Experiences and Expectations of (Mal)nutrition by Oncology Patients at Auckland City Hospital

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A thesis submitted in fulfilment of the requirements for the degree of
Master of Health Sciences, University of Auckland, 2020

ABSTRACT

Background

Malnutrition is prevalent in oncology patients at 30 to 40% (1), with even higher prevalence in those with head and neck cancer (HNC), upper gastrointestinal (UGI) and lung cancers. Identification and treatment of malnutrition can reduce morbidity and mortality (2-6). Nutrition screening tools identify malnutrition; they have been endorsed globally within each guideline, protocol or recommendation dedicated to nutrition in oncology patients (2, 3, 5, 7, 8). The benefit to District Health Boards (DHB) is the reduction in the associated cost of malnutrition (9, 10) and even a valuable revenue stream for DHBs (11).

Aim

Audit: identify weight change before and during active treatment in 300 patients with HNC, UGI or lung cancers at Auckland City Hospital (ACH).

Questionnaire: characterise malnutrition, cancer and treatment-related side effects, nutrition behaviours, beliefs and sources of nutrition information; through a questionnaire and analysed using qualitative approaches.

Design and participants

Audit: a quantitative study using a retrospective audit of weight change in 200 patients (100 in each tumour group) for UGI or lung cancer and a prospective audit for 100 patients with HNC, all receiving treatment at the Regional Cancer and Blood Services, ACH.

Questionnaire: following a pilot trial of the questionnaire and adaptation, a prospective observational study with a qualitative questionnaire was offered to any patient receiving cancer treatment at ACH. The questionnaire was available as a paper copy from receptions or treatment staff or as an online version with access from a quick response (QR) code or a Uniform Resource Locator (URL) (bit.ly/NutritionHaveUrSay) for a one-month timeframe. It contained 16 questions, with a combination of closed-ended and open-ended questions depending on the information and level of detail required. Malnutrition was assessed, in part, using the Patient Generated-Subjective Global Assessment (PG-SGA).

Main findings

Those with UGI cancer had an overall weight loss during treatment of 17%, which was 2-3 fold higher than seen in patients with HNC and lung cancer. Overall weight loss was 6% and 8% for patients with HNC and lung cancer, respectively. Weight loss was likely minimised in the HNC group with weekly nutritional intervention from a dietitian for all patients; for UGI cancer patients, 34 received dietitian intervention and 16 patients in those with lung cancer at ACH.

Responses from the questionnaire (n=290) confirmed that malnutrition levels were similar to the peer-reviewed literature, with 53% of patients considered well-nourished, and 47% malnourished (SGA score B+C). The levels of nutrition impact symptoms showed 40% having multiple side effects likely to impact food intake and contribute to weight loss. Over half of the patients (58%) changed their diet due to these side effects.

Nutrition and awareness of malnutrition is everyone's responsibility. Oncology patients receive their nutrition advice primarily from their oncology doctors (47%) followed by nursing staff at 29%, then dietitians within the hospital and community settings (27%) along with family and friends (27%). Nearly a third of cancer patients change their diet to improve their overall health outcomes (32%).

Conclusion

Malnutrition is underdiagnosed and undertreated for oncology patients at ACH. Nutrition screening should be completed for all patients at each clinic review. Ideally, an electronic screening tool will reduce staff burden and allow for an audit of success with the implementation of malnutrition screening. For those who screen at high-risk for malnutrition, there should be access to timely nutritional intervention. Patients with HNC, UGI and lung cancer should have a routine nutritional intervention. A website dedicated to nutrition for cancer patients could allow patients to manage treatment side effects and evidence-based advice to improve health outcomes.

ACKNOWLEDGEMENTS

I want to express my special thanks to:

- The patients who completed the questionnaire and expressed their rationale for dietary changes, impressions on nutrition and its impact on their lives.
- My colleagues at Auckland Regional Cancer and Blood services, particularly the radiation therapists, nurses at chemotherapy and radiotherapy day stay. They were an immense help with the promotion and distribution of questionnaires and pens.
- Anne Fortune, Margaret Edmunds and Seiaute Moe deserve extra special thanks for stocking and distributing the questionnaire to patients.
- My primary supervisor Associate Professor Lindsay Plank for his knowledge, time, motivation and on-going assistance throughout the research.
- Supervisors Dr Andrea Braakhuis and Dr Karen Bishop for direction, feedback and motivation.
- My fellow dietitians for their ideas and feedback on the questionnaire development.

PREFACE

The foundation for this thesis has come from over a decade of working as a specialist oncology dietitian. This experience has raised many questions and stems from a passion for helping people maintain and improve their nutritional status through a difficult life phase. Many patients engage with extreme dietary changes; with the belief, it will cure their cancer when it can cause a great deal of harm, leading to malnutrition. The study's author has seen these changes borne from desperation and often encouraged by well-meaning family or friends.

This thesis was inspired to support oncology patients with evidence-based nutritional advice, with the belief that all oncology patients should have access to nutritional intervention from a dietitian. As health resources are not infinite, this thesis wanted, in part, to direct nutritional intervention where it would be of the utmost benefit.

The idea for this thesis was the study's author, with guidance and support from supervisors. The extent of involvement in this thesis is listed below:

- Setting aims and objectives and research question
- Liaising with ACH and the oncology department for approval to undertake research
- Preparing the application for Health and Disability Ethics Committee exemption approval
- Preparing the application for Auckland Health Research Ethics Committee (AHREC) approval and He Kamaka Waiora Māori Health Research approval at Waitematā and Auckland District Health Board (ADHB)
- Sourcing a list of patients who met the audit eligibility criteria
- Audit of 300 patient weights for HNC, UGI and lung cancer patients
- Questionnaire development
- Peer review and pilot testing of the questionnaire
- Distribution and collection of the questionnaire
- Recruitment of oncology patients for the questionnaire
- Interpretation of the data
- Writing of the thesis
- Dissemination of the audit and questionnaire findings to Nutrition Services and Oncology and Blood services at ACH

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GLOSSARY

ACH	Auckland City Hospital
ADHB	Auckland District Health Board
AHREC	Auckland Health Research Ethics Committee
AIOM	Italian Society of Medical Oncology
ASPEN	American Society for Parenteral and Enteral Nutrition
BMI	Body mass index
CMDHB	Counties Manukau District Health Board
COSA	Clinical Oncology Society of Australia
CRT	Chemo-radiotherapy
CT	Computerised tomography
DA	Dietitians Australia
DHB	District Health Board
DNZ	Dietitians NZ
DRG code	Diagnosis-related groups code
ESMO	European Society of Medical Oncology
ESPEN	European Society for Clinical Nutrition and Metabolism
ESTRO	European Society for Therapeutic Radiology and Oncology
GP	General Practitioner
HBV	Hepatitis B virus
HCC	Hepatocellular carcinoma
HCP	Health care professional
HCV	Hepatitis C virus

HIT	Health Information and Technology
HNC	Head and neck cancer
HPV	Human papillomavirus
ICD-10-AM	Classification of Diseases and Related Health Problems code
MNA	Mini Nutritional Assessment
MNA-SF	Mini Nutritional Assessment-Short Form
MOH	Ministry of Health
MST	Malnutrition Screening Tool
MUST	Malnutrition Universal Screening Tool
NDHB	Northland District Health Board
NHI	National Health Index
NRS-2002	Nutrition Risk Screening 2002
NZHS	NZ Health Survey
OPC	Oropharyngeal cancer
PG-SGA	Patient Generated-Subjective Global Assessment
PG-SGA SF	Patient Generated-Subjective Global Assessment Short Form
QR	Quick response
RT	Radiotherapy
SGA	Subjective global assessment
SINPE	Italian Society of Artificial Nutrition and Metabolism
UGI	Upper gastrointestinal
URL	Uniform Resource Locator
WDHB	Waitematā District Health Board

CHAPTER 1. INTRODUCTION

In New Zealand (NZ), cancer affects one in three people and is the leading cause of death (12). Cancer is an increasing concern that many New Zealanders will experience, either personally or with a loved one. With the thought of a potentially life-limiting diagnosis, the impact on the individual and their families' can be enormous, financially, physically and emotionally. However, cancer can be successfully treated. Even with a recurrence of the disease, many treatment options are available; cancer can now be considered a chronic disease (13).

Modification of crucial lifestyle factors can reduce the risk for many cancers; such factors include avoiding tobacco use, vaccination, maintaining a healthy weight, a diet containing fruits, vegetables, whole grains, and limited processed foods, reducing alcohol intake, and being physically active. All these risk factors are imperative public health messages that could reduce the ever-increasing health burden of cancer on our society if heeded. While reducing the risk of cancer is imperative, cancer will always be present, and treatment required. For people in Northland, Waitematā, Auckland Central and Counties Manukau area, the Regional Cancer and Blood Services at ACH provides the publicly funded specialist oncology services for their needs (14). The Auckland and Northland regions are diverse; it has a large geographical area and the largest populated area of NZ. The ethnic profile of the Auckland region includes 53.5% European, 11.5% Māori, 15.5% Pacific people, 28.2% Asian and 2.3% Middle Eastern/Latin American/African (15).

The specialist oncology dietitian at Auckland Regional Cancer and Blood Service is responsible for supporting and educating patients to meet their nutritional needs, and adapting plans based on the treatment, evidence and the circumstances for the patient and their whānau. The role requires liaison with all the DHBs to provide support and services for these high needs' patients. Nutrition has a vital role in each phase of the cancer continuum; from cancer initiation to supporting a patient during cancer treatment. For those with a cancer diagnosis, weight loss is a genuine risk. Unintentional weight loss can result in malnutrition (16, 17). Malnutrition results from a complex interaction between systemic inflammation, anorexia and tissue breakdown (6). When combined with a physical inability to consume sufficient nutrition due to tumour or treatment side effects, it will lead to malnutrition and, ultimately, sarcopenia. The impact of malnutrition is severe and costly; it can increase morbidity and mortality (2-6).

Due to the detrimental effects and cost of malnutrition, early detection and treatment are of great importance. Screening tools can identify those at risk of malnutrition; this enables a targeted dietitian referral for timely intervention. Often with a life-changing diagnosis, combined with tumour and treatment side effects, many patients seek further information to reduce this burden. Patients source this information from the internet or receive unsolicited advice from friends and family. This advice often includes complementary therapies or integrated medicine to improve perceived health outcomes and manage the treatment or tumour side effects when evidenced-based nutrition advice is pertinent (18).

This thesis's focus is the impact of nutrition, particularly malnutrition, in the presence of cancer. It will take a patient-related focus, to hear the patient's thoughts and considerations with food, nutrition impact symptoms and changes to their usual eating pattern with a cancer diagnosis and treatment. The literature review describes the epidemiology of cancer globally, and in NZ, and investigates modifiable risk factors in cancer development risk. While modifiable risk factors in cancer development might seem unrelated to malnutrition, these patients have high tumour burden and arduous oncological treatment, covered in the latter part of the literature review.

Based on the study author's insight as a specialist oncology dietitian for the past 12 years, many patients at ACH do not receive nutritional intervention based on their needs or requirements; however, this is from the study author's experience; hence, a formal investigation is required. There were two main aims for this thesis. The first aim was to identify weight change before and during treatment in 300 patients, with HNC, UGI or lung cancers at ACH. The objective was to complete a retrospective audit of weight change using electronic medical records for UGI and lung cancer patients, with a prospective audit for HNC patients during their weekly nutritional intervention.

The second aim was to investigate the changes to patients' normal dietary behaviours and nutritional status, the rationale for these changes and where patients source their nutrition information, using a questionnaire. The questionnaire's objectives required oncology patients to self-assess their malnutrition degree, side effects from cancer, and treatment burden leading to nutrition impact symptoms. It ascertained from whom patients receive their nutrition advice and the use of biologically based complementary medicines. Furthermore, the questionnaire investigated what dietary changes patients have made and the rationale for these changes. The goal was to establish targeted nutritional intervention for oncology patients if indicated from the audit results; then account for all oncology patients' broader needs based on the questionnaire results and establish a long-term nutrition plan in the Regional Cancer and Blood Services, ACH.

CHAPTER 2. LITERATURE REVIEW

2.1 EPIDEMIOLOGY OF CANCER

2.1.1 INCIDENCE OF CANCER IN NZ IN A GLOBAL CONTEXT

Cancer is an increasing health burden both worldwide and in NZ. Globally 18.1 million new cases of cancer are diagnosed each year (19). The increasing incidence and mortality rates are complex but reflect both an ageing and growing population (20, 21). Socio-economic developments contribute to geographical variation in cancer incidence and mortality; in many low- to middle-income countries, access to screening programmes are limited or inadequate (19, 20).

Worldwide, lung and breast were the most frequently diagnosed cancer, followed by prostate (7.1%), and colorectal (6.1%) cancers (19). In NZ, prostate (10.6%) was the most frequently diagnosed cancer, followed by breast (9.8%), colorectal (9.6%), melanoma (6.8%), and lung (6.7%) cancers (21). In NZ, Māori males were more likely to be diagnosed with lung cancer, followed by prostate and colorectal cancer; Māori females had higher breast cancer rates, followed by lung and colorectal cancers (7).

Statistics NZ data from 2017 showed rates of new cancer registrations at 331.1 per 100,000; with 53% in males and 47% in females. The rate of new cancer registrations for non-Māori was 320.8 per 100,000, with rates 1.3 times higher for Māori at 430.2 per 100,000 (22). Over the past 20 years, the numbers of new cancer patients have increased by near two-fold from 16,136 in 1997 to 24,453 in 2017. However, compared to the age-standardised rates, figures have reduced from 346.1 in 1997 to 331.1 per 100, 000 in 2017 (23).

