece of data was placed in an appropriate code, and new codes were created if none of the existing codes were applicable (Maxwell, 2012). For example, the open code ‘protein is important for muscle’ had quotes regarding the positive impact certain high-protein foods (meats and plant based proteins) have on muscle maintenance.

The researcher then completed axial coding. Axial coding is where open codes are categorised, and the broad ideas within them are connected to create more refined codes that retain sufficient contextual detail (Bhattacharya, 2017; Maxwell, 2012). Lastly, the researcher completed reflective coding. The reflective coding process aims to provide insight into the implicit and explicit suggestions in the data and establishes overarching concepts (Maxwell, 2012; Renjith et al., 2021; Williams & Moser, 2019). An example of the coding process is presented in Table 3.

Table 3

Example of the Three step Coding Process

Open code	**Axial code**	**Theme**
Sugar feeds cancer	Participants were aware of the theory — that sugar is detrimental for HNC, but they did not all believe it	Food and nutrition-related perceptions pertaining to treatment and recovery.

The Likert scale quantitative data was analysed using the assigned number (one to five) that correlated with each level of importance on the scale. These ratings were totalled and averaged using the number of participants who answered that specific question to give the percentage of importance for each topic. The percentages of importance calculated from the Likert scale question are presented in Chapter 4, Table 5.

3.9 Chapter Summary

This chapter has discussed the choice of and rationale for the methodological processes for this research project, including the research and survey design, participant criteria, the data collection, handling, and analysis processes, and all the ethical considerations. The following chapter, Results (Chapter 4), will present the data obtained from the survey.

Chapter 4: Results

This chapter presents the themes identified in the coding process. Firstly, the participants' demographics are presented. Then, the focus moves to presenting the outcomes of the qualitative coding process (as outlined in Chapter 3).

4.1 Contextual Overview of Study Participants

A total of 39 participants participated in the survey. There was one partial completion. Gender identification was split between female participants (64%) and male participants (36%). Participants selected five ethnicities they identified as, and 12 different HNC sub-types with which they had collectively been diagnosed. The amount of time since participants were diagnosed was also collected, and the mean number of years was confirmed as two and a half years.

Locational information was also sought from participants. Firstly, in relation to the region where they were initially diagnosed. The region with the most initial diagnoses in this study sample was Auckland (28.2%). The regions with the least initial diagnoses were Southland and Taranaki (2.6%). Participants were also asked to note the city or town where treatment was primarily received. The city where the most participants received treatment was Auckland (43.6%). The cities where the least participants received treatment were Napier and Hutt Valley (2.6%). A full list of participants' contextual information is summarised in Table 4.

Table 4

Contextual Overview of Study Participants

Respondent (Code)	Age	Gender	Ethnicity NZE=New Zealand European	Type of HNC	Year Diagnosed	Diagnosis location	Treatment Location
JY83	41	Female	NZE	Tongue, throat (nasopharynx, oropharynx, hypopharynx)	2024	Auckland	Auckland
TP88	89	Male	NZE	Throat (nasopharynx, oropharynx, hypopharynx)	2008	Auckland	Auckland
LX99	57	Female	NZE	Mouth and tongue	2023	Bay of Plenty	Hamilton
MN77	78	Female	NZE	Tongue	2007	Bay of Plenty	Auckland
DB25	46	Male	NZE	Tongue	2023	Auckland	Auckland
GE55	69	Male	NZE	Salivary glands	2022	Canterbury	Christchurch
CR53	71	Female	NZE	Tongue	2018	Waikato	Hamilton
BJ9	*Not stated*	Male	NZE	Tongue	2020	Otago	Dunedin
KG67	57	Female	NZE	Tongue	2011	Wellington	Wellington
MS56	68	Male	NZE	Neck, squamous cell	2023	Auckland	Auckland
HN88	45	Female	NZE	Tongue	2023	Otago	Dunedin
BN99	53	Male	NZE	Mouth	2023	Waikato	Hamilton
NU72	52	Female	Māori	Mouth, upper left jaw, maxilla	*Not stated*	Hawkes bay	Auckland/ Napier
SA18	53	Female	NZE	Throat (nasopharynx, oropharynx, hypopharynx)	2021	Northland	Auckland
CS57	39	Female	Asian	Throat (nasopharynx, oropharynx, hypopharynx)	2023	Wellington	Wellington
SE76	77	Female	NZE	Tongue	2023	Manawatu	Palmerston North
NM07	61	Female	NZE	Tongue	2017	Auckland	Auckland
NN23	71	Male	NZE	Salivary glands	2024	Waikato	Hamilton
DA99	72	Male	NZE	Tonsil	2008	Auckland	Auckland
MC37	50	Female	NZE	Salivary glands	2020	Hawkes bay	Palmerston North
GT18	66	Male	NZE	Mouth	2015	Northland	Auckland
IH26	76	Male	NZE	Salivary glands	2023	Waikato	Hamilton
LS70	54	Female	European	Throat (nasopharynx, oropharynx, hypopharynx)	2022	Canterbury	Christchurch
AL09	67	Female	NZE	Tongue, salivary glands	2017	Northland	Auckland
KN36	32	Female	NZE, Māori, Samoan	Salivary glands	2023	Manawatu	Palmerston North
DG20	65	Female	NZE	Nose, sinuses, salivary glands	2014	Auckland	Auckland
KS51	73	Male	NZE	Throat (nasopharynx, oropharynx, hypopharynx)	2010	Northland	Auckland
AH11	62	Female	NZE	Nose, neck, cheek	2023	Waikato	Hamilton
BK56	28	Female	NZE	Nose, salivary glands, soft tissue sarcoma of right side of face	2006	Canterbury	Christchurch
AY11	49	Male	NZE	Tongue	2023	Wellington	Wellington
LS24	61	Female	NZE	Tongue	2024	Northland	Auckland
TR11	44	Female	NZE	Salivary glands	2020	Taranaki	Hutt Valley
LG68	69	Female	NZE	Tongue	2015	Southland	Dunedin
FE12	68	Female	NZE	Voice box (larynx)	2012	Canterbury	Christchurch
DR43	81	Male	NZE	Throat (nasopharynx, oropharynx, hypopharynx)	2022	Auckland	Auckland
JM24	69	Male	NZE	Throat (nasopharynx, oropharynx, hypopharynx), HPV	2022	Auckland	Auckland
SN19	48	Female	NZE	Throat (nasopharynx, oropharynx, hypopharynx)	2018	Auckland	Auckland
LX50	57	Female	NZE	Mouth, tongue	2023	Bay of Plenty	Hamilton
SN18	48	Female	NZE	Throat (nasopharynx, oropharynx, hypopharynx)	2018	Auckland	Auckland

4.2 Participant Sources and Perceptions of Nutrition Information

Participants commented on the determined credibility and importance of the nutrition information sources they identified. Several participants reported that dietitians were credible and important because they completed extensive training in nutrition [AL09, BJ9, KN36], were registered and supported by reputable health organisations [AL09, CR53, HN88], and had significant experience providing nutrition support to people who experienced eating difficulties [KN36]. For example, participant KN36 noted that “For me it was largely about people's qualifications and experience, especially with people dealing with head and neck cancer, and understanding the difficulties and concerns we have”. Similarly, participant AL09 stated:

> If they have professional qualifications in dietetics (not just nutrition) are backed by a highly recognised organisation such as Cancer Society or use international guidelines such as the IDDSI framework. There are a lot of quasi nutritionists on the internet offering advice on food an *[sic]* cancer.

Additionally, three participants mentioned that if a source of information did not understand or relate to them, it could not provide appropriate nutrition information [TR11, SA18, BN99]. For example, SA18 noted, “Nurses knowledge greatly varied, some knew and where *[sic]* very supportive of eating difficulties, others didn't know so much and were less understanding”. Similarly, participant MN77 stated that:

> dietitians have the greatest credibility but they don't always understand the limitations on eating that HNC patients have… They don't always understand how revolting some people find Fortisip and Ensure. They might not understand the patients values… some people are purists and don't want highly refined foods or foods where the manufacture is bad for the climate.

People with, and survivors of, HNC were identified by 13 participants as an additional albeit important and credible nutrition information source. Participants noted that they were sceptical of nutrition information from these sources because it was based on opinion and not universally applicable to every patient [CR53, HN88, BK56, CS57]. For example, participant HN88 reported, “I use the H&N cancer support group and people share their stories and advice which are anecdotally useful. but I do always take that with a grain of salt, recognising everyone is on a different journey”.

With regard to the internet and social media, participants explained they would rate a source highly credible if it met certain guidelines. These guidelines included the use of referenced information [HN88, DG20], support from scientific articles [GE55, CS57, TR11], authorship by reputable healthcare professionals [GE55, CR53, GT18, TR11], evidence of peer review [HN88] and if the information remained accurate after cross-checking [GT18, AY11, TR11]. For example, participant HN88 noted, “I searched for peer reviewed data, or registered cancer support charities, or medical clinics who gave references for the info provided”. Similarly, participant CR53 stated, “I look for appropriate qualifications of the author or institutions I trust such as WHO, Mayo clinic, Harvard etc”. The identified sources of nutrition information and their considered importance are summarised in Table 5.

Table 5

Nutrition Information Sources and Importance Ratings

Source	Participants (%)	Considered Importance Rating (%)
Dietitian	97.4	86.4
Nurse	84.6	64.8
Doctor	84.6	60.6
Internet Resources	82.0	60.0
Social Media	79.5	59.4
Friends	79.5	48.0
Family	76.9	47.6
Books	53.8	46.4
Other	23.0	43.8

4.3 Perceptions of Food and Nutrition in HNC

This section details the varied participant perceptions of food and nutrition in HNC. Responses to the survey questions have been coded and themed based on food and nutrition-related perceptions pertaining to 1) prevention, causation, diagnosis and 2) treatment and recovery.

Food and nutrition-related perceptions pertaining to HNC prevention, causation, and diagnosis

Five participants reported that overall, food and nutrition had a role in HNC prevention. Participant TR11 illustrated this concept, noting, “Nutrition presumably can also influence prevention given that nutrition and lifestyle play a role in preventing some other cancers”.

Furthermore, multiple participants identified specific foods and nutrients they believed held a role in HNC causation. The association between alcohol consumption and an increased risk of HNC was stated by six participants. For example, Participant HN88 reported, “I know theres [sic] a higher link associated with high volume alcohol use.” Likewise, participant LS70 elaborated on this belief, noting, “Alcohol! … I do wonder if early exposure at a young age [alcohol] and then ongoing has had an impact”.

Similarly, several participants conveyed suspicion towards processed foods and preservatives [CR53, LS70, DG20, MN77]. Participant DG20 stated, “I am concerned about the relationship between processed foods and alcohol on head and neck cancer”. Additionally, participant CR53 described the influence of preservatives, reporting, “I don't think food has much to do with prevention other than avoiding known carcinogens such as preservatives”.

Sugar was also identified by various participants to have a negative influence on cancer causation and diagnosis [CS57, BN99]. Participant BN99 elaborated, noting, “Sugar gives you high and lows which you don't need when your *[sic]* dealing with any cancer diagnosis”. One participant stated that they had initially believed this, however, their opinion had since changed:

> I had misconceptions before regarding sugar and carbs intake and the significance it had in being diagnosed with cancer. A lot of people were saying that sugar is the major source of having cancer and thus need to be avoided. But during my treatment and recovery, I had asked various members of the healthcare team about it and was told that that was a misconception [participant CS57].

In contrast to the opinions presented above, 10 participants reported that food and nutrition did not have a pivotal role in HNC causation. Participant NU72 provided a prime example, reporting, “I don't believe there is any specific food that causes cancer. Cancer doesn't discriminate, it can affect anyone, any age, gender or race”. Further describing this opinion, participant MN72 noted, “I don't think you can prevent or cure cancer with food. I 80% believe it is a roll of the genetic dice and 20% believe lifestyle factors play a part”.

Food and nutrition-related perceptions pertaining to treatment and recovery

Twenty-seven participants reported that food and nutrition had a role in HNC treatment and recovery. This belief was depicted by participant MS56, who stated that adequate food intake was *“*CRUCIAL! Not only in nutrition for recovery, but in preparedness for entering into treatment”. More specifically, some participants expressed that obtaining adequate nutrition was essential for preparing for and completing HNC treatments [HN88, GT18, KN36, AY11]. For example, participant AY11 reported, ”If your body is provided with the nutrition it needs it will be better able to fight on, and cope with radiation and chemotherapy”. Participant KN36 further reiterated this, noting nutrition was:

> So important especially to heal. I noticed a massive difference in coping with healing with surgery when I was given good info and could therefore nourish my body properly compared to when I wasn't and was running on about half the calorific intake i needed.

Regarding the importance of nutrition in HNC recovery, six participants emphasised the significance of consuming enough energy, and eight participants highlighted the value of sufficient protein. These participants described that adequate energy and protein intake were essential for maintaining muscle mass and an optimal weight during treatment, especially during a period of increased requirements [LG68, HN88, KS51]. Participant CR53 described this, stating, “I think fats and protein are incredibly important during treatment. I think this because during treatment your body has increased needs”. Similarly, participant CS51 reported:

> One of the specialists I have seen lately also talked about me needing to consume a high calorie diet (I still keep on losing weight) as my body needs a lot more calorie especially now that I am at the recovery stage.

Additionally, some participants mentioned the significant contribution dietary protein had in promoting tissue healing, which is commonly required after HNC treatments [KS51, LX99]. For example, participant LX99 noted, “Protein for recovery to assist with healing the tissue etc”.

Furthermore, several participants identified that adequate nutrition was instrumental in reducing the severity of their symptoms [BJ9, GT18]. Participant BJ9 demonstrated this by stating that “food is critical in your response to treatment. Without it you lose weight rapidly and potentially face hospitalisation for the remainder of treatment and being fed through a tube”. Similarly, participant GT18 reported, “I think the power nutrition helped me by perhaps a lower symptom / lesser effect radiation and possibly as a quicker recovery”.