2.1.2 MORTALITY RATES

Globally an estimated 9.6 million deaths or 1 in 6 deaths resulted from cancer in 2018 (19). Lung cancer was the leading cause of cancer death (18.4%), followed by colorectal (9.2%), stomach (8.2%), and liver (8.2 %) cancers (19). Lung cancer (18.4%) is also the leading cause of cancer death in NZ, followed by colorectal (12.6%), prostate (7.2%) and breast (7.1%) cancers (24).

In NZ, 2016 data showed that 9,517 deaths resulted from cancer, or nearly one in three (30.3%), with 52.8% males and 47.2% females (12). Cancer mortality has overtaken cardiovascular mortality for the past ten years, as seen in Figure 1 (25). Cancer was also the leading cause of death in Māori males and females (12). Compared with non-Māori, cancer death rates were 1.8 and 1.7 greater for Māori females and males, respectively (24).

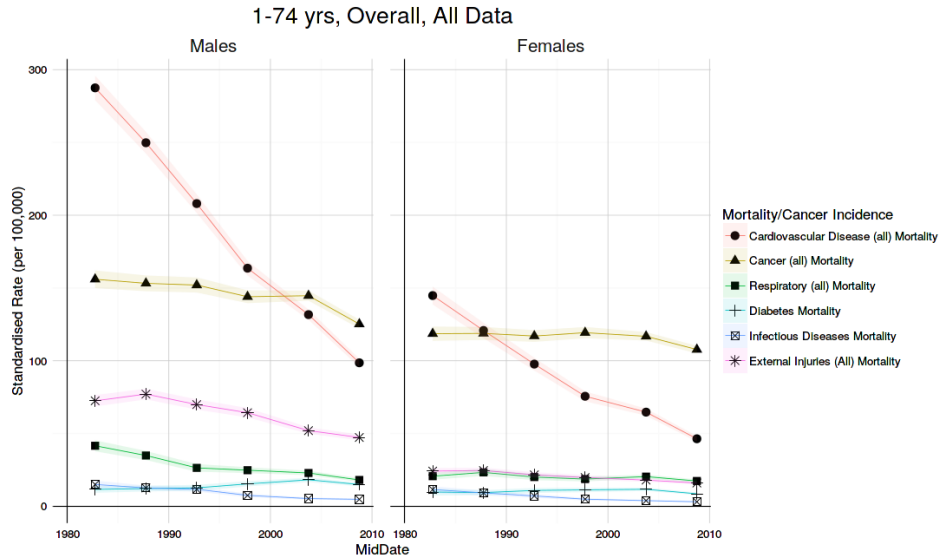

Figure 1 Standardised mortality rates in NZ (per 100,000) (25)

NZ incidence and mortality rates give a context of cancer's impact on our community and discrepancies within our society. A particular focus on Māori health is required to reduce these health disparities based on ethnicity and improve health outcomes for Māori in alignment with the NZ Public Health and Disability Act 2000 (26).

2.1.3 MODIFIABLE RISK FACTORS

Despite increasing cancer cases, people have improved survival with early diagnosis and improved treatment options; however, the ultimate aim should be to prevent cancer development. Improving lifestyle factors could avoid many associated cancers (27). The NZ Health Survey (NZHS) monitors health behaviours, risks and protective factors in our population over time (28). With the significant impact of our lifestyle and behaviours on cancer risk, the correlation can be seen with the changing health patterns within NZ's population over decades. Major risk factors, such as smoking, obesity, diet, alcohol consumption, and viruses, are discussed.

Tobacco use is the leading preventable cause of cancer. The majority of lung cancer cases are attributed to smoking tobacco and often diagnosed at an advanced stage (29-31). In the latest NZHS 2018/19, 14.2% of adults were current smokers. There has been a significant decrease in smoking rates, from 18.2% in 2011/12 (32). While the rates of Māori who smoke have reduced to 34%, it remains higher than the overall population rate (32); sadly, this reflects the higher incidence and mortality rates for lung cancer in our Māori population (12). Smoking rates amongst the Pacific people and Asian populations remain unchanged at 24% and 8.4%, respectively, since the 2011/12 NZHS (32).

The prevalence of obesity in NZ has increased from 12.8% in 1975 to 32.6% in 2016 but stabilised at 31-33% since the 2012/13 survey (33). Rates are 1.8 times and 2.5 times higher in Māori and Pacific adults respectively than non-Pacific adults. Those of Asian descent had minimal change over this time, with obesity rates at 13.8% (32). There was a significant reduction in adults achieving the recommended daily intake of two fruit and three vegetable servings from 43% in 2006/7 to 32.5% in 2018/19 (32). Fruit and vegetable intake combined with whole grains and fibre has a positive association with reduced weight gain, and obesity levels (34). In the context of cancer risk, there is convincing evidence that greater body fatness is a causal factor in many cancers, including oesophageal (adenocarcinoma), pancreas, liver, colorectal, breast (postmenopausal) and kidney, with a probable cause in many other cancers (34).

The 2018/19 NZHS shows four of every five adults (80.3%) consumed alcohol over the past year, relatively unchanged since the 2011/12 survey (32). There is strong evidence for alcohol consumption as a causal factor in many cancers, including mouth, pharynx and larynx, oesophageal, liver, colorectal, breast and stomach (34).

Vaccination has proven its success in reducing cancer rates. Hepatitis B virus (HBV) and hepatitis C virus (HCV) cause more than 80% of hepatocellular carcinomas (HCC) (25). New Zealand included HBV vaccination as part of the vaccination schedule for all newborn infants' in 1988 (27). Global vaccination programmes have resulted in a reduction in HCC (26). Human papillomavirus (HPV) vaccination was introduced in 2008 for females aged 12 years (35), and when combined with cervical cancer screening from 1990 (36), incidence rates of cervical cancer have halved, as seen in Figure 2 (25).

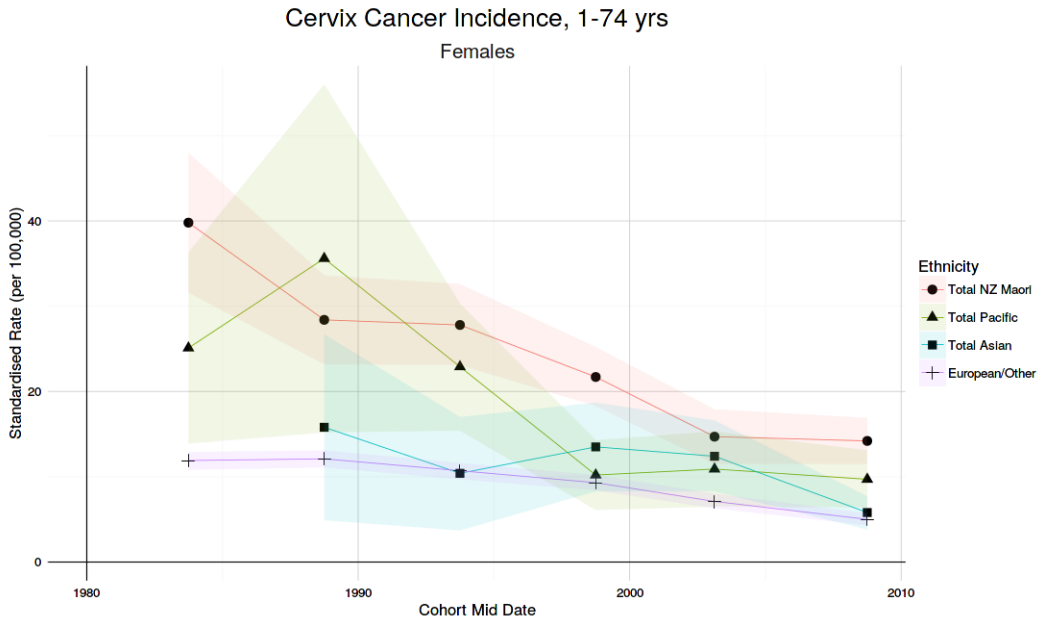

Figure 2 Cervical cancer incidence rates, by ethnicity, in NZ (per 100,000) (25)

Increasing incidence rates of oropharyngeal cancer (OPC) observed globally can be attributed to the HPV, with a higher proportion of males, younger and of European descent (37-39). In 2017, NZ extended HPV vaccination to males and females aged 26 and under (35). It is likely to take decades for the effect of vaccination to result in the reduction of OPC cancers related to HPV.

Modifiable risk factors are associated with the potential development of cancer, as mentioned above. Many of the cancers associated with these risk factors, such as HNC, UGI and lung cancers are strongly associated with nutritional deficiencies; before and during treatment (1), as demonstrated in the following sections.

2.2 MALNUTRITION IN CANCER

Malnutrition is the broad term given to undernutrition of macro or micronutrients or overnutrition related to overweight or obesity (40). Cachexia and malnutrition are often used synonymously in the clinical oncology setting (41). Cancer cachexia could be regarded as a specific form of disease-related malnutrition with inflammation, as seen in Figure 3 (42).

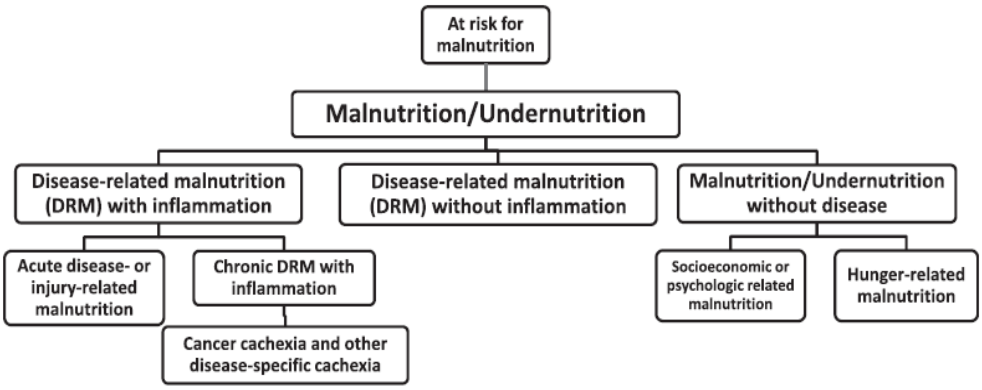

Figure 3 Diagnosis tree of malnutrition; from at risk for malnutrition, basic definition of malnutrition to etiology-based diagnoses (42)

2.2.1 MALNUTRITION IN THE PRESENCE OF CANCER

Malnutrition, in the presence of cancer, results from systemic inflammation, anorexia and tissue breakdown. These factors result in weight loss, change of body composition and reduced physical function (6). Operationally, malnutrition can be diagnosed as unintended weight loss of greater than 5% in one month or 10% in six months or a body mass index (BMI) less than 18.5kg/m^2 (43-46); however current research is directed at determining the ideal criteria for this diagnosis (47).

A distinguishing characteristic of malnutrition is sarcopenia, a term first proposed by Rosenberg (48) to describe the age-related decline in skeletal muscle mass and function. Baumgartner et al. (49) initially described sarcopenia as loss of muscle mass of over two standard deviations below that of a typical healthy adult or overall loss of skeletal muscle mass. Thresholds for sarcopenia based on skeletal muscle area from abdominal cross-sectional imaging by computerised tomography (CT) have been established by analysing cancer patient survival (50). Sarcopenia can result in fatigue, reduced strength and physical function, thereby resulting in diminished functional status, reduced quality of life, and in some cases, death (1, 6). Sarcopenic obesity is the loss of skeletal mass in an obese individual; it is associated with the same functional decline and is an independent predictor of lower survival than obese patients without sarcopenia (51).

2.2.2 CAUSES OF MALNUTRITION

Patients with cancer are at high risk of malnutrition due to a combination of disease burden and treatment side effects. There is a potential imbalance between energy and protein availability and inability to meet the individual's nutritional requirements (5). There is a reduced ability to consume and digest nutrients due to tumour burden or treatment side effects, excessive loss of nutrients and altered metabolic substrate utilisation (52, 53).

2.2.3 BURDEN OF MALNUTRITION

The causes of malnutrition vary depending on the type and stage of cancer and treatment; the burden can be high. Those with cancer-related malnutrition experience fatigue, loss of muscle mass, and impaired muscle function, leading to reduced physical activity and reduced functional capacity (53, 54). Malnutrition and sarcopenia are underdiagnosed in obese patients (6, 55). Toxicity from chemotherapy can be related to the degree of sarcopenia (53, 54, 56).

Malnutrition reduces immune function and increases infection rates (6, 9, 56). There is a well-documented association between the increasing degree of malnutrition and the likelihood of hospital admission, length of stay, repeated hospital admissions, and health care costs (9, 10). There is an increase of around five days of hospital stay for malnourished patients than those who are well-nourished (57-59).

Not only does malnutrition and unintentional weight loss present a physical burden, but it substantially impacts psychological well-being. A dramatic change in body image can result in social isolation and depression, further reducing a person's quality of life (6, 53, 54, 60-64). Ultimately, malnutrition, rather than the malignancy *per se,* can shorten survival in cancer patients (6, 16, 56, 65-67).

2.2.4 PREVALENCE OF MALNUTRITION

The impact of malnutrition in cancer patients was initially established in the historical paper by DeWys et al. (17) 40 years ago; data from 3,047 patients undergoing chemotherapy showed a correlation between median survival and weight loss. Fifteen per cent of all cancer patients lost greater than 10% body weight, with a further 17% of patients losing between 5 to 10% weight. A third of patients with metastatic gastric cancer lost greater than 10% weight, followed by a quarter of pancreatic cancer patients. Lung and colon cancer patients also had high rates of weight loss. For those who experienced weight loss, survival was reduced irrespective of tumour type (17).

In 1982 Bozzetti et al. (16) analysed the nutritional status of 280 patients with cancer and 41 control subjects. Those with cancer of the oesophagus and stomach (n=54) were at the highest risk of malnutrition and experienced the most substantial weight loss, with 10% for those with resectable tumours and 13% in non-resectable tumours. Colorectal, head and neck, testicular and lung (n=113) were in the second group, and those with non-resectable tumours also experienced significant weight loss at 5% (16).