Healthy food, ONS, sugar, honey, and vitamin C were other foods identified by some participants to have an influence on HNC treatment and recovery. In relation to the significance of healthy food in HNC treatment and recovery, fruit and vegetables were mentioned by six participants to have a positive impact. For example, participant CR53 noted, “I believe fruit, vegetables, pulses and grains are all important”. However, some participants reported negative attitudes towards the involvement of healthy foods in HNC treatment [CR53, BK56]. This perspective was described by participant BK56, who stated:

> I don’t agree with it. If you want to go healthy ect. Go for it. If you think it’s helping you in some way, fantastic. It didn’t help me. It didn’t cure me. It made me more miserable not being able to enjoy the sweeter side of things especially when you’ve been told the worst.

A number of participants mentioned an apprehensive attitude towards ONS despite acknowledging their benefits. In this study, five participants reported their dislike of ONS. For example, participant HN88 reported, “high calorie powdered drinks literally made me retch”. Although some participants identified dissatisfaction with these products, five individuals highlighted their value. Participant SA18 demonstrated this, noting, “I hated the taste of the shakes you had to drink but I tried hard to drink them as I knew they would benefit me”.

Several participants reported an awareness of the belief that sugar adversely impacts HNC treatment [BN99, HN88, CS57]. For example, participant BN99 stated, “What I find strange is that there is a belief that sugar feeds cancer but after my surgery I was given ice-cream, jelly ect… Recovery after treatment is better with no alcohol and sugar”. However, other participants emphasised that this belief had been disproven [HN88, CS57]. For example, participant HN88 reported, “But *[sic]* if *[sic]* a buzz around sugar and vit c which I think have been largely debunked”.

In a similar fashion to sugar, a number of participants identified an awareness of the belief that vitamin C [NM07, AL09, JM24] and honey [TR11, GT18, NM07] influence HNC treatment and recovery. For example, participant NM07 noted:

> I understand that honey and vitamin C have a place in treatment, but it may have an impact on the effectiveness of radiotherapy. In terms of recovery, I took high dose vitamin C and I believe it helped with my overall energy levels post treatment.

However, as mentioned earlier in this text, several participants acknowledged that there was limited evidence supporting the use of vitamin C and honey in HNC treatment and recovery [HN88, GT18]. Participant GT18 reiterated this, stating the importance of “Manuka honey in particular but that is probably not something that I could prove but I felt it was effective”.

The ketogenic diet was the final food-related item identified to negatively influence HNC treatment [CR53, MN77, BN99, AY11]. Participant CR53 noted, “I have heard of some people trying keto diets. I think that it is dangerous and inappropriate”. Similarly, participant MN77 reported, “Keto comes up from time to time. I am not a fan. A lot of us lose dangerous amounts of weight during treatment”.

4.4 Participants Desire for Additional Support

This section presents the desires survivors of HNC had for additional support throughout their cancer treatment process. Identified themes included general treatment and decision-making support, HNC specific advice, and the healthcare teams’ receptiveness.

Multiple participants identified how important it was to be involved and adequately supported in making treatment and recovery decisions [DR43, SA18, KG67]. Thirty-four participants reported that their healthcare team ensured they (as patients) were completely involved in decisions regarding their health and treatment. For example, participant KG67 noted, “The decisions are always mine, but I need the input of specialists and therapist in their field to advise me on my options so that I can make informed decisions”.

Despite many study participants confirming their involvement in decision-making, the data coding process identified a spectrum of personal experiences and associated emotions. For example, participant SA18 stated they were “happy with the support and information given to me from a team of people”. Towards the other end of the spectrum, several participants reported dissatisfaction with the support they received [TR11, MC37]. For example, “I am involved as much as I can be, but often feel a bit lost and insignificant” [participant SE76].

Many participants reported a strong desire for specific dietary advice in HNC, particularly regarding weight loss and nutrient requirements in long-term recovery. Seven participants mentioned the difficulty they had maintaining or pre-emptively gaining weight during and after treatments. These participants identified that they would have appreciated information about weight loss in HNC and support in limiting it from occurring prior to treatment. For example, participant TR11 reported, “Identify slim people who are likely to require radiation treatment, and support them with a nutritional plan that will enable them to gain weight prior to radiation starting, in order to reduce their likelihood of relying on a PEG.” Similarly, participant NU72 noted, “I believe I could have better prepared mysef *[sic]* had I been given the information needed. For example, foods that promote healing, liquids that that are packed with all the nutrition and how much you need to consume to build/maintain weight." Additionally, several participants reported a desire for dietary recommendations concerning long-term HNC recovery [CS57, AH11, TP88, MN77]. For example, participant AH11 stated:

> I feel the support during treatment or shortly after is good. But as time goes by and the cancer seems relentless you are virtually on your own. It's trial and era *[sic]* and often painful and too tiring to contemplate eating. This is when people really need help.

A number of participants disclosed how important it was that their healthcare team was understanding and listened to their opinions [BK56, NU72]. Many comments noted a lack of receptiveness [BK56, MS56, TR11]. For example, participant MS56 did not believe their healthcare team had been as receptive as they had hoped, noting that "the supposed specialists over-rode my requests". However, two participants mentioned they had adapted and learnt to overcome this resistance. For example, participant NU72 reported, "I am always asking questions, challenging my medical team when I feel I'm not being listened to or the options I've been given don't align with my beliefs. I appreciate honest and upfront communication". Likewise, participant BK56 stated, "I still highly appreciate the input of others (dietitians and family) but I'm also very pleased I can choose for myself and not be pushed and shoved anymore (within reason of course)".

4.4 Chapter Summary

This chapter presented the themes developed from the data analysis regarding participants' choice and assessment of nutrition information, their perceptions of nutrition in HNC, the social role of food, and participants' desire for additional support. The following chapter, Chapter 5 (Discussion), proceeds to discuss and interpret the themes to conclusively address the research question.

Chapter 5: Discussion

The purpose of this study was to explore the attitudes and beliefs people with HNC hold towards food and nutrition. A qualitative online survey with a series of open-ended questions was used to gather in-depth responses and explore participants' perceptions. In the literature, there are limited studies investigating the perspectives that people with any cancer hold towards nutrition, much less the perspectives of people with HNC. The first objective was to investigate participants' perceptions of sources of nutrition information. The second objective was to identify specific foods or nutrients participants believed were significant in HNC prevention, causation, diagnosis, treatment, and recovery. Finally, the third objective was to understand any overarching nutrition beliefs participants held concerning HNC. In this chapter, the key findings of this research project are discussed. The themes are interpreted, compared, and contrasted to existing literature. Then, their theoretical and practical applications are considered.

5.1 Participant Sources and Perceptions of Nutrition Information

Registered dietitians are the nutrition information source most commonly accessed and rated the most important and credible in this study. Registered dietitians in NZ are overseen by a governing body (the Dietitians Board), which regulate and audit their practice (Dietitians Board NZ, 2024). The high access and high regard for dietetic services in this study suggests that people with HNC are aware of dietitians' expertise and the importance of the evidence-based nutrition support they provide. This finding is supported by other studies that similarly identified dietitians as the preferred source of nutrition information for individuals with cancer (Peniamina & McLean, 2022; Towle et al., 2023).

Furthermore, these positive perceptions could be explained by the nature of participants who engage in health research. Scanlon et al. (2021) found that if people trust conventional healthcare and their healthcare providers, they are more inclined to participate in research. Therefore, it is reasonable to assume that this effect could have contributed to the high regard for dietitians across the present study and existing literature.