These pioneering studies showed the impact of tumour location and size, and treatment burden on weight loss (16, 17). Table 1 presents malnutrition prevalence, according to the subjective global assessment (SGA) tool in a variety of patient settings amongst those with cancer. The SGA tool is used for consistency and to enable comparison of malnutrition prevalence. The significance of the SGA tool is explored in the following sections of this literature review. In brief, SGA is used to establish a patient's nutritional status and monitor change; an SGA score of A indicates a person is well-nourished, score B indicates mild to moderate malnutrition and severe malnutrition has an SGA score of C; often results for SGA B and C are combined (SGA B+C) (68). Where available, weight change as a percentage is also included in Table 1. The studies include outpatient and inpatient settings; they involve patients before and during oncological treatment, and those having palliative care.

Table 1 shows a wide variation in malnutrition prevalence, with 8% for a mixed cancer population at six months after treatment completion (69) up to 76% in an acute inpatient setting (70). Studies with 15 or fewer participants were excluded. It is difficult to see a clear pattern of malnutrition prevalence in Table 1. The lack of clarity could be due to the variability in the studies regarding the types and stages of cancers, and time point the SGA was completed, e.g., at diagnosis, during treatment, and six months after completion of treatment. Differing oncological treatments, study settings from outpatient clinic to an inpatient ward, study protocols and sample sizes are all likely to contribute to the variation in malnutrition prevalence in the studies presented in Table 1.

Generally, those studies which assessed malnutrition at three to six months post-treatment showed a lower prevalence of malnutrition (69, 71), as expected when cancer treatment has mitigated tumour burden, and the patient has recovered from the treatment side effects. Over half of patients with advanced cancers are malnourished, likely due to the tumour catabolism, and increased nutrition impact symptoms from tumour burden (72, 73). Hospitalised patients also have a higher prevalence of malnutrition, resulting from nutrition impact symptoms (70, 74, 75). There is wide variation in the prevalence of malnutrition in Table 1; earlier studies reported the prevalence of malnutrition up to 76% (70), with recent studies showing the prevalence of malnutrition at around 50% for oncology patients (75, 76).

Cancer patients are at high risk of malnutrition along their journey from diagnosis, during and after treatment, and in palliation, as seen in Table 1. Hospitalised and advanced cancer patients have the highest prevalence of malnutrition, with over half of patients likely to experience malnutrition. Weight loss can be as high as 26% in those with advanced cancer (73), and 80% of patients with advanced cancer experienced over 5% weight loss in the previous six months (74). Table 1 shows that many oncology patients experienced a 5% weight loss in the previous six months (71, 77-79). Weight loss is a critical marker of malnutrition risk and forms the basis of nutrition screening tools, as shown in later sections.

2.2.5 COST OF MALNUTRITION

As the number of cancer patients and treatment options increases, so does our health system's cost. The economic impact of cancer is enormous and increasing. Globally, the total estimated cost in 2010 was 1.16 trillion United States (US) dollars (80). A decade ago, the estimated cost of cancer treatment was $526 million in NZ; however, the actual cost was 40% higher at $880 million (81). Those with comorbidities had higher health cost when diagnosed with cancer (82). The highest cost in cancer care was from inpatient discharges at 47%, followed by outpatient attendance at 22% (83). In 2011, the Ministry of Health (MOH) estimated that cancer treatment cost would be $117 million by 2021 (83); it will be fascinating to note the actual cost when published. Costs associated with cancer are rapidly changing (81); overall cancer patients have more treatment options leading to improved survival and more complications, including malnutrition (19).

When a cancer patient is malnourished, there is a substantial healthcare cost (6, 84, 85). The cost associated with malnutrition is an additional 20 to 35% (57, 86). Malnutrition is a recognised complication with an International Statistical Classification of Diseases and Related Health Problems (ICD) code (ICD-10-AM), these costs can be reimbursed to hospitals and provide a useful funding strategy for DHBs (11). There is a cost-benefit to our health system with nutritional intervention reducing malnutrition burden (11, 87).

Table 1 Rate of malnutrition in cancer patients

Citation	Population	Weight loss	SGA outcomes	Malnutrition* %
Bauer et al. 2002 (70)	Oncology patients, admitted to acute care ward, mixed diagnosis, n=71	**Past 6/12** **C** 14.6% **B** 6.9%	**C** n=12 (16.9%) **B** n=42 (59.2%) **A** n=17 (23.9%)	76.1
Thoresen et al. 2002 (73)	Advanced cancer, mixed diagnoses, n=46	**As per SGA score** **C** 26% ± 8.2 **B** 13% ± 10.9 **A** 4.1% ± 5.0	**C** n=17 (37.0%) **B** n=13 (28.3%) **A** n=16 (34.8%)	65.3
Isenring et al. 2003 (71)	RT outpatients, head and neck, rectal or abdominal cancers, pre-treatment, n=60	**Past 6/12** 2.8%	**C** n=4 (6.7%) **B** n=17 (28.3%) **A** n=39 (65.0%)	35.0
Gupta et al. 2005 (88)	Newly diagnosed advanced colorectal cancer, outpatients n=234	**-**	**C** n =38 (16.2%) **B** n= 75 (32.1%) **A** n=104 (44.4%) **Unknown** n=17 (7.2%)	48.3
Read et al. 2006 (89)	Newly diagnosed cancer patients, mixed diagnosis, n =141	**Past 1/12** 0.52kg ± 4.33	**C** n=14 (10%) **B** n=79 (56%) **A** n=48 (34%)	66

Unsal et al. 2006 (69)	RT outpatients, pre, post, 3 and 6 months follow up, mixed diagnosis n=207	-	**Pre tx** **B+C** n=54 (26.1%) **A** n=153 (73.9%)	26.1
			Post tx **B+C** n=88 (42.5%) **A** n=119 (57.5%)	42.5
			6 mths **B+C** n=16 (8%) **A** n=184 (92%)	8
Laky et al. 2007 (79)	Gynaecological cancers, n=93 (64%)	**Past 1/12** 4.4% ± 3.3 **Past 6/12** 5.9% ± 4.4	**C** n=0 **B** n=23 (24.7%) **A** n=70 (75.3%)	24.7
Gupta et al. 2008 (72)	Ovarian cancer, n=132 • Newly diagnosed, n=24 • Recurrence, n=108	-	**C** n=31 (23%) **B** n=35 (27%) **A** n = 66 (50%)	50
Isenring et al. 2010 (90)	Oncology patients, n=191 • Chemotherapy unit / oncology ward n=65 • Outpatient cancer clinic, n=126	-	**C** n=4 (2.1%) **B** n=90 (47.1%) **A** = 97 (50.8%)	49.2
Koom et al. 2012 (77)	RT patients, 3 weeks into treatment, mixed diagnosis n=1000	**Past 6/12** 3.9% ± 4.8	**C** n=47 (4.7%) **B** n=345 (34.5%)	39.2

	• Gastrointestinal cancer, n=444 • Head and neck cancer, n=286 • Lung cancer, n=270	**As per SGA, ≥5% in 6/12** **B+C** 56.9% **A** 17.8%	**A** n=608 (60.8%)	
Kissova et al. 2015 (91)	Hospitalised patients, n=202 • Oncology patients, n=62	**-**	**B+C** n=31 (50%) **A** n=31 (50%)	50
Silva et al. 2015 (74)	Oncology and palliative care inpatients units, undergoing various treatments n=277	**≥ 5% in 6/12** n=101, 80%	**C** n= 99 (35.7%) **B** n=98 (35.4%) **A** n = 80 (28.9%)	71.1
Maasberg et al. 2017 (92)	Neuroendocrine tumours, n=203 • Inpatient unit n=177 • Outpatients n=26	-	**B+C** n=51 (25.1%) **A** n=152 (74.9%)	25.1
Opanga et al. 2017 (93)	Oncology outpatients receiving treatment, mixed diagnosis and treatments, n=471	-	**C** n=53 (11.3%) **B** n= 93 (19.7%) **A** n=325 (69.0%)	31.0
Alkan et al. 2018 (78)	Oncology patients, mixed diagnosis, undergoing treatment, n=104	**Past 6/12** 5.3% ± 9.9%	**C** n=34 (32.7%) **B** n= 28 (26.9%) **A** n=42 (40.4%)	59.6
Kang et al. 2018 (76)	Hospitalised patients, n=300 • Oncology patients, n=52	-	**B+C** n=17 (33%) **A** n=35 (67%)	33

Na et al. 2018 (94)	Lung, GI tract cancers undergoing treatment n=1,588	-	**B+C** n=485 (30.5%) **A** n=1103 (69.5%)	30.5
de Pinho et al. 2019 (75)	New diagnosed cancer patients, mixed diagnosis, inpatients, undergoing treatment, multicentre, n= 4,783	-	**C** n=565 (11.8%) **B** n=1,602 (33.5%) **A** n=2,616 (54.7%)	45.3
Marshall et al. 2019 (95)	Oncology patients, mixed diagnosis and treatment, over 2 time points • 2012 (17 sites) n=1677 • 2014 (27 sites) n=1913	**2012** ≥ **5% wt loss** n=267,15.9%	**2012** **C** n=75 (5.3%) **B** n=444 (26.5%) **A** n=89 (5.3%)	**2012** 31.8
		2014 ≥ **5% wt loss** n=235,12.3%	**2014** **C** n=83 (4.3%) **B** n=418 (21.9%) **A** n=122 (6.4%)	**2014** 26.2
Nitichai et al. 2019 (96)	Oncology patients, mixed diagnosis and treatments, n=195	**Past 1/12** 3.9% ± 6.9 **As per SGA, past 1/12** **B+ C** 6.0% ± 8.0 **A** 0.5% ± 1.6	**C** n= 67 (34.4%) **B** n=53 (27.2%) **A** n=75 (38.5%)	61.6

* Malnutrition is defined as SGA B+C

ABBREVIATIONS: 1/12 = one month, 6/12 = six months, mths = months, RT = radiotherapy, SGA = subjective global assessment, wt = weight

2.2.6 TUMOUR STREAMS AT HIGH RISK FOR MALNUTRITION

A cancer diagnosis in the head and neck area, upper or lower gastrointestinal and thoracic area, combined with treatment, particularly, radiotherapy (RT) to the respective area, results in the highest risk of malnutrition. The malnutrition risk increases for patients over 65 years and with an advanced cancer stage (1). HNC, UGI and lung cancers are the highest risk groups for malnutrition. The prevalence of malnutrition in these cancers is investigated in the following sections, to establish the rationale for these risks and prevalence of malnutrition using the SGA tool to measure malnutrition.

Malnutrition in HNC patients

HNC encompasses a range of complex anatomy, including the paranasal sinuses, nasopharynx, oropharynx and hypopharynx, oral cavity, salivary glands, tongue, larynx and neck area (97, 98). These cancers can be locally advanced or with the possibility of metastasis in the neck area. Treatment is a combination of modalities, including surgery, RT, chemotherapy and combined chemo-radiotherapy (CRT) (97).

In NZ, new case numbers of the lip, oral cavity and pharyngeal cancers have increased over the past 70 years; however, overall rates remain stable (23), as seen in Figure 4. Between 1981 to 2010, there has been a rapid increase in HNC cases related to the oral cavity and oropharynx, particularly for males, of European descent and those aged 40 years and older (98). The HNC patient's changing profile is observed globally, attributed to the rising diagnosis of HPV-related cancers and declining tobacco use (37-39). There is the potential for numbers and rates of HNC related to HPV to reduce with increasing uptake of the HPV vaccination, as seen in reducing cervical cancer rates presented in Figure 2 (25).

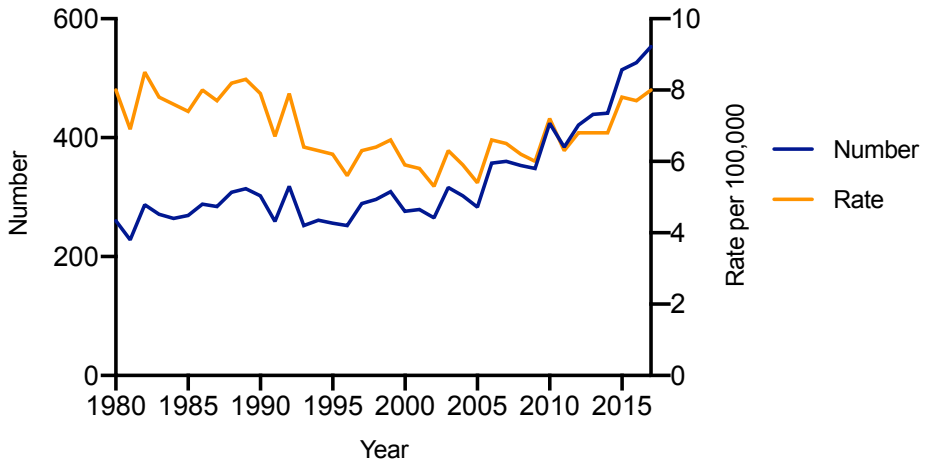

Figure 4 Number of new cases and age-standardised registration rates for lip, oral cavity and pharynx, NZ, 1980–2017 (5, 6)

Despite the rising numbers of HNC, mortality rates have reduced, as seen in Figure 5. The five-year survival for both males and females with HNC between 1998 to 2011 was 63%; with females faring better than males at 66% compared with 62%, respectively. Those who identified as Māori, five-year survival between 1998 to 2011, was substantially lower than non-Māori at 55% compared to 66%, respectively (99).

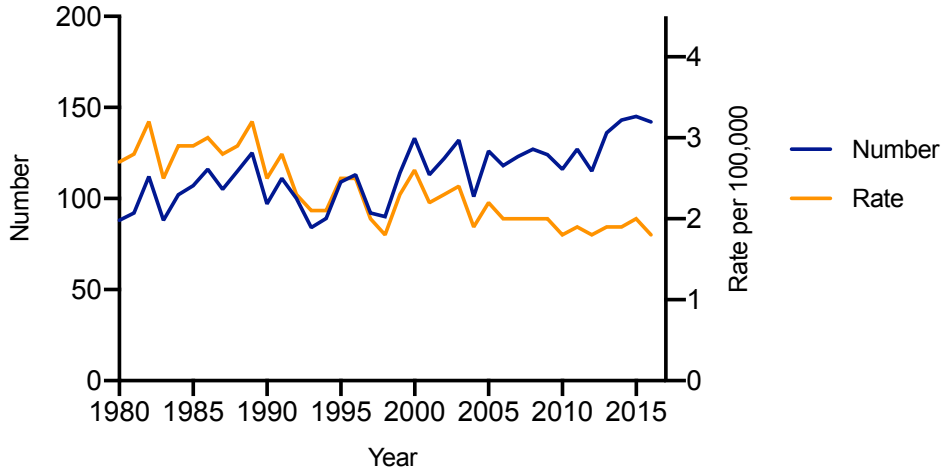

Figure 5 Number and age-standardised mortality rates for lip, oral cavity and pharynx, NZ, 1980–2016 (22, 23)

Side effects of the tumour and treatment burden are listed in Table 2. Nutrition impact symptoms and increased catabolism from the tumour and treatment can compromise nutritional status for those with HNC (100).

Table 2 Nutrition impact symptoms related to HNC and treatments (101-104)

- Reduced appetite/early satiety
- Masticatory/swallowing dysfunction due to surgery, tumour
- Edentulous, poor dentition or ill-fitting dentures
- Dysphagia due to surgery, radiotherapy or tumour
- Swallowing impairment of oral phase or pharyngeal phase
- Trismus
- Odynophagia due to mucositis, oral lesions, surgery
- Mucositis due to chemotherapy or radiotherapy
- Fatigue
- Xerostomia
- Changes in saliva, thick tenacious secretions
- Nausea and vomiting
- Anosmia, hyposmia, hyperosmia
- Dysgeusia
- Altered food preferences, food avoidance, food aversion
- Osteoradionecrosis
- Stricture of the upper oesophagus

As seen from the extensive list in Table 2, both the tumour and treatment impact are great, with a high likelihood of significantly impacting the patient's nutritional status. There are often multiple nutrition impact symptoms leading to compromised nutritional status.

Those at considerable risk of significant weight loss during treatment for HNC include patients undergoing combined CRT, salvage surgery, or a recurrence one-year after treatment completion. During RT, neck metastasis results in a more extensive treatment field, and for those with higher-dose treatment, there is an increased malnutrition risk due to the accumulating impact of treatment side effects, seen in Table 2 (105-108). Those with weight loss and a higher number of nutrition impact symptoms before treatment have accelerated weight loss and risk of malnutrition during treatment (107). Proactive measures can be taken to maximise nutrition intake and minimise weight loss for those at the highest risk of malnutrition; thereby reducing morbidity and improving survival. Measures, such as nutritional intervention with a dietitian has been shown to minimise weight loss, and improve nutritional status, treatment tolerance and quality of life; leading to improved prognosis (77, 100, 102, 109, 110). In high-risk groups, particularly those with HNC, prophylactic feeding tubes have shown benefit in reducing weight loss during CRT (111-114).

Table 3 summarises the published studies on malnutrition prevalence for those with HNC using the SGA tool to measure the malnutrition risk. Malnutrition prevalence varies widely in Table 3, from 24% to 100%, with an average of 60% in the nine studies presented. When the prevalence of malnutrition is considered at diagnosis, there remains a wide variation with 24% to 68%. When CRT is completed, the prevalence of malnutrition increased substantially to 88 to 100%, shown in Table 3 (69, 115) due to the plethora of side effects and nutrition impact symptoms experienced. At three months after treatment completion, two of the three studies had at least three-quarters of patients remaining severely malnourished (109, 115), in the remaining study over a quarter of patients had an SGA outcome indicating severe malnutrition.

Overall, malnutrition is markedly high for the patient with HNC, particularly on completion of treatment and three months after treatment. As mentioned in the previous sections, this can significantly impact treatment outcomes, quality of life and cost to the health system. Mixed HNC groups and various cancer stages, treatment types, low sample sizes, and the time point when the SGA tool was completed, can explain the considerable variation with malnutrition prevalence presented in Table 3. Results from Table 3 show that the risk of malnutrition for those with HNC is high; it will be of interest to compare results from Table 3 with the degree of weight loss for patients having treatment at ACH.

Table 3 Malnutrition rates in Head and Neck cancers

Citation	Population	Weight loss	SGA outcomes	Malnutrition* %
Read et al. 2006 (89)	Newly diagnosed cancer patients, no prior treatment, mixed diagnosis, n=141 • HNC, n=33, 23%	-	**C** n=2, 6.1% **B** n=13, 39.4% **A** n=18, 54.5%	45.5
Unsal et al. 2006 (69)	RT outpatients, pre, post, 3 and 6 months follow up, n=207 • HNC, n=34	-	**Pre-tx** **B+C** n=8, 23.5% **A** n=26, 76.5%	23.5
			Post-tx **B+C** n=30, 88.2% **A** n=4, 11.8%	88.2
			3-months tx **B+C** n=9, 27.3% **A** n=24, 72.7%	27.3
Koom et al. 2012 (77)	RT patients, 3 weeks into treatment, mixed diagnosis, n=1,000 • HNC, n=286	-	**B+C** n=114, 39.9% **A** n=172, 60.1%	39.9

Arribas et al. 2017 (109)	HNC patients, undergoing CRT, n=20	**During tx** 4.9kg, 7% **3-mths tx** 7.44kg, 10.4%	**Baseline** **C** n=3**, 15%** **B n=3, 15%** **A n=14, 70%**	30
			3-months tx **C** n=8, **40%** **B n=7,35%** **A n=5, 25%**	75
Opanga et al. 2017 (93)	Cancer outpatients receiving treatment, n=471 • HNC, n=87	-	**C** n=9, 10**.3%** **B n=23, 26.4%** **A n=55, 63.2%**	36.7
Mulasi et al. 2018 (115)	HNC patients, undergoing CRT, n=19	**Pre-tx** Significant wt loss 39% (7/18)	**Pre-tx** **C** n=2**, 10.5%** **B n=11, 57.9%** **A n=6, 31.6%**	68.4
		-	**Post-tx** **C** n=8, 47.1% **B** n=9, 52.9% **A** n=0	100
		3-months tx Significant wt loss 86% (12/14)	**3-months tx** **C** n=3**, 21.4%** **B n=10, 71.4%** **A n=1, 7.1**%	92.8

Nitichai et al. 2019 (96)	Cancer patients – outpatient and inpatient, undergoing surgery, chemotherapy and/or RT, n=195 • HNC, n= 48	-	**B+C** n=32, 66.7% **A** n=16, 33.3%	66.7
Marshall et al. 2019 (95)	Cancer patients, receiving treatment, multicentre trial at 2 time points 2012 n=1,677, 17 sites • HNC, n=110, 6.5% 2014 n=1,913, 27 sites • HNC, n=117, 6.1%	-	Data not provided	**2012** 40 **2014** 36
Jager-Wittenaar et al. 2020 (116)	HNC patients, inpatients, treatment not specified, n=59	-	**C** n=**15, 25.4%** **B n=17, 28.8%** **A n=27, 45.8%**	54.2

* Malnutrition is defined as SGA B+C

ABBREVIATIONS: CRT = chemo-radiotherapy, HNC = head and neck cancer, mth = months, RT = radiotherapy, SGA = subjective global assessment, tx = treatment

Malnutrition in UGI cancer patients

UGI cancers include the oesophagus, stomach, small bowel, pancreatic, liver and the biliary system. These areas are essential in the breakdown and absorption of our food and fluids. Dysfunction related to cancer in the digestive organs will likely result in malnutrition. Treatment depends on the diagnosis stage and can be challenging due to the complex anatomy, extent of surgery, multimodal treatment, and often poor prognosis (117).

Stomach, liver, oesophagus, pancreas and gallbladder, respectively, are all in the fifteen leading cancers for new diagnosis and death worldwide. These cancers affect males at rates two to three times more than females, except for gallbladder cancer (19). In NZ, rates of new stomach cancers have dramatically reduced since 1980, liver cancer rates have steadily increased, and those diagnosed with oesophageal and pancreatic cancers have been relatively steady over this period, as seen in Figure 6 (22, 23).

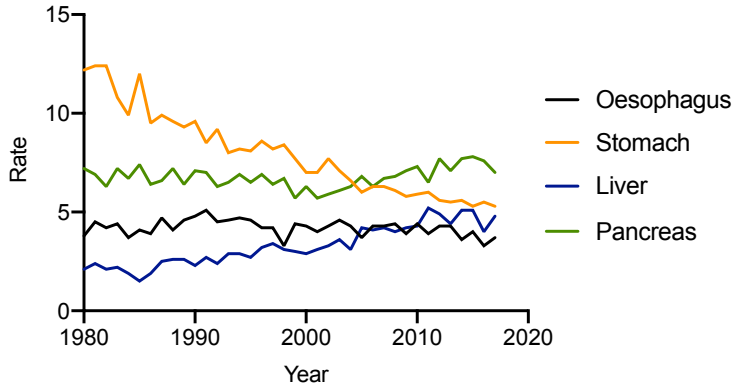

Figure 6 Age-standardised rates of new cases for oesophageal, stomach and pancreatic cancers, NZ, 1980–2017 (22, 23)

Figure 7 demonstrates the dramatic reduction in stomach cancer mortality rates, an increasing rate for liver cancer patients, with no change for those with oesophageal or pancreatic cancer (23). The five-year survival rates of UGI cancers are amongst the poorest of all tumour types, with 4.7% in pancreatic, 11.5% in liver and intrahepatic bile ducts, 11.5% in oesophageal and 21.8% in stomach cancers (99). For those with oesophageal cancer, there is a substantially lower five-year survival for Māori at 6% compared with non-Māori at 12%. For UGI cancers of the pancreas, stomach and liver, there is minimal difference between Māori and non-Māori (99).

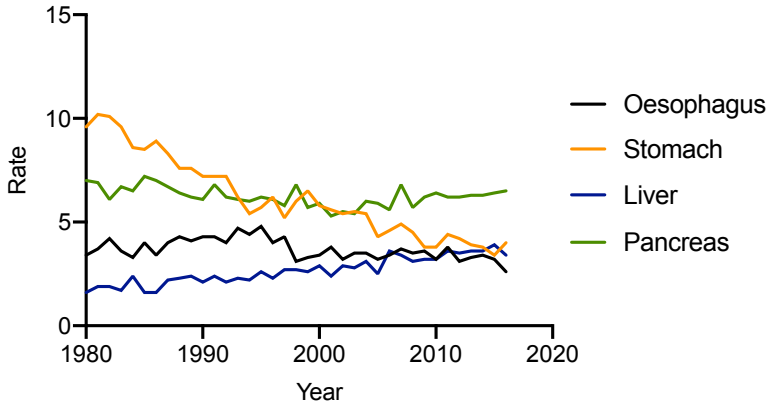

Figure 7 Age-standardised mortality rates for oesophageal, stomach and pancreatic cancers, NZ, 1980–2016 (23)

Frequent nutrition impact symptoms for all UGI cancers include reduced appetite, early satiety, food aversion, impaired utilisation of nutrients, nausea and pain. Nutritional implications following gastric cancer surgery are smaller stomach capacity, dumping syndrome, diarrhoea, vomiting, anaemias, and malabsorption. Potential nutrition consequences for oesophageal cancer are reflux, oesophagitis, dysphagia due to anastomotic stricture, disease recurrence or oedematous, inflamed and swollen tissue as a result of RT. Pancreatic cancer can result in pancreatic insufficiency causing diabetes mellitus and steatorrhoea. The potential consequence of surgery, include pancreatic fistulae, abdominal chyle leaks, and delayed gastric emptying (103). Nutrition impact symptoms from UGI cancers influence a person's ability to maintain adequate nutrition due to the tumour and treatment burden, leading to weight loss and risk of malnutrition (103).

Weight loss before and during treatment for UGI cancers is usual, with half of the patients losing significant weight (118, 119). Bozzetti et al. (120) found that average weight loss for those with stomach cancer was 15%, and those with oesophageal and pancreatic cancers were 16.3 and 16.4%, respectively. Weight was taken at various time points on 1000 patients, including diagnosis, treatment, or a follow-up appointment (120).

Table 4 summarises the published studies with the prevalence of malnutrition for UGI cancer patients using the SGA tool to indicate malnutrition. The average prevalence of malnutrition in Table 4 was 57%, with a wide variation from 14% to 100%. The wide variation for this group reflects the range of UGI cancers, timing of the SGA, e.g., at baseline, during or after treatment, stage of the disease and treatment modality. Results are presented for UGI cancers as a sub-analysis from more extensive studies in 11 of the studies presented; five studies in Table 4 had fewer than 50 participants presenting a limitation with reduced study power and increased margin of error.

Results from Table 4 demonstrate the high level of malnutrition in patients with UGI cancers; nearly 60% experienced malnutrition. Wu et al. (121) showed that those with severe malnutrition experienced 23% weight loss, while those at moderate risk experienced nearly 10% weight loss (121). Persson et al. (122) showed weight loss at near 8% in six months (122). The consequences of malnutrition have been demonstrated in previous sections; ultimately, the consequence is reduced survival (6, 16, 17, 56, 65-67).