In contrast to this finding, Lee et al. (2023) found that although a number of people with cancer reported accessing dietetic care, it was not the preferred information source. Lee et al. (2023) reported this was because dietetic support provided primarily focused on weight and presenting symptoms instead of the advice people with cancer desired (impact of diet on cancer). This suggests that the severity and consequences of unintentional weight loss were not completely understood. This finding highlights the importance of understanding the values of people with HNC, as these affect who people choose to accept advice from.

In addition to registered dietitians, another frequently accessed and highly regarded nutrition information source were other people with, and survivors of, HNC. A 2022 systematic review (Jablotschkin et al., 2022) found people with cancer are often encouraged to connect with peers, especially through support groups and social media. The connection with peers provides an opportunity for people with cancer to learn about common experiences, gain valuable advice, and receive relatable support (Jablotschkin et al., 2022). The strong reported credibility of support groups and other people with, and survivors of, HNC may be due to the sharing of lived experiences and the trust that arises from these strong relationships. To the authors knowledge, there are three online HNC support groups in NZ, as well as several in-person cancer support groups facilitated by the Cancer Society (Cancer Society, 2024). The largest support group, run by the HNCSA, provides support to over 700 members using evidence-based resources via a website and a private social media group on Facebook (Head & Neck Cancer Support Aotearoa, n.d.). The evidence-based focus of groups such as HNCSA could be another potential explanation for their high regard amongst people with HNC, as the importance of evidence-based information was reiterated several times in the present study, particularly regarding the internet and social media.

The positive perceptions identified towards peer support in the present study could be a result of the recruitment method, which was via such support groups, as it is likely that individuals involved in these groups would appreciate the supportive goals and nature thereof. Although other research has identified that HNC survivors used other support methods, they also valued the advice of other people with, and survivors of, cancer. Therefore, the recruitment method in the present study may not have had an effect as peer support is, in general, a valued resource (Alberda et al., 2017; Hiatt et al., 2022).

In contrast, across the literature, several people with cancer reported they were more likely to seek the help of peers and social media if they believed professional nutrition support was inadequate (Beeken et al., 2016; Mullee et al., 2020; Sullivan et al., 2021). Utilising peer support for this reason could be harmful, as information shared between peers in self-help support groups or on social media is not consistently reliable. Individuals sharing information through these platforms do not have the same obligation or experience in verifying information as health professionals (Cancer Council Australia, 2006). Furthermore, the information shared may be influenced by personal bias and an individual's own experiences with food or healthcare, which may not apply to all people with HNC. Therefore, understanding why people with HNC utilise peers as an information source is important as it provides support groups with insight into the information desired, allowing them to allocate their resources effectively. Furthermore, it highlights that professional nutrition support needs to be patient-centred to engage and meet the needs of people who require nutrition support.

5.2 Attitudes and Beliefs Towards Specific Foods and Nutrients in HNC

While a few participants were aware of the opinion that sugar negatively influences cancer, none, bar one, believed this was accurate. Similarly, several participants thought that the ketogenic diet was harmful. This concept of the ketogenic diet having benefits in cancer was first introduced over 100 years ago when rapidly dividing cancerous cells were observed to utilise glucose at a higher rate than non-cancerous cells (Calvo et al., 2010; Warburg et al., 1927). This observation developed the theory that the ketogenic diet (low carbohydrate) would limit the fuel for, and halt the growth of, cancerous cells (Warburg et al., 1927). Therefore, it is not surprising that many participants across the literature have reported beliefs that sugar is carcinogenic and detrimental to cancer recovery and survival (Beeken et al., 2016; Depeint et al., 2018; Sullivan et al., 2021). However, this theory has been disproven as although a reduction in exogenous glucose would reduce the immediate energy available to cancerous cells, any subsequent nutrients required by the tumour would be harvested from nearby cells or synthesised (NCI, 2021). These processes accelerate weight loss and increase the risk of malnutrition (NCI, 2021). Therefore, some studies and organisations such as the European Society for Clinical Nutrition and Metabolism, have expressed the danger low carbohydrate diets pose to people with cancer in treatment and recovery (Arends et al., 2017; Klassen et al., 2020). Despite the debunking of this theory, ketogenic diets are still encouraged for cancer by unaware health professionals and scaremongering social media (Depeint et al., 2018).

Perhaps the reason this theory was not believed by most participants in the present study was because, as demonstrated in *Section 5.1,* many of them used and valued dietitians as a nutrition information source. Because dietitians provide evidence-based recommendations, they educate against misinformation such as this theory due to the overwhelming opposing evidence. Therefore, this finding reinforces the importance of dietetic input to explain and discredit misinformation, such as the idea that sugar negatively influences people with cancer. Ensuring that people with HNC have access to dietetic care will reduce the prevalence and negative consequences of these beliefs.

Vitamin C was reported by participants in the present study to be potentially beneficial in cancer treatment. The rationale behind this belief involves the now disproven pro-oxidant theory of vitamin C, whereby vitamin C was thought to destroy cancerous cells when delivered intravenously at high-doses (Roa et al., 2020). However, because vitamin C is an anti-oxidant, it has a protective effect on cells. Therefore, vitamin C counteracts the effects of chemo and radiation therapy by preventing their pro-oxidant action and reducing their efficacy (Conklin, 2004; Dong et al., 2020). Additionally, several participants reported they believed vitamin C could increase their energy in HNC recovery. The limited research that supports this belief states vitamin C supplementation could reduce complaints of chemotherapy-related fatigue (Carr et al., 2014; Vollbracht et al., 2011; Zasowska-Nowak et al., 2021). However, there is currently no evidence from placebo-controlled trials, and therefore, the placebo effect of vitamin C cannot be disregarded. Although currently there is no existing literature investigating the perceptions people with cancer have towards vitamin C, the number of clinics advertising this service and various news articles reporting success with vitamin C indicate that these beliefs may be present in NZ (Bay of Plenty Times, 2016; Gore Medical Centre, 2024; Rowan, 2014). Of note, more participants in the present study believed vitamin C was beneficial than believed sugar had a negative effect. This may be due to the prevalent belief that vitamin C is beneficial for immune-related conditions such as the common cold and flu in the general population (InformedHealth.org, 2006). Whereas the belief that sugar is detrimental to cancer is very specific to cancer and therefore, less prevalent. Additionally, it may be because the proposed benefits of vitamin C outweighed the proposed harm of sugar. Furthermore, it is significantly easier for an individual to obtain high-dose vitamin C than it is to remove all sugar from their diet. Overall, this finding suggests that people with HNC may not be receiving adequate nutrition support regarding topics such as vitamin C.

Prioritising fruits and vegetables in HNC treatment and recovery to a large degree over other foods was another belief identified by many participants in the present study. However, one participant disagreed, believing a particular focus on healthy foods was not a priority in comparison to obtaining adequate energy from their diet. While a diet high in fruits and vegetables has been linked to a reduced risk of several cancers, the most important dietary aim of HNC treatment and recovery is to maintain muscle mass and body weight to reduce the risk of malnutrition (Hu et al., 2023; Ravasco, 2019). Therefore, a diet high in energy and protein is frequently emphasised in HNC treatment and recovery (Ford et al., 2022; Ravasco, 2019). This was reflected in the present study's results and was the primary focus of many participants, including the individual who believed fruits and vegetables were an undue priority. This finding is significant because, while fruit and vegetables are important for health, if people with HNC believe they are a priority, they may emphasise these over protein or high-energy foods, which are crucial to support optimal HNC treatment and recovery. Therefore, this finding reinforces why it is important for dietitians and healthcare professionals to be aware of these views and provide the appropriate education to avoid any negative consequences.