Table 4 Malnutrition rates in Upper Gastrointestinal cancers

Citation	Population	Weight loss	SGA outcomes	Malnutrition* %
Persson et al. 1999 (122)	Gastrointestinal and urological tumours outpatients, undergoing chemotherapy n=87 • Gastric, pancreatic, bile duct cancers n=22	**As per SGA score - 6/12** **C** 11.2% **B** 7.5% **A** 4.5% **As per SGA score - 12/12** **C** 14.6% **B** 11.7% **A** 5.4% **Overall** 6-mths = 7.8% 12-mths = 9.8%	**C** n=5, 22.7% **B** n=12, 54.5% **A** n=5, 22.7%	77.2
Read et al. 2006 (89)	Newly diagnosed cancer patients, n=141 • UGI cancer, n=29, 21%	-	**C** n=8, 27.6% **B** n=21, 72.4% **A** n=0, 0%	100

Unsal et al. 2006 (69)	RT outpatients, pre, post, and 6 months follow up, n=207 • Gastric cancer, n=31	-	**Pre tx** **B+C** n=17, 54.8% **A** n=14, 45.2%	54.8
		-	**Post tx** **B+C** n=18, 58.1% **A** n=13, 41.9%	58.1
		-	**6 mths** **B+C** n=4, 13.8% **A** n=25, 86.2%	13.8
Wu, et al. 2009 (121)	Stomach, colon and rectal cancers, prior treatment, n=751 • Gastric cancer, n=384, 51%	**As per SGA score** **C** 23.2% **B** 9.7% **A** 2.2%	**C** n=30, 4.0% **B** n=332, 44.2% **A n**=389, 51.8%	48.2
Koom et al. 2012 (77)	RT patients, 3 weeks into treatment, mixed diagnosis n=1,000 • GIT, including oesophageal cancer patients n=444	-	**B+C** n=169, 38.1% **A** n=275, 61.9**%**	38.1
Silva et al. 2015 (74)	Oncology and palliative care inpatients units, undergoing various treatments n=277 • UGIT n=43, 15.5%	≥ **5% wt loss 6/12** n=20, 47%	**C** n=28, 65.1% **B** n=8, 18.6% **A** n=7, 16.3%	83.7

Klute et al. 2016 (123)	Gastrointestinal carcinoma, having chemotherapy, n=184 • UGI n=57, 31.0%	**>10% wt loss in 6/12** **B+C** n=10 (45.5%) **A** n= 12 (54.5%)	**B+C** n=23, 40.4% **A** n=34, 59.6%	40.4
Esfahani et al. 2017 (124)	Gastric cancer, before chemotherapy, n=71	-	**C** n=27, 38% **B** n=35, 49% **A** n=9, 13%	87
Maasberg et al. 2017 (92)	Neuroendocrine tumours, mixed tumour groups, n=203 • UGIT cancer, n=136, 67%	-	**B+C** n=35, 25.7% **A** n=101, 74.3%	25.7
Opanga et al. 2017 (93)	Cancer outpatients receiving treatment, n=471 • Digestive organs, n=99	-	**C** n =26, 26.3% **B** n=25, 25.3% **A** n=48, 48.5%	51.6
Ozorio et al. 2017 (125)	Digestive system cancers undergoing chemotherapy, n=101 • UGIT n=56, 55% • LGIT n=45, 45%	-	**C** n =16, 15.8% **B** n=48, 47.5% **A** n=37, 36.6%	63.3
Na et al. 2018 (94)	Lung, upper or LGIT cancers undergoing chemo and/or RT, n=1,588 • UGIT, n=844, 53.1%	-	**B+C** n=263, 31.2% **A** n=581, 68.8%	31.2

Nitichai et al. 2019 (96)	Cancer patients - outpatient and inpatient, undergoing surgery, chemotherapy and/or RT, n=195 • Digestive cancers, n=24	-	**B+C** n=21, 87.5% **A** n=3, 12.5%	61.6
Marshall et al. 2019 (95)	Cancer patients, receiving treatment, multicentre trial at 2 time points 2012 n=1,677, 17 sites • UGIT, n=143, 8.5% 2014 n=1,913, 27 sites • UGIT, n=188, 9.8%	-	-	**2012** 61 **2014** 48
Guo et al. 2020 (126)	Gastric cancer, multicentre, hospitalised patients n=2,322	-	**C** n=1047, 45.1% **B** n=820, 35.3% **A** n= 455, 19.6%	80.4

* Malnutrition is defined as SGA B+C

ABBREVIATIONS: 6/12 = 6 months, 12/12 = 12 months, LGIT = lower gastrointestinal tract, RT = radiotherapy, SGA = subjective global assessment, UGIT = upper gastrointestinal tract, wt = weight

Malnutrition in lung cancer patients

In NZ, lung cancer is the fifth most common cancer, with the highest number of deaths amongst all cancer groups (8). Rates of new diagnoses have declined since 2008; however, notable disparities exist between Māori and non-Māori in both new cases and mortality rates, as seen in Figures 8 and 9 (22). These disparities are potentially related to the higher smoking rates of Māori compared to the overall population (32). Five-year survival rates have remained relatively unchanged at 9.8%, with females rates slightly higher than males (99).

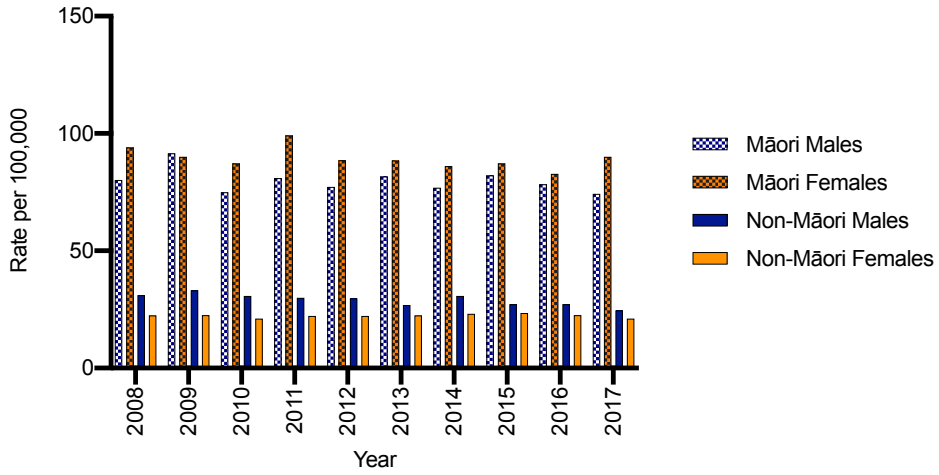

Figure 8 Lung cancer registration rates per 100,000, by ethnic groups and sex, 2008-2017 (22)

Figure 9 shows that the lung cancer mortality rate is over three times higher for both Māori males and females than rates for non-Māori (24).

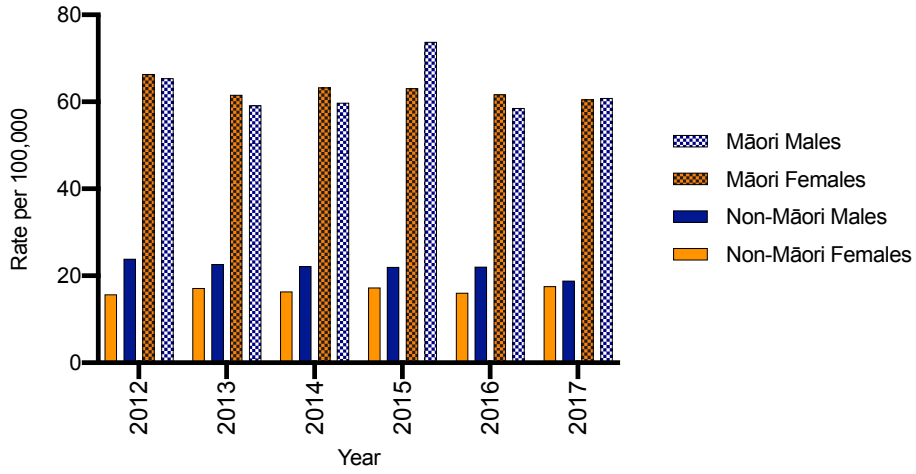

Figure 9 Lung cancer mortality rates per 100,000 population, by ethnic groups and sex, 2012-2017 (12, 24, 127-130)

Treatment options for lung cancer may include surgery, chemotherapy or RT, or any combination of these modalities. Emerging immunotherapies show promise with improved survival, but only when the immune system can recognise cancer cells with the specific genetic mutation (8). Treatment depends on the stage of the disease, weight loss and performance status; with age and comorbidities also considered (8, 131).

With low survival rates for those with lung cancer, treatment burden can be high. Side effects from treatment can range from loss of appetite, nausea, vomiting, fatigue, dysphagia, odynophagia and oesophagitis; all create difficulties in eating for patients. Metabolic disturbance and treatment-induced catabolism contribute to increased nutrient requirements, while anxiety, depression and other psychosocial distress add to the challenges of meeting nutritional requirements. These nutrition impact symptoms compromise a patient's ability to consume sufficient nutrition, leading to increased risk of malnutrition among lung cancer patients (131, 132).

Individualised nutritional intervention and dietary counselling can reduce the prevalence of malnutrition for this high-risk group (133). Treatment of malnutrition may involve various interventions, including intensive nutritional intervention, pharmacology, and physical activity to improve treatment potential and quality of life (8, 29, 133).

Studies investigating malnutrition diagnosed by SGA in lung cancer are shown in Table 5. SGA was used at multiple time points in the various studies, including before, during or months after treatment. Lung cancer patients were a sub-analysis from more extensive studies in six of the 19 studies.

The average prevalence of malnutrition in the 16 studies from Table 5 was 55%, with a wide variation from 7 to 92%. For the studies with advanced-stage lung cancer patients, the prevalence of malnutrition increased to 66% (30, 134-139). The high prevalence of malnutrition is understandable when considering the long list of nutrition impact symptoms related to treatment and tumour burden, and the catabolic nature of lung cancer. Treatment options vary from chemotherapy, combined CRT, immunotherapies, and palliation, reflecting the variety of treatments available, and often dependent on the disease stage (139). Of the studies that presented percentage weight loss, patients experienced around 6% in the previous six months (134, 135, 138). Silva et al. (74) reported that up to 45% of lung cancer patients experienced 5% or greater weight loss. Cehreil et al. (136) reported weight loss in 76% of patients in the past three months; the actual weight loss was not presented. Weight loss leading to malnutrition has a detrimental impact on patient survival (6, 16, 56, 65-67).

Table 5 Malnutrition rates in Lung cancer

Citation	Population	Weight loss	SGA outcomes	Malnutrition* %
Unsal et al. 2006 (69)	RT outpatients, mixed diagnosis, n=207 • Lung cancer undergoing CRT, n=36, 18%	-	**Pre-tx** **B+C** n=12, 33.3% **A** n=24, 66.7%	33.3
			Post-tx **B+C** n=18, 50% **A** n=18, 50%	50.0
			6 mths **B+C** n=4, 12.5% **A** n=28, 87.5%	12.5
Read et al. 2006 (89)	Newly diagnosed cancer patients, mixed diagnosis, n=141 • Lung cancer, n=32, 23%	-	**C** n=3, 10% **B** n=19, 59% **A** n=10, 31%	69.0
Arrieta et al. 2010 (140)	Advanced NSCLC undergoing chemotherapy, n=100	-	**C** n=17, 17% **B** n=34, 34% **A** n=49, 49%	51.0
Klarod et al. 2011 (141)	Newly diagnosed lung cancer, advanced NSCLC n=48, SCLC n=1	-	**C** n=25, 52.1% **B** n=19, 39.6% **A** n=4, 8.3%	91.7

Li et al. 2011 (134)	Lung disease n=148 • Newly diagnosed advanced lung cancer, n=96, 64.9%	**Past 6/12** **C** 6.0% **B** 2.6% **A** 0%	**C** n=39, 40.6% **B** n = 25, 26.0% **A** n=32, 33.3%	66.6
Xará et al. 2011 (139)	NSCLC, outpatients, variety of treatments modality, n=56	**Early stage** n=8, 57.1% gained wt	**Early stage** **B+C** n=1, 7.1% **A** n=13, 92.9%	7.1
		Advanced stage n=22, 52.4% lost wt	**Advanced stage** **B+C** n=19, 45.2% **A** n=23, 54.8%	45.2
Koom et al. 2012 (77)	RT patients, 3 weeks into treatment, mixed diagnosis, n=1,000 • Lung cancer patients, n=270	-	**B+C** n=109, 40.4% **A** n=161, 59.6%	40.4
Sánchez-Lara et al. 2012 (138)	Newly diagnosed advanced NSCLC, before chemotherapy, n=119	8.4% ± 8.7%	**C** n=32, 26.9% **B** n=39, 32.8% **A** n=48, 40.3%	59.7
Silva et al. 2015 (74)	Oncology and palliative care inpatients units, undergoing various treatments, n=277 • Lung n=32, 11.6%	≥ **5% wt loss in 6/12** n=15, 45%	**C** n=10, 31.3% **B** n=17, 53.1% **A** n=5, 15.6%	84.4

Barata et al. 2017 (142)	Lung cancer, inpatients, n=37	-	**C** n=3, 8% **B** n=27, 73% **A** n=7, 19%	81.0
Ma et al. 2018 (10)	Lung cancer patients, completed concurrent chemo RT, n=150	-	**C** n=5, 3.3% **B** n=25, 16.7% **A** n=120, 80.0%	20
Na et al. 2018 (94)	Lung, upper or lower GI tract cancers undergoing chemo and/or RT, n=1,588 • Lung cancer, n=386, 24.3%	-	**B+C** n=165, 42.8% **A** n=221, 57.2%	42.8
Cehreli et al. 2019 (136)	Newly diagnosed advanced NSCLC, before chemotherapy, n=25	**Past 3/12** n=19, 76%	**C** n=8, 32% **B** n=12, 48% **A** n=5, 20%	80.0
Lin et al. 2019 (135)	Advanced lung cancer, baseline and post 4 cycles of chemotherapy, n=465	**During tx** 2.4kg, 3.7%	**Before chemo** **C** n=53, 11.4% **B** n=305, 65.6% **A** n= 107, 23.0%	77.0
			After chemo **C** n=157, 33.8% **B** n=246, 52.9% **A** n=62,13.3%	86.7

Marshall et al. 2019 (95)	Oncology patients, mixed diagnosis and treatment (2012: n=1,677, 17 sites and 2014: n=1,913, 27 sites) • 2012 (17 sites), Lung cancer, n=140, 8.4% • 2014 (27 sites), Lung cancer, n=187, 9.8%	-	-	**2012** 37 **2014** 33
Turcott et al. 2020 (137)	NSCLC patients, advanced, newly diagnosed, baseline n=65	-	**B+C** n=25, 38.5% **A** n=40, 61.5%	38.5

* Malnutrition is defined as SGA B+C

ABBREVIATIONS: 6/12 = 6-months, chemo = chemotherapy, CRT = chemo-radiotherapy, GI = gastrointestinal, NSCLC = non-small cell lung cancer, SCLC = small cell lung cancer, RT = radiotherapy, SGA = subjective global assessment, tx = treatment, wt = weight

2.3 NUTRITIONAL INTERVENTION

The impact of malnutrition on cancer patients is convincing, with the increased risk of morbidity and mortality (2-6) and the cost associated with these complications to our health system (57, 86). Timely nutritional intervention by an expert trained in nutrition, a dietitian, can reduce malnutrition; however, as with every health service, this is a limited commodity. This section explores the benefits and international practices for nutrition screening and intervention, and how to focus dietitian resources where they are most needed. Would there be a benefit to the Auckland Regional Cancer and Blood Services to routinely screen for malnutrition and if indicated, offer appropriate nutritional intervention from a dietitian?