Multiple participants in this study believed alcohol could cause HNC. Indeed, alcohol consumption is associated with a range of cancers and is reported to be responsible for approximately 5% of HNC cases across numerous American and European studies (Hashibe et al., 2009; Rumgay et al., 2021). It is proposed that the risk of HNC increases proportionally with the frequency and intensity of alcohol consumption (Di Credico et al., 2020; Koo et al., 2021). The belief that alcohol causes cancer has been noted in populations around the world (Kiviniemi et al., 2021; Wiseman & Klein, 2019). However, there is limited literature investigating the perceptions of people with cancer themselves, despite these people being the most affected. One American study identified that people with and survivors of cancer continued to consume alcohol, and approximately 40% drank to hazardous levels, which suggests this population had an unawareness or indifference to the risk alcohol poses (Shi et al., 2023). Becker's Health Belief Model proposes that a person must have an awareness of the risk and severity of a condition as well as self-efficacy to make a successful health change (Janz & Becker, 1984). Therefore, this model may help to explain why these participants choose to continue drinking alcohol despite it likely contributing significantly to their cancers. Additionally, alcohol is an addictive substance, and some people may not have the resources to rehabilitate (Wang et al., 2020). Alcohol consumption was not assessed in the present study. However, it is possible that participants' awareness of alcohol's negative effect could be in part attributed to their belief in evidence-based information.

5.3 Support Desired by Participants

An overarching theme in the present study regarded gaps in healthcare support. In NZ, people with HNC are offered a range of nutrition support. Within the public health system, dietitian reviews are available by referral from inpatient medical and nursing staff or in the community by a general practitioner. Referral criteria for input by a registered dietitian include an oncology-related impact on nutritional status, increased nutrient requirements, and a diagnosis or risk of malnutrition (Auckland DHB, 2021). However, every person diagnosed with HNC in NZ has a dietitian as a part of their multidisciplinary team. Although there is nutrition support available for people with HNC in NZ, such support can be difficult to access outside of the acute setting. Many people recovering from HNC are medically managed in outpatient clinics or the community. Difficulty accessing dietetic support in these settings could be due to a lack of awareness regarding the early symptoms and severity of malnutrition and potentially confusion around the correct time to make referrals.

Regarding the capacity dietitians have to support people with cancer in NZ, the recommended ratio of people requiring dietary support to dietitians in 2021 was well exceeded (NZIER, 2021). This indicates that dietitians could not safely review and follow up every person diagnosed with cancer (NZIER, 2021). Furthermore, the costs associated with a dietetic review may be challenging for people living in rural areas who may need to travel to main centres for dietetic input. These challenges may result in limited or no long-term nutrition support for people with HNC and could explain why several participants reported beliefs not supported by the literature, such as those discussed above in *Section 5.2.*

Participants in this study specifically desired additional support in managing unintentional weight loss, a common and devastating side effect of HNC treatment. Unintentional weight loss can occur quickly and can be difficult to manage with cancer-induced fatigue, appetite loss and taste change (Beirer, 2021). Furthermore, consequences of unintended weight loss can include muscle wasting, reduced strength, fatigue, and ultimately, reduced recovery and survival (Beirer, 2021). As people are diagnosed with different stages of cancer and receive dietetic referrals at different times, they may experience significant weight loss before they receive any nutrition support. Therefore, in this regard, early and consistent dietary intervention is the best indicator of positive health outcomes (Aversa et al., 2017). It is likely that the participants who reported this desire are now aware of these benefits. Therefore, their desire may have reflected information they would have appreciated in their treatment or recovery. Additionally, the results suggest that participants wanted to raise awareness of this gap in nutrition support to ensure that people diagnosed with HNC in the future are better supported. This finding builds on what was previously discussed as it indicates there may be a lack of or low referral rate to dietitians in NZ regarding support for people with HNC to avoid and treat unintentional weight loss. This further emphasises the importance of an awareness of nutrition, malnutrition, and optimal referral times in outpatient multidisciplinary teams.

While some participants felt supported and included in decision-making regarding their treatments, several others did not and desired this support. Involvement of the individual in decision-making is a collaborative approach to providing patient-centred healthcare, otherwise known as shared decision-making, which facilitates treatment that best matches the preferences of the individual (Montori et al., 2023). Shared decision-making is crucial for high-quality care and is generally considered best practice (Driever et al., 2020; Montori et al., 2023). Additionally, shared decision-making has been linked to lower patient anxiety and greater adherence to treatment (Veilleux et al., 2018). In existing literature, the desires of people with cancer vary, with some participants having reported a preference for an active role in decision-making, while others favoured a more passive approach (Elkin et al., 2007). In regard to the lack of support participants perceived in decision-making, it may be important to consider the range of feasible treatments available. Limited treatment options could be interpreted as a lack of choice and could lead to a sense of powerlessness. Furthermore, when support is minimal, the inherent power imbalance between the person and healthcare professional may intensify and add to feelings of vulnerability (Molina-Mula & Gallo-Estrada, 2020). These negative impressions could be addressed if healthcare professionals engaged in open and honest communication with the people they support, as this would ensure people with HNC are constantly aware of their treatment options.

Additionally, effective communication, particularly within the patient-centered approach, has been found to improve quality of care, self-efficacy, and adherence to treatments (Derksen et al., 2020; Elkefi & Asan, 2023).

Similarly, several participants wished for receptiveness from their healthcare team regarding their opinions. This is a finding recognised across the literature, where many other participants have reported they do not feel they were heard or that their healthcare team considered their opinions when planning treatments (Ingersoll et al., 2018). This is perhaps because healthcare professionals often manage large patient loads, and therefore, may have less opportunity to listen to and discuss individual patient opinions (Neilson, 2023; NZIER, 2021). Listening to and validating opinions is an effective way for health professionals to provide reassurance and comfort to people in a situation where they have limited control. This links back to the previous finding that emphasises the importance of communication and patient-centred care in achieving positive health outcomes. Furthermore, understanding the perceptions people with HNC have towards the support they receive is important because if they do not feel listened to, they may withdraw from healthcare professionals and be less motivated to engage in treatment.

Lastly, participants specifically desired additional support in understanding nutrition requirements in long-term HNC recovery. It can be difficult to navigate changing requirements in cancer without continued support, and because people in cancer recovery do not have as acute or severe needs, they can become a lower priority for healthcare professionals (Rock et al., 2012). However, people recovering from HNC may still experience severe side effects such as dysphagia, taste changes, and appetite loss that make eating extremely difficult (Willemsen et al., 2020). Adequate nutrition during HNC recovery is crucial to reduce the likelihood of other negative side effects, such as malnutrition, from developing or worsening (Rock et al., 2012). Therefore, nutrition support at this time is essential. This desire was reflected by participants in Peniamina et al. (2021), who wished for more dietary support in long-term recovery. Likewise, a desire for continued nutrition support was reported by participants in Beeken et al. (2016), who explained that although information was provided, it was generally basic and was often provided early in treatment when people were too overwhelmed to understand it. This finding links back to and reinforces previous themes in this section that regard gaps in nutrition support and a lack of dietetic input for people with HNC in the community in NZ.