2.3.1 NUTRITION SCREENING

A nutrition screening tool aims to identify those at risk of malnutrition. When a patient is identified as high risk for malnutrition, it indicates the need for further in-depth nutrition assessment. Nutrition screening should be completed on diagnosis and during treatment to detect and correct deficiencies promptly (4, 85). There are many screening tools available; these include Mini Nutritional Assessment-Short Form (MNA-SF), Malnutrition Screening Tool (MST), Malnutrition Universal Screening Tool (MUST), and Nutrition Risk Screening 2002 (NRS-2002) (5). The PG-SGA tool and PG-SGA Short Form (PG-SGA SF) can also be used as screening tools (143).

2.3.2 NUTRITIONAL ASSESSMENT

Nutritional assessment tools are applied once the risk of malnutrition or need for dietetic input has been identified. These tools gather information from medical, dietary, psychological and social history, nutrition impact symptoms, physical examination and anthropometry. These assessments enable interventions by a dietitian, based on the individual's requirements and treatment (85). Assessment tools include Mini Nutritional Assessment (MNA) and PG-SGA (143); the PG-SGA tool is a validated, and well-referenced tool initially developed for use in oncology patients (2). The PG-SGA tool evaluates a patient's overall nutrition status and defines specific nutritional interventions based on the score and can show the prevalence of malnutrition when used as a research tool. An SGA score of A is for a well-nourished person, SGA B for mild to moderate malnutrition and SGA C for severe malnutrition; SGA B and C are often combined (SGA B+C) (68).

2.3.3 BENEFITS OF NUTRITION SCREENING AND ASSESSMENT

Screening for malnutrition at regular intervals reflects the changing nature of cancer burden and the treatment impact. Focussed nutritional intervention with a dietitian can minimise and correct nutritional deficits promptly (4, 85). Improving a patient's nutritional status, if compromised, will reduce the frequency of hospital admissions, length of stay, infection rates, and ultimately lower the risk of mortality (84, 85). Improving a patient's nutritional status, if compromised, can reduce the hospital system costs (57, 144-146), using nutrition screening and identifying those with a high risk of malnutrition (11, 147). Identifying malnutrition using the diagnosis-related groups (DRG) code can provide a valuable revenue stream (11). The DRG code for malnutrition is applicable in NZ with dietitians able to identify and code for malnutrition (148).

2.3.4 ENDORSEMENT OF NUTRITION SCREENING AND ASSESSMENT

Dietitians Australia (DA) and Dietitians NZ (DNZ) recommend nutrition screening in all RT patients. Evidence for chemotherapy patients supports screening; further robust research is required due to the lack of research (3, 149). Current studies with chemotherapy patients lack intensive, individualised nutritional intervention or a nutrition diagnosis. Current studies have included variable tumour groups and may reflect chemotherapy and cancer (3). Despite the lack of robust research for chemotherapy patients, best practice indicates nutrition screening is beneficial for all oncology patients, unless in their last days of life. The nutrition screening tool recommended by DA and DNZ for oncology patients is the MST; it is validated and reliable for oncology patients (149).

The European Society for Clinical Nutrition and Metabolism (ESPEN) guidelines strongly recommend using nutrition screening for all cancer patients (5). A position paper from the Italian Society of Medical Oncology (AIOM) and the Italian Society of Artificial Nutrition and Metabolism (SINPE) on 'Nutritional Support in Cancer Patients' also endorse nutrition screening. It is recommended that nutritional intervention be vigorously managed and directed towards the individual patient (7). The European Society for Therapeutic Radiology and Oncology (ESTRO) and the European Society of Medical Oncology (ESMO) endorse nutrition assessment before and during treatment for lung cancer patients by a trained nutrition expert (8). European guidelines have not specified a specific nutrition screening tool.

The Academy of Nutrition and Dietetics from the United States of America (USA) published the Oncology Evidence-Based Nutrition Practice Guidelines in 2017. There is strong evidence for screening using the MST for all oncology patients, and nutrition assessment using the PG-SGA for those identified at risk of malnutrition (2). The American Society for Parenteral and Enteral Nutrition (ASPEN) also state that patients with cancer should undergo screening for malnutrition risk to ensure that those who require further assessment and intervention are identified (150).

Those with lung, pancreatic, head and neck, or gastrointestinal cancers require special consideration due to the higher prevalence of malnutrition and have been selected in many international guidelines for routine nutritional intervention. Nutritional intervention is recommended before treatment, and at regular intervals during treatment (8, 150-152).

Guidelines on nutrition for oncology patients from NZ, Australia, Europe, and the USA all recommend nutrition screening during the continuum of cancer care; with regular access to nutritional intervention by a dietitian for those at risk of malnutrition. The benefit of reducing malnutrition for both morbidity and mortality are definitive (2-7). The Regional Cancer and Blood Services at ACH should implement nutrition screening, with nutritional intervention for those at high risk of malnutrition. MST is the most appropriate tool for oncology patients; MST is a fast and simple screening tool for untrained staff in the oncology setting (2, 55). It is both valid and highly reliable (2, 149). The PG-SGA tool should be used for nutrition assessment of those identified at risk for malnutrition to plan the appropriate intervention and monitor progress (2, 143).

2.4 COMPLEMENTARY THERAPIES AND MEDICINES

Complementary therapies or integrated medicine are used concurrently with conventional medical treatments, often taken to manage treatment side effects and improve perceived health outcomes (18). Complementary therapies and medicines can range from mind-body techniques such as meditation, acupuncture, body-based techniques such as aromatherapy, reflexology, and biologically-based therapies that refer to substances found in nature, including dietary changes, herbs, vitamins or minerals (153). Social media and the internet are becoming an increasingly popular source of nutrition information; however, patients should have a cautionary approach to the information they provided (154, 155). Deception and dubious practices found on social media and the internet target vulnerable people, particularly those with cancer, in an unregulated business (156, 157).

2.4.1 USE BY ONCOLOGY PATIENTS

There is limited research on complementary medicines used in NZ, particularly in oncology patients. Trevena and Reeder (158) found 32% thought that alternative therapies could be used instead of conventional cancer treatments in a random telephone survey of the general population; however, only 16% could name any form of alternative treatment. One in three patients used some form of complementary medicine, with 29 patients (2.8%) using traditional Māori therapy in a cross-sectional survey in the emergency department (n=1043) at Waikato Hospital (159). Pledger et al. (160) published data from the 2002/2003 NZHS, where 23% of the general population used complementary services; most used a massage therapist and chiropractor over the past 12 months. This study did not investigate the use of biologically based therapies.

In a 2015 qualitative study by Dew et al. (161) of 19 patients who underwent cancer treatment, eight identified as Māori used alternative therapies, with four patients considering their use. There was a greater desire for Māori patients to consider traditional medicines (Rongoā Māori) with conventional treatments, but patients reported a lack of open discussion with medical professionals. The authors attributed a philosophical difference with health care due to whānau influences and cultural dissonance.

Chrystal et al. (162) surveyed biologically based supplement use in NZ oncology patients. Nearly half of oncology patients in Palmerston North and Taranaki Hospitals used some form of complementary medicines. Vitamins, antioxidants, alternative diets and herbal therapies were the most common form. Only 41% had discussed the use of complementary medicines with their oncologist. In a survey of doctors in the Otago region; only 14% of doctors felt their medical training prepared them for incorporating the use of complementary medicines and therapies into their practice, and 27% felt they had sufficient knowledge of products used. Many wanted more knowledge about therapies (58%) and a holistic view of Māori health (62%) (163).

The use of complementary medicines showed considerable variation amongst studies, with the reported use between 17 to 87% of cancer patients (164-167). Typically, complementary therapies are used by around half of cancer patients (168), with a typical patient being female, young, with higher education and income (4, 92, 160, 168, 169). The Clinical Oncology Society of Australia (COSA) released a position statement in 2014 that encouraged medical professionals to discuss the use of complementary medicines with patients openly, direct patients to reputable sources of information, and respect a patient's autonomy decide their outcome (18).

2.5 DIETARY EXPERIENCES AND EXPECTATIONS FOR ONCOLOGY PATIENTS

An essential aspect of cancer care is for the patient to understand the key messages from the health care professional (HCP), and in turn, to feel heard. A tailored nutritional intervention considers the patient's and their whānau's needs for a holistic consultation and acceptance from the patient. It considers multifaceted aspects such as cultural needs, financial constraints, specific dietary requirements to optimise nutritional status (2, 4-6).

Qualitative studies investigating patients' understanding of nutrition and health care messages have found a gap between these two aspects. A study in women with breast cancer found that patients had unexpected and detrimental weight gain during treatment. Patients identified more dietary information and support to mitigate the treatment's adverse side effects (170). Dutch HCPs also supported these findings, with the need for more knowledge about the long-term side effects of breast cancer treatment and weight gain. Researchers reported a need for further information for patients to self-manage their nutritional requirements to prevent the weight gain associated with treatment (171).

The lack of clarity regarding nutrition was seen for males undergoing prostate treatment in the United Kingdom (UK). The men and their partners had a different recall of nutrition advice compared with the HCP's perception. Patients and their partners valued clear, evidenced-based information early into their treatment, contrary to the HCPs' thoughts that the men and their partners might feel overloaded with information initially. Nutritional intervention early into the treatment process was seen as a teaching moment and valued by the participants and their partners (172).

Patients with oesophageal and HNC reported similar themes to those observed in breast and prostate cancers, with a desire for further nutrition advice and support during their treatment. Those with oesophageal cancer were stressed, frightened and concerned by the tumour burden. All patients expressed concern about the degree of side effects and impact on their ability to eat. There was also concern with the lack of dietitian input and guidance. Patients stated a need for individualised support for themselves and their whānau. Conflicting messages between HCP added to the uncertainty and stress they experienced with treatment (173). Marshall et al. (174) also confirmed that patients favoured receiving health information in various forms, including personalised HCP input based on their requirements, with written information and reinforcement. A collaborative intervention with the patient and their whānau in an outpatient or home setting was preferred.

2.6 NUTRITION DURING CANCER TREATMENT AT ACH, GAPS IN THE RESEARCH

Malnutrition is a risk for cancer patients, particularly for high-risk cancers, such as HNC, UGI and lung cancers. Malnutrition can impact the patient's treatment, increase the health system's costs (57, 86), and reduce a patient's quality of life (6, 53, 54, 60-64). International guidelines on nutrition for oncology patients indicate the need for nutrition screening, and when identified as high-risk for malnutrition, nutritional intervention (3, 5, 7, 8, 149-152).

It is also evident from the anecdotal reports to the study author from staff, patients and their whānau that nutrition is a high priority for patients during oncology treatment. Food and diet are something patients can control, with families and friends' support in challenging situations. There is a need to explore the patient's opinion regarding nutrition and risk of malnutrition, treatment side effects and tumour burden. There is also a lack of evidence-based research on the use of complementary medicines in NZ oncology patients.

The level of malnutrition present in oncology patients at ACH is unknown. This thesis will provide the foundation work on malnutrition at the Regional Cancer and Blood Services, ACH. It will investigate weight loss rates in the highest risk patients to establish if these patients experience the same degree of weight loss, as reported in the literature.

A priority for dietitians working in cancer treatment is the personal impact on a patient's food and dietary choices. Unanswered questions for NZ oncology patients include what nutrition advice do patients receive and from whom? Likewise, does the tumour burden or oncological treatments act as a barrier to optimising nutritional status? What is the level of supplement use in patients at the Regional Cancer and Blood Service, ACH? The literature review has endeavoured to investigate these challenges compared to the published peer-review evidence; this thesis intended to examine these themes at a local level.

CHAPTER 3. METHODS

3.1 STUDY AIMS

This Master's thesis explored two themes – weight loss in patients at high risk of malnutrition and patient experiences with nutrition during their oncological treatment at ACH. The first aim was to identify the degree of weight loss experienced in the three groups at the highest risk of malnutrition – HNC, UGI and lung cancers at ACH. The second aim explored the changes to patients' normal dietary behaviours, the rationale for these changes, and where patients received their nutrition information source using a questionnaire.