Overall, the findings discussed in this chapter draw back to one common consequence—that incorrect information or beliefs and a lack of evidence-based nutrition support places people with HNC at an increased risk of malnutrition in treatment and recovery. This chapter ultimately highlights the importance evidence-based nutrition support has throughout HNC in directing people to reliable and correct resources, disproving harmful misinformation, and achieving positive health outcomes. Additionally, this chapter has emphasised gaps in, and areas of improvement for, the current community dietetic support available in NZ for people with HNC.

5.5 Chapter Summary

This research project explored the attitudes, beliefs, and sources of food and nutrition information, as well as the support people with HNC desire regarding nutrition. This chapter discussed why dietitians, HNC support groups, and evidence-based information were the most accessed, important, and credible sources of nutrition information. Findings that referred to specific foods and nutrients importance in HNC were next interpreted. Lastly, the support desired by participants was discussed, including unintentional weight loss and long-term recovery advice, as well as participants' desire to be involved in treatment decisions, and have receptiveness regarding their opinions from healthcare professionals. The following chapter, Chapter 6 (Conclusion), presents the overall conclusions, critiques strengths and limitations and provides recommendations for future research.

Chapter 6: Conclusion

6.1 Achievement of Research Aims and Objectives

The aim of this research project was to explore the attitudes and beliefs people with HNC living in NZ hold towards food and nutrition in HNC causation, treatment, and recovery. This study used a qualitative online survey and a sample of 38 people who have a diagnosis of HNC. To achieve the research aim, three objectives were created.

The first objective was to investigate the perceptions people with HNC held towards sources of nutrition information. The sources people with HNC valued and rated the most credible were dietitians and other people with, and survivors of, HNC. Registered Dietitians may have been highly regarded because they are qualified healthcare professionals who have a strong focus on evidence-based information, which participants reported was of significant value. Other people with, and survivors of, HNC including support groups, may have been considered important and credible because, as peers, they could share relatable advice and personal experiences, which offered people with HNC a unique perspective of HNC information. It is important to know the sources of nutrition information that people with HNC access and perceive as credible because inaccurate nutrition information can have devastating effects on HNC treatment and survival.

The second objective was to identify specific foods and nutrients people with HNC believed were significant in prevention, causation, treatment, and recovery. The foods/ nutrients identified by participants were sugar, vitamin C, fruits, vegetables, energy, protein, and alcohol. The attitude that sugar is detrimental for people with HNC was not believed by many participants. In contrast, several participants believed that vitamin C reduces fatigue and is beneficial in HNC treatment and recovery. Although the literature supports neither of these ideas, participants' awareness of the inaccuracy of one theory but not the other may reflect the nutrition support available to people with HNC in NZ. This finding suggests that evidence-based support may be available regarding certain alternative dietary therapies but not others.

Participants' belief that fruits and vegetables should be prioritised over other foods in HNC treatment and recovery additionally raised concerns as this practice may remove the dietary focus from energy and protein which are critical for reducing malnutrition risk. With this consideration in mind, many participants mentioned the significance of energy and protein in HNC treatment and recovery. Likewise, alcohol was correctly reported as a contributor to HNC causation and negative health outcomes in HNC. In this context, the agreement of participants' opinions with the literature may be another reflection of the value people with HNC associate with dietitians and evidence-based information.

The third objective was to identify any overarching nutrition beliefs that people with HNC hold. These beliefs encompassed participants' desire for healthcare support, specifically to have their opinions heard, to be involved in treatment decision-making, and advice regarding unintentional weight loss and nutrient requirements in long-term recovery. Participants' desire to feel heard and understood is natural, particularly as in times of illness, people have limited control and validation from healthcare professionals can provide reassurance and comfort. Similarly, participants' desire to be involved in treatment decision-making may result from a need for open communication with healthcare professionals. Together, these findings highlight that healthcare professionals building honest and trusting relationships is important to ensure people with HNC feel adequately supported. Advice regarding unintentional weight loss may have been important for participants as it is a particularly debilitating symptom of HNC that has severe effects on HNC treatment and recovery outcomes. Similarly, participants' expressed need for advice regarding nutrient requirements in long-term recovery may have arisen from a desire to avoid negative consequences such as unintentional weight loss and malnutrition.

This study highlighted the significant benefit that high-quality, evidence-based nutrition support has on HNC health outcomes. These findings align with the current literature. This study also identified the key areas of nutrition support that that could be improved.

6.2 Research Impact

At the time of writing, to the authors knowledge, this study is the first to exclusively investigate the nutrition beliefs of people with HNC living in NZ. Therefore, this study provides novel scientific insight into an under-researched topic and offers healthcare professionals tangible evidence surrounding the food and nutrition beliefs people with HNC in NZ hold. Specifically, this research raises awareness of the value people with HNC in this study assigned to evidence-based information and nutrition support. Additionally, this study provides healthcare professionals with knowledge concerning the areas of HNC nutrition education and support that need improving from the perspective of the lived experiences of people with HNC. Overall, this study's findings add to the limited pool of literature and provide additional feedback regarding potential improvements to dietary education that could enhance health outcomes and support for people with HNC throughout their cancer journey.

6.3 Strengths and Limitations

This study had several strengths. The first strength concerns the extent to which this study sample was representative of the population. In relation to gender, 25 participants were female (64%), and 14 were male (36%). Although there was not an even number of participants from each gender, enough people of each were included to represent any potential differences in opinions.

Similarly, a range of ages were recruited into this study, taking into consideration that this is a disease that typically affects older adults. The median age at the time of the survey was 61 years. The youngest participant was 28 years of age, and the oldest was 89 years of age. The spread of participants' ages signifies that this study received responses from multiple generations, especially the age groups where HNC is most commonly diagnosed (Kouka et al., 2023).

Furthermore, participants in this study had been diagnosed with 12 different types of HNC. A number of common (oral cavity and oropharyngeal) and rare HNC types were captured (salivary glands, rhabdomyosarcoma), indicating the sample was representative of individuals with a diverse range of HNC (Cancer Research UK, 2024).

Additionally, this study sample included individuals with a range of durations since their first diagnosis. The median number of years since participants were first diagnosed with HNC was 2.5 years. The earliest diagnosis was in 2006, 18 years ago, and the most recent was in 2024. As half the participants had been diagnosed less than 2.5 years ago, it is likely that the attitudes formed during treatment and recovery were still prominent in participants' memories. This indicates that the gathered opinions were likely accurate, enhancing the credibility of the present study.

A variety of regions (11 of the 13 in NZ) and cities (8) were reported as participants' diagnosis and treatment locations. This suggests that the sample was likely representative of the opinions of people with HNC from across NZ.

the perceptions people with HNC in NZ held towards food and nutrition were analysed in-depth using a qualitative method. This approach allowed participants to share and elaborate on their personal opinions, which is a perspective that quantitative methods cannot capture (Hennink et al., 2020). Additionally, the unique design of this study—an online written survey—minimised the burden on participants and allowed people from across NZ to participate. This design allowed participants to type their responses, choose when they wished to complete the survey, and take as long as they needed. This let participants avoid the difficulty, fatigue, and/or embarrassment of verbal communication that can often occur as a result of common surgical treatments such as glossectomies and laryngectomies (Braun et al., 2021; Hickey et al., 2024).

This study had three main limitations. Firstly, various ethnicities present in NZ were underrepresented in this study sample, particularly Māori, Pacific, and Asian groups. One Māori individual, one individual of Māori, Samoan, and NZ European descent, one Asian, and one European individual were recruited into this study. The remaining 35 participants identified as NZ European. In comparison to the 2018 NZ census, NZ European people comprised 70.2% of the population, Māori constituted 16.5%, Pacific 8.1%, and Asian individuals 15.1% (Stats NZ, 2018). Therefore, the NZ European ethnicity was overrepresented in this study population and Māori, Pacific, and Asian groups were severely underrepresented. Consequently, this study did not capture a representative sample of minority and indigenous cultural opinions in NZ.

Secondly, the voluntary nature of this study may have introduced selection bias. People are more likely to participate in research if they are trusting of healthcare professionals (Scanlon et al., 2021). Therefore, this may mean that this study recruited a subset of people with HNC who may not be representative of the HNC population in NZ. To reduce the risk of selection bias researchers could have recruited through a range of channels, including those that are independent of healthcare, such as newspapers, word of mouth, or general social media advertisements.

Finally, several questions in the survey lacked sufficient detail and therefore, collected only brief surface-level responses. Some participants seemed to be confused by the wording of several questions. For example, the questions including the terminology “culture” and “alternative dietary therapy” had some responses querying the type of answer desired by researchers or focusing on an unrelated point. Therefore, many participants did not explain or elaborate on statements they made. This meant it was difficult to determine exactly what certain responses referred to and that some of the background reasoning for participants’ choices was left undiscovered.

6.4 Recommendations and Direction for Future Research

As the number of people in NZ diagnosed with HNC increases each year, further qualitative and quantitative nutrition research is required in this population to understand the prevalence, origin, and strength of nutrition beliefs such as those identified in this study. This knowledge will add to the limited body of literature and allow healthcare professionals to adjust their practice and better support the people with HNC they serve. Future research could include investigation of:

- The opinions of people with HNC from a broad range of ethnicities and cultures present in NZ, especially people of Māori, Pacific, and Asian populations. Because these groups were severely underrepresented in this study, and because Māori and Pacific bear a greater burden of inequitable cancer outcomes.
    - Additionally, investigation into people with HNC from a wider and representative range of ethnicities would help to reveal any potential effects culture could have on choices and perceptions of nutrition information.

- The number of people with HNC that have utilised alternative dietary treatments such as those identified in the present study. This will provide healthcare professionals with evidence of the prevalence and lived consequences of these beliefs.
    - Furthermore, investigation into the outlying foods and nutrients reported in participants’ responses would be beneficial, as several items were only mentioned once and did not constitute a theme in the present study.

- The nutrition perceptions of people with HNC recruited independently of support groups. People who engage in peer support, such as support groups, tend to be more engaged and actively involved in their health (Hickmann et al., 2022). Therefore, it would be interesting to understand if support group recruitment had an effect on this study's results and if people recruited through other avenues would report similar findings.
    - Additionally, the opinions of people with HNC regarding the present study's method of data collection. As this research project used a unique study design, due to this study population's communication difficulties, it would be beneficial to determine how effective the method was and if it was acceptable to participants. This research would help to strengthen the reliability of this study's design and provide an evidence-based template for future research.

- The nutrition perceptions of people with other cancer types and chronic diseases that also have significant effects on a person's ability to obtain adequate nutrition (such as Irritable bowel syndrome, irritable bowel disease, stomach or bowel cancer, and endometriosis. It would be beneficial to understand if the perceptions are similar or different from those identified in the present study, and therefore, if the findings of this study are applicable to other health conditions.

In summary, this research provides an in-depth discussion of the attitudes and beliefs people with HNC hold towards food and nutrition. It presents an opportunity to focus and strengthen the nutrition support available for people with HNC in NZ. These findings could enhance patient-centred care, leading to improved health outcomes.

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Appendices

Appendix A

Literature Review Research Strategy

In approaching this literature review, studies involving the nutrition attitudes and beliefs of people with HNC nutrition were searched as below in MedLine (65 hits), PubMed (76 hits), APA psycINFO (28), CINAHL (248 hits) and Scopus (631 hits) from 5 December 2023 to 26 July 2024. Approximately 50% were duplicates.

Search terms:
Head OR neck OR mouth OR tongue OR voice* OR larynx OR sinus* OR orofacial OR saliva
AND diet* OR nutrition* OR food*
AND cancer* OR neoplasm* OR tumour OR malignancy OR carcinoma
AND "patient* attitude*" OR "patient* belief*" OR "patient* perception*" OR “patient* views”

Excluded were articles on the practitioners’ or clinicians’ attitudes, beliefs, or perceptions.

Appendix B

Nutrition Beliefs in Head and Neck Cancer Survey

Prologue: Thank you for choosing to participate in the Nutrition Beliefs in Head and Neck Cancer Study. This survey gathers both demographic data and information about your perceptions, attitudes, and beliefs towards food and nutrition, as someone who has or has had head and neck cancer. We ask that you think carefully about each question and give in-depth responses to allow our researchers to fully understand your opinions.

Your participation in this survey is voluntary, and you may choose not to answer any questions that you find uncomfortable. Any statements that you make will be anonymous. Research findings will be reported without identifying any specific respondents.

If you have any questions about this survey or anything about the Nutrition Beliefs in head and neck cancer study, please contact student dietitian and master's student Ruby Young at R.g.young@massey.ac.nz or the primary researcher supervisor Maria Casale at M.Casale@massey.ac.nz

Participant code: In order to retain participant anonymity, survey respondents are asked to establish an unidentifiable participant code. In order to do this please use the first letter of your first name, the last letter of your last name, and two numerical digits of your choice (e.g., RG21).

Section 1: THE QUESTIONS OF THIS PAGE RELATE TO DEMOGRAPHIC INFORMATION.

1) What gender do you primarily identify with?

○ Male

○ Female

○ Non-binary / third gender

○ Prefer not to say

2) What year were you born?

____

3) Which ethnic group or groups do you identify with?

☐ Pakeha / NZ European

☐ Māori

☐ Samoan

☐ Cook Islands Māori

☐ Tongan

☐ Niuean

☐ Chinese

☐ Indian

☐ Other, please specify

____

4) Where in New Zealand did you live at the time of your (first) diagnosis?

○ Northland

○ Bay of Plenty (Lakes)

○ Taranaki

○ Auckland (Waitemata, Counties Manukau, Central)

○ Waikato (Taupo)

○ Hawkes Bay (Tairawhiti)

○ Manawatu (Whanganui)

○ Wellington (Hutt Valley, Capital and Coast, Wairarapa)

○ Nelson Marlborough

○ West Coast

○ Canterbury

○ Otago

○ Southland

5) What city or town did you receive the majority of your treatment in?