3.2 STUDY OBJECTIVES

- Identify the degree of malnutrition present in 100 patients within each of the following tumour groups – HNC, UGI, lung – before, during and completion of their oncological treatment at ACH.
- Investigate where and from whom oncology patients receive their nutrition advice during treatment.
- Identify side effects from cancer burden or treatment and the impact on the patient's nutritional status.
- Identify the use of biologically based supplements, e.g., vitamins, minerals, herbal products or dietary supplements, and the disclosure of use to the oncology doctor.

3.3 STUDY DESIGN

This thesis's first component was a quantitative study using a retrospective audit of weight change in 200 patients with UGI or lung cancer (100 in each tumour group) and a prospective audit for 100 patients with HNC, all receiving treatment at ACH. The second component was a prospective observational study with a qualitative questionnaire to any patient receiving oncological treatment at ACH.

3.4 ETHICAL APPROVAL

Auckland Health Research Ethics Committee (AHREC) (reference number: AHREC000132) granted ethical approval on 30 August 2019. He Kamaka Waiora, Waitematā and Auckland DHB - Māori Research Committee approved ethics applications on 5 September 2019 and ADHB Research Review Committee (reference number: A+ 8566) on 19 September 2019, see Appendix A.

3.5 STUDY SETTING

The study location was a single centre study based at Auckland Regional Cancer and Blood Services, Grafton site, ACH.

3.6 STUDY POPULATION

Participants in both the audit and respondents to the questionnaire had a cancer diagnosis and underwent oncological treatment at ACH. The weight change audit focussed on patients with one of the following diagnoses: HNC, UGI or lung cancer.

3.7 AUDIT

An audit on weight change was used to establish the degree of weight loss experienced in the three groups identified as at the highest risk of malnutrition (i.e., HNC, UGI and lung) compared with the prevalence of malnutrition and weight loss in peer-reviewed literature. While a crude method to establish nutritional status, it will provide a foundation for further investigations on the barriers faced by oncology patients at ACH to achieve weight stability during treatment.

3.7.1 ELIGIBILITY CRITERIA

- Patients having oncological treatment at the Regional Cancer and Blood Services, ACH
- 16 years of age or older
- Cancer diagnosis:
    - HNC (ICD-10-CM C00-C14)
    - UGI (ICD-10-CM C15-17)
    - Lung (ICD-10-CM C34)

3.7.2 EXCLUSION CRITERIA

- Receiving palliative cares
- Oncological treatment outside ADHB catchment area

3.7.3 DATA EXTRACTION

An official request was submitted to the Health Information and Technology (HIT) Service at ADHB for data extraction of National Health Indexes (NHI) for patients undergoing oncological treatment for UGI or lung cancer from 1 January 2018 until 31 October 2019.

The complete list of NHIs supplied by the HIT service was randomised using an online randomising tool (www.random.org/lists). Each NHI was manually reviewed by the study author using the ADHB electronic clinical notes (Concerto and 3M) to establish if participants met the study inclusion criteria. Data were extracted from the ADHB electronic clinical records into a Microsoft® Excel® spreadsheet until the target of 100 participants in each tumour group was achieved.

Patients with HNC undergoing RT have weekly dietitian input as part of the standard treatment protocol; data were extracted prospectively by the study author after each review appointment from 01 January 2019 until complete data on 100 patients was obtained and entered into a Microsoft® Excel® spreadsheet.

3.7.4 OUTCOME MEASURES

The primary outcome measure was weight change as a percentage and in kilograms (kg). Weight was recorded at three points, usual weight, weight on diagnosis and treatment completion or final recorded weight on 31 January 2020. The study author completed a thorough investigation of electronic clinical notes (Concerto and 3M) to obtain the full data collection on height (cm), weights (kg), gender, ethnicity, tumour group, date of birth and death, if applicable, until completion of the audit on 31 January 2020. Usual weight was defined as a weight taken at least six months before the cancer diagnosis. The usual weights were found in electronic medical records, including General Practitioner (GP) referrals or other DHB services. BMI (kg/m^2) was calculated from the data extracted. The author of the study entered the information into a spreadsheet on Microsoft® Excel®. Data collection continued until full data collection for 100 patients within each tumour group was completed.

A second official request was submitted to the HIT service to establish if the randomly selected patients with UGI or lung cancer had a dietetic consultation at ADHB, either as an inpatient or outpatient.

3.7.5 STATISTICAL ANALYSIS

Data are presented as mean ± standard deviation (SD), mean ± standard error of the mean (SEM) or, for non-normal data, median (range). Groups were compared using one-way analysis of variance (ANOVA) for continuous variables, Kruskal-Wallis test for skewed continuous data, and chi-squared or Fisher's exact test for categorical data. Pairwise comparisons were made using Student's t-test when ANOVA was significant or Mann-Whitney U-test after a significant Kruskal-Wallis test. The analysis was performed using SAS v.9.4 (SAS Institute, Cary, NC). P values <0.05 indicated statistical significance.

3.8 QUESTIONNAIRE

The second component of this thesis added patients' opinions of their nutritional needs while undergoing oncological treatment using a questionnaire. The questionnaire's purpose was to understand the nutritional implications of a cancer diagnosis, cancer treatment and tumour burden, and the self-assessed risk of malnutrition. It was designed to explore from whom patients receive their nutrition advice; changes patients have made to their usual diet and rationale for these dietary changes and use of biologically based complementary medicines.

3.8.1 QUESTIONNAIRE DEVELOPMENT

A questionnaire was chosen rather than face-to-face interviews to ensure a larger sample size and avoid interviewer bias when sensitive questions about food and nutrients were asked by the study author – a dietitian (175). The choice to offer both paper and electronic versions of the questionnaire enable increased response rates; questionnaires could be completed while waiting for their appointments or treatment. Paper and electronic questionnaires are comparable in terms of the outcome data collected (175).

The electronic questionnaire was published using Qualtrics (Version October 2019 of Qualtrics, Provo, UT, USA. http://www.qualtrics.com), including a suitable view for mobile phones. Access was using a QR code or a URL address – bit.ly/NutritionHaveUrSay. The questionnaire contained no identifiable markers; it was designed to be anonymous as clearly stated on the participant information sheet (PIS) to mitigate privacy concerns (175); completing the questionnaire was consent.

Questions were designed with fewer than 20 words and avoided complex medical terminology or abbreviations, to ease understanding and avoid misinterpretation. Use of 'unsure' was limited to avoid non-responses; the phrase was used in two instances, treatment types (Q7) and the standardised MST (Q14) (176). Free text boxes were available for questions relating to supplement use, dietary changes and the rationale for these changes; this style allowed an in-depth and non-judgemental response. Free text boxes were limited with the awareness these questions are difficult to analyse but offer valuable insight from patients (177).

Section A included demographic questions adopted from the 2013 NZ Census (178). Section C incorporated questions from validated nutrition assessment tools. The MST is a validated and reliable tool to assess malnutrition risk in cancer patients (2, 55, 149). Nutrition impact symptoms in this question were from the 'symptoms' box of the PG-SGA form (143). These symptoms were added to create a nutrition impact point score described in the PG-SGA form (143).

Consultation from an expert panel of dietitians, researchers and clinicians regarding the questionnaire design was sought. The questionnaire was then peer-reviewed by the expert panel and then pre-tested on five participants for comprehension and understanding (176).

3.8.2 QUESTIONNAIRE STRUCTURE

The paper copy was four pages in length (Appendix B) and 500 copies were printed. The questionnaire was published as an online version, using the platform Qualtrics. (Version October 2019 of Qualtrics, Provo, UT, USA. http://www.qualtrics.com).

The online and paper questionnaires were in English; however, a nominated spokesperson could complete the questionnaire; the first question gained consent for the spokesperson to complete the questionnaire on the patient's behalf.

The questionnaire contained three sections.

Section A: 'personal history.'

This section included demographic questions of gender, ethnicity, age, (Q1-3, respectively) as recorded in the 2013 NZ Census (178). Other demographic information included domicile DHB, cancer diagnosis, and the time since the first cancer diagnosis and the associated treatments (Q4-7, respectively).

Section B: 'expectations towards food and nutrition.'

This section explored if the participant had received nutrition advice and the source of nutrition information (Q8). Biologically based complementary medicines (Q9-12) and disclosure of their use to the oncologist was included (Q13). Participants listed the supplements taken in a free text box; each supplement was counted.

Section C: 'treatment symptoms affecting your food choices.'

The final section enabled self-assessment of malnutrition risk using the MST form (Q14) (55), followed by nutrition impact symptoms from the 'symptom' box in the SGA form (Q15) (143). Dietary changes made, and the rationale for these changes (Q16) was included as free text questions to allow for in-depth responses (177).

3.8.3 PARTICIPANT INFORMATION SHEET

The PIS (Appendix C) explained the rationale for the questionnaire, ethics approval, contact details for the study author and the supervisor. The PIS explained that the questionnaire was anonymous and once completed, could not be withdrawn as no identifiable markers were included. The PIS was available as a paper copy, or on posters using the QR code or shortened URL address (bit.ly/NutritionHaveUrSay). The online version and paper copy were identical. The PIS was written in English; the option for the non-English speaking patients was to allocate a nominated spokesperson to translate questions, a checked box from the patient acknowledged consent.

3.8.4 ELIGIBILITY CRITERIA

- 16 years or older
- Receiving oncological treatment at Cancer and Blood Services, ACH

3.8.5 EXCLUSION CRITERIA

- No cancer diagnosis
- Oncological treatment outside ADHB catchment area

3.8.6 SAMPLE SIZE CALCULATION

Patient numbers provided by the HIT service indicate under typical circumstances approximately 1200 patients receive chemotherapy and a further 400 patients attend RT treatment monthly. All adults receiving oncological treatment at ACH were eligible to complete the questionnaire during a designated month. It is reasonable to assume a 20% response rate which translates to 320 questionnaires expected over one month.

3.8.7 PARTICIPANT RECRUITMENT

All patients who had oncological treatment at ACH from 1 October to 01 November 2019, who met the inclusion criteria were eligible to complete the ‘questionnaire.

3.8.8 PROMOTION MATERIAL

The questionnaire was promoted with posters on display in Auckland Regional Cancer and Blood services on the Grafton site at ACH in the following locations – medical review clinics, treatment locations in both medical and radiation oncology outpatients and the infusion room. The advertising material is provided in Appendix D. Posters provided access to an online version of the PIS and questionnaire, using a QR code and a shortened URL address (bit.ly/NutritionHaveUrSay). Administration staff, nurses and radiation therapists actively promoted and distributed the PIS and questionnaire to patients in the designated locations.

3.8.9 DISTRIBUTION AND COLLECTION

All patients attending oncology outpatients at the Grafton site, ACH, for treatment or a medical review appointment had the opportunity to complete the questionnaire. A total of 500 copies of the PIS and questionnaire were printed and available from receptions. Patients could collect the PIS and questionnaire at five strategic locations including two reception desks at medical review clinics, radiation treatment waiting room, chemotherapy reception and the acute oncology location. Participants were encouraged to complete only one questionnaire, as reinforced on the PIS and posters.

Staff in the oncology department actively distributed the questionnaire while patients were having treatment. The administration staff placed a paper copy of the PIS and questionnaire with the chemotherapy prescription for the patients to complete while having their chemotherapy infusion. The RT administration staff gave a copy of the PIS and questionnaire to patients while waiting for their treatment and radiation therapist also distributed while patients were waiting for their radiation treatment. Administration staff offered a questionnaire to patients while they waited for their doctor review appointments.

Collection of the questionnaires was in marked boxes at the five locations in the Oncology department, including the doctors review clinics for both RT and medical oncology, treatment areas for both chemotherapy and RT, and the fifth collection box was located in the infusion room. Collection boxes identified the study name and study author's contact details [Appendix E]. Boxes were located with the paper copies of the questionnaire and were securely fastened with cable ties and cleared daily by the study author.

3.8.10 ANALYSIS OF THE QUESTIONNAIRE

Results from the paper questionnaire were entered into an electronic version using Qualtrics Survey Software (version October 2019, Qualtrics, Provo, UT, USA, http://www.qualtrics.com), by the study author. Results of the online version and manually entered questionnaire were then combined into one version, using Qualtrics. These results were then exported into a Microsoft® Excel® spreadsheet for further analysis.

Quantitative analysis of the questionnaire

Data are presented as the number of patients (%) or median (range). Comparison of the SGA scores between groups was made using the Mann-Whitney U-test. The analysis was performed using SAS v.9.4 (SAS Institute, Cary, NC). P values <0.05 indicated statistical significance.

Qualitative analysis of the questionnaire

Responses to the free text box on dietary changes with a cancer diagnosis and treatment and the rationale for these changes (Q16) were exported into a Microsoft® Excel® spreadsheet for analysis. The analysis was performed using the general inductive approach described by Thomas 2006 (179). Responses were studied on multiple occasions for opinions and concepts for the dietary changes and the rationale for these changes. Within each response, identification and coding of meaningful phrases and keywords were noted. Groups of repeated phrases and keywords established common themes and recurrent philosophies within the text. Each theme was refined and then defined; questionnaire responses were sorted and coded into each of the main themes. A conceptual map was used to sort the questionnaire responses; these responses were analysed and categorised according to repeated concepts and themes using the map [Appendix F].

3.8.11 OUTCOME MEASURES

- Degree of malnutrition for oncology patients at ACH using self-assessed MST.
- Potential side effects from cancer and treatment burden leading to nutrition impact symptoms identified from the SGA form.
- From whom do patients receive their nutrition advice.
- Use of biologically based complementary medicines.
- Dietary changes made and the rationale for these changes.