____

6) What year were you first diagnosed with head and neck cancer?

____

7) What head and neck cancer have you been diagnosed with?

☐ Mouth

☐ Tongue

☐ Throat (nasopharynx, oropharynx, hypopharynx)

☐ Voice box (larynx)

☐ Nose and sinuses

☐ Salivary glands

☐ Skin of the head and neck (including scalp and ear)

☐ Other ____

Section 2: THE QUESTIONS ON THIS PAGE RELATE TO SOURCES OF INFORMATION AND YOUR ASSESSMENT OF THAT INFORMATION

8) What sources have you sought out or received nutritional information from, and how do you rate their importance?

1 = Not important
2 = Neutral
3 = Somewhat important
4 = Important
5= Significantly important

	0	1	2	3	4	5
Doctor						
Nurse						
Dietitian						
Friends						
Family						
Social media						
Internet resources						
Books						
Other						

9) Based on the sources of information you have sought or received (identified in the question above), please describe how you determine their credibility?

____

Section 3: THIS PAGE RELATES TO ASPECTS THAT MAY IMPACT YOUR ASSESSMENT OF NUTRITIONAL INFORMATION

10) How does your culture and cultural beliefs influence your choice and assessment of nutritional information sources?

____

Section 4: THE QUESTIONS ON THIS PAGE RELATE TO YOUR BELIEFS AROUND THE ROLE FOOD AND NUTRITION PLAYS IN HEAD AND NECK CANCER DIAGNOSIS, TREATMENT, PREVENTION AND/OR RECOVERY

11) What role, if any do you believe food and nutrition plays in head and neck cancer (e.g., in diagnosis, treatment, prevention, and recovery)?

____

12) Are there any specific foods or nutrients you think hold high significance in cancer causation, treatment, or recovery and why?

____

Section 5: THIS PAGE RELATES TO YOUR AWARENESS AND USE OF ALTERNATIVE DIETARY TREATMENTS AND THERAPIES

13) Are you aware of any alternative dietary treatments used in head and neck cancer? Do you have any opinions relating to these therapies?

____

Section 6: THIS PAGE RELATES TO YOUR LEVEL OF INVOLVEMENT IN YOUR TREATMENT AND HEALTH

14) How involved are you in decisions around your treatment and health?

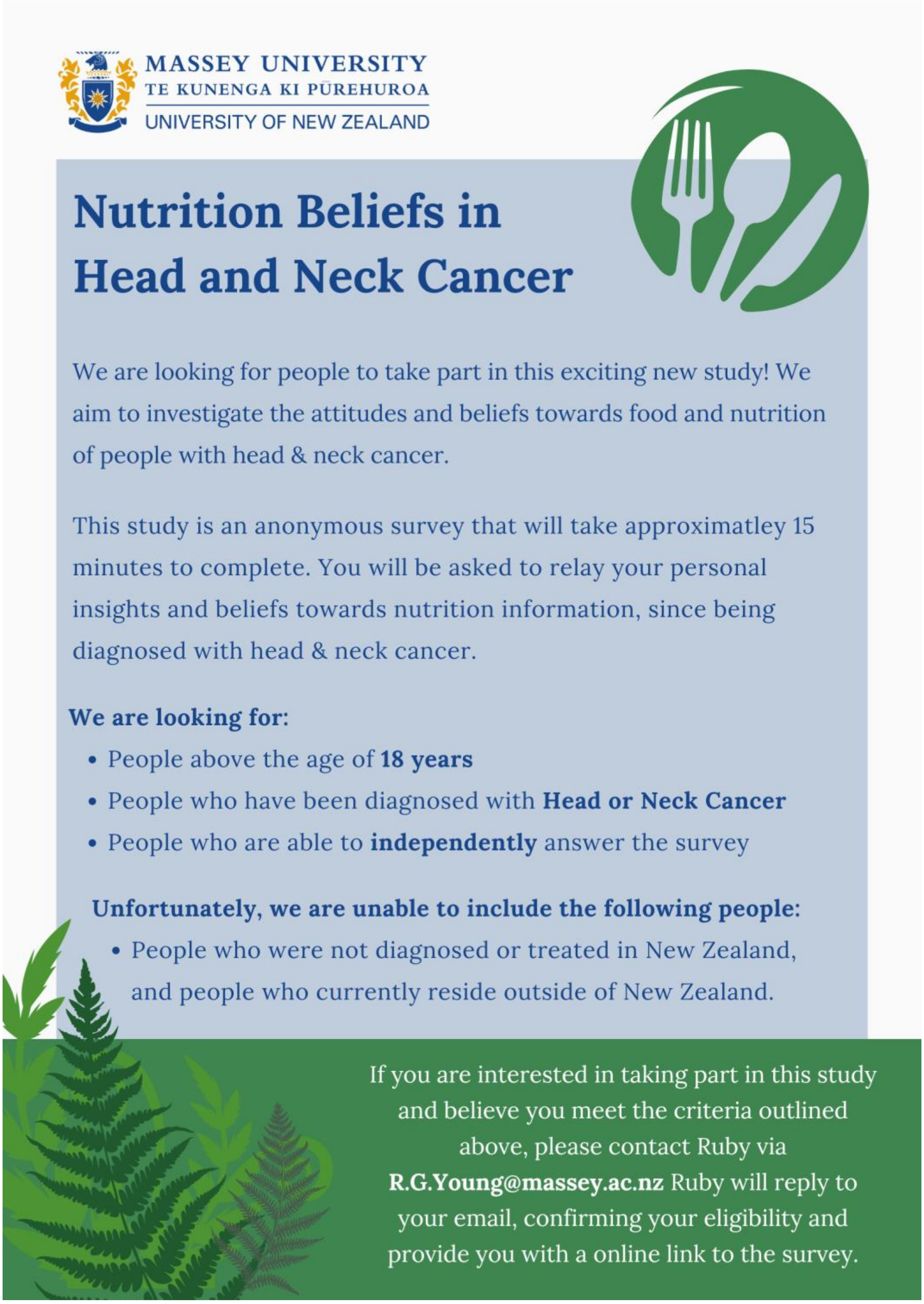
____

15) Lastly, what do you think is important for your healthcare team to know about nutrition for people with head and neck cancer?

____

Appendix C

Recruitment Poster



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Nutrition Beliefs in Head and Neck Cancer

We are looking for people to take part in this exciting new study! We aim to investigate the attitudes and beliefs towards food and nutrition of people with head & neck cancer.

This study is an anonymous survey that will take approximatley 15 minutes to complete. You will be asked to relay your personal insights and beliefs towards nutrition information, since being diagnosed with head & neck cancer.

We are looking for:

- People above the age of **18 years**
- People who have been diagnosed with **Head or Neck Cancer**
- People who are able to **independently** answer the survey

Unfortunately, we are unable to include the following people:

- People who were not diagnosed or treated in New Zealand, and people who currently reside outside of New Zealand.

If you are interested in taking part in this study and believe you meet the criteria outlined above, please contact Ruby via **R.G.Young@massey.ac.nz** Ruby will reply to your email, confirming your eligibility and provide you with a online link to the survey.