CHAPTER 4. RESULTS

4.1 AUDIT

4.1.1 PATIENT CHARACTERISTICS

Data extraction was completed on 300 patients in the three groups at high risk of malnutrition - HNC, UGI and lung cancer at ACH. Table 6 shows the patients' demographic characteristics, with a relatively even spread between males and females with UGI and lung cancers, but significantly more males had HNC. There was a statistically significant age difference across the three groups of cancer patients; however, as those with lung cancer were only three to four years older than the other groups, this difference is unlikely to be clinically significant for treatment or outcomes.

Overall, a higher proportion of patients identified as European, particularly in those with HNC. Patients who identified as Māori and Asian appear overrepresented in the lung cancer group compared to those with HNC and UGI cancers.

Table 6 Demographic characteristics of cancer patients

	HNC	**UGI**	**Lung**	**P value**
	n=100	n=100	n=100	
Gender				<0.0001*
Male	87	59	55	
Female	13	41	45	
Age, y				
Mean ± SD	62.8 ± 10.0 [a]	63.0 ± 12.1 [a]	66.4 ± 8.8	0.021**
Range	34.3 – 85.9	28.1 - 82.8	42.2 - 85.9	
Ethnicity				0.0002*
European	77	50	44	
Māori	11	15	20	
Pacific people	1	12	10	
Asian	9	19	25	
Middle Eastern	-	1	1	
Not Stated	2	3	-	

ABBREVIATIONS: HNC=head and neck cancer, UGI=Upper gastrointestinal cancer, SD=standard deviation, y=year
**ANOVA
*Chi-square test.
[a] P<0.05 for comparison with lung

4.1.2 WEIGHT CHANGE

Baseline characteristics between the three groups showed significant differences in height and well weight; however, BMI was similar between the groups [Table 7]. Start of treatment and final weights for UGI and lung cancer patients were significantly lower than those with HNC.

Table 7 Patient characteristics for three types of cancer

	HNC	UGI	Lung	P value
	n=100	n=100	n=100	
Height (cm)				
Mean ± SD	174.7 ± 9.3	169.3 ± 9.6 [a]	168.2 ± 9.6 [a]	<0.0001
Range	146 – 197	151 – 196	140 – 187	
Well weight (kg)				
Mean ± SD	83.7 ± 17.5 [b]	82.0 ± 18.3 [b]	76.8 ± 18.0	0.018
Range	49 – 148	53 – 149.1	40 – 126.1	
BMI (kg/m^2)				
Mean ± SD	27.3 ± 4.9	28.5 ± 5.5	27.1 ± 5.9	0.145
Range	17.3 – 39.9	19.2 – 46.0	17.2 – 48.6	
Start treatment weight (kg)				
Mean ± SD	81.9 ± 17.8	75.2 ± 17.6 [a]	73.6 ± 17.5 [a]	0.002
Range	48 – 147.6	47 – 141.2	40.7 – 116	
Final weight (kg)				
Mean ± SD	78.4 ± 17.1	68.3 ± 16.8 [a]	70.7 ± 17.9 [a]	0.0001
Range	45 – 148.5	33.1 – 121	33.6 – 114	
Weight change – pre-treatment				
Mean ± SD (kg)	-1.8 ± 3.3 [c]	-6.8 ± 6.8	-3.2 ± 5.6 [c]	<0.0001
Range (kg)	-13 – 6	-29.1 – 12.5	-22 – 14.6	
P value	<0.0001	<0.0001	<0.0001	
Mean ± SD (%)	-2.2 ± 3.9 [c]	-8.1 ± 7.9	-4.0 ± 6.8 [c]	<0.0001
Range (%)	-15.7 – 6.6	-29.0 – 18.1	-18.8 – 19.2	
P value	<0.0001	<0.0001	<0.0001	
Weight change – during treatment				
Mean ± SD (kg)	-3.5 ± 3.9 [c]	-6.9 ± 10.4	-2.9 ± 7.7 [c]	0.0006
Range (kg)	-15.1 – 2.1	-64.6 – 11.5	-39.1 – 12.9	
P value	<0.0001	<0.0001	0.0003	
Mean ± SD (%)	-4.1 ± 4.7 [c]	-8.7 ± 11.9	-3.7 ± 9.8 [c]	0.0002
Range (%)	-20.7 – 2.7	-45.8 – 14.3	-42.4 – 19.4	
P value	<0.0001	<0.0001	0.0002	
Weight change – overall				
Mean ± SD (kg)	-5.4 ± 5.0 [c]	-13.7 ± 12.1	-6.0 ± 9.2 [c]	<0.0001
Range (kg)	-3.8 – 24.2	-21 – 72.5	-23.6 – 44.4	
P value	<0.0001	<0.0001	<0.0001	
Mean ± SD (%)	-6.3 ± 5.8 [c]	-16.8 ± 12.5	-7.6 ± 11.1 [c]	<0.0001
Range (%)	-29.5 –5.0	-48.6 – 30.4	-42.8 – 31.1	
P value	<0.0001	<0.0001	<0.0001	
Tx timeframe				
Median (mths)	2.0	7.0 [a]	8.5 [a]	<0.0001
Range (mths)	0.9 – 3.2	0.7 – 54.1	0.8 – 81.5	
Dietitian review	100	34	16	<0.0001

ABBREVIATIONS: HNC = head and neck cancer, kg = kilogram, mths = months, SD = standard deviation, UGI = upper gastrointestinal cancer

[a] P<0.05 for comparison with HNC

[b] P<0.05 for comparison with lung

[c] P<0.05 for comparison with UGI

Weight changes in kilogram and percentage of 'well' weight for those with HNC, UGI and lung cancers are shown in Table 7. For the comparison between the three groups, weight change was expressed as a percentage, as shown in Figures 10 to 12. All three groups experienced significant weight loss (absolute and percentage). Patients with UGI cancer lost 8.1% weight before treatment started, with a wide variation of weight change, as seen in Figure 10 and Table 7. Those with HNC lost 2.2%, and 4% for lung cancer patients before treatment, as seen in Figure 10 and Table 7.

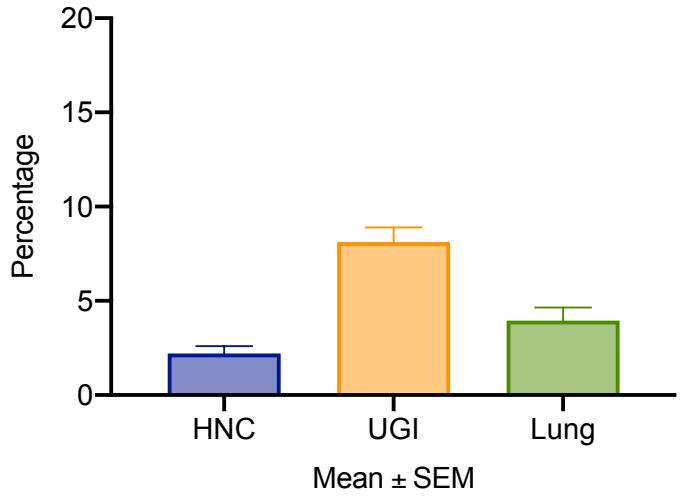

Figure 10 Percentage weight loss before treatment in patients with HNC, UGI and Lung cancers (mean ± SEM)

Figure 11 displays further weight loss experienced by patients as they undergo cancer treatment to the head and neck, UGI and lung area. Patients with UGI cancer experienced 8.7% (6.9kg) weight loss during treatment, which was significantly higher ($P<0.005$) than those with HNC and lung cancer, at 4.1% (3.5kg) and 3.7% (2.9kg), respectively. Figure 11 and Table 7 also show despite this significant weight loss during treatment, 34% of UGI cancer patients and 16% of lung cancer patients had nutritional intervention with a dietitian at ACH, compared with 100% of the HNC patients.

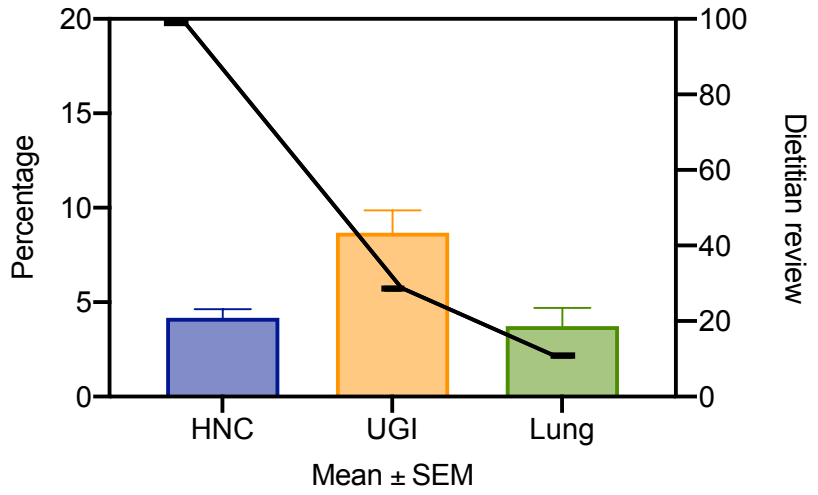

Figure 11 Percentage weight loss during treatment in patients with HNC, UGI and Lung cancers (mean ± SEM). Black line indicates number of patients receiving dietitian review.

Overall weight loss from well weight until the final weight for those with UGI cancer was significantly more (16.8%, 13.7kg) compared to patients with HNC (6.3%, 5.4kg; P<0.05) and lung cancer (7.6%, 6kg; P<0.05) [Table 7, Figure 12].

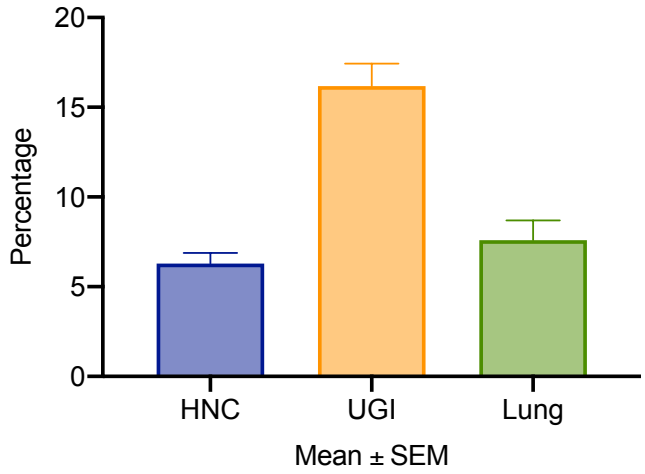

Figure 12 Overall percentage weight loss for patients with HNC, UGI and Lung cancers (mean ± SEM)

4.2 QUESTIONNAIRE

Two hundred and ninety patients responded to the questionnaire, 34 (12%) used the online format, and 256 (88%) responded with the paper format. The expected response rate was 20% of the 1600 patients having oncological treatment at ACH in one month; the actual response rate was 18%.

4.2.1 PATIENT CHARACTERISTICS

Table 8 shows that slightly more males responded to the questionnaire compared to females. The majority (67.3%) of participants were over 60 years and identified as of European descent (72.1%). For ethnicity, 13 participants selected two ethnicities (n=9 NZ European and Māori, n=3 Māori and Pacific People, n=1 NZ European and European) and one selected three ethnicities (Asian, European, Māori). If Māori was selected this defaulted as the primary ethnicity (n=13), and European for the remainder (n=1).

Genitourinary cancers include prostate, bladder, and kidney. Gastrointestinal cancers include the oesophagus, pancreas, stomach, colon, rectum, anus, liver, biliary system, and small intestine. A broad range of tumour groups was seen, but the majority presented with gastrointestinal or breast cancers, 21.5% and 21.1%, respectively.

Table 8 Questionnaire – demographic details, section A

	n=290 (%)
Gender	
Male	163 (56)
Female	122 (42)
Not specified	5 (2)
Age	n=290 (%)
18 – 29	6 (2.1)
30 – 39	15 (5.2)
40 – 49	19 (6.6)
50 – 59	55 (19.0)
60 – 69	93 (32.1)
70 – 79	82 (28.3)
>80+	20 (6.9)
Ethnicity	n=290 (%)
European	209 (72.1)
Māori	36 (12.4)
Pacific	18 (6.2)
Asian	23 (7.9)
Other*	4 (1.4)
DHB	n=290 (%)
ADHB	98 (33.8)
CMDHB	70 (24.1)
NDHB	28 (9.7)

WDHB	92 (31.7)
Unsure	2 (0.7)
Time since cancer diagnosis	n=290 (%)
Less than 3 months	42 (14.5)
3 to 6 months	73 (25.2)
6 to 12 months	57 (19.7)
12 to 18 months	26 (9.0)
More than 18 months	89 (30.7)
Not specified	3 (1.0)
Types of cancer**	n=298 (%)
Brain	7 (2.3)
Breast	63 (21.1)
Gastrointestinal	64 (21.5)
Genitourinary	39 (13.4)
Gynaecological	30 (10.1)
Haematological	7 (2.3)
Head and neck	11 (3.7)
Lung	31 (10.4)
Melanoma and non-melanoma skin	10 (3.4)
Others***	11 (3.7)
Not specified	24 (8.1)
Types of treatment	n=290 (%)
Surgery alone	7 (2.4)
Chemotherapy alone	53 (18.3)
Radiotherapy alone	28 (9.7)
Surgery + Chemotherapy	74 (25.5)
Surgery + RT	32 (11.0)
Chemotherapy + RT	38 (13.1)
Not specified	2 (0.7)

* Other includes Kenyan, Brazilian, and 2 did not specify
** Two primary cancers n=8
*** Others include neuroendocrine tumour n=3, dorsal hand scc n=1, pituitary adenoma n=1, sarcoma n=5, spindle cell n=1

4.2.2 SUPPLEMENT USE

Supplement use is commonplace in cancer patients; nearly half of the patients used some form of a supplement (49.7%), as seen in Table 9 and Figure 13. Of the five patients (1.7%) who consumed ten or more biologically based supplements, none discussed the use with their doctor, of the 17 (5.9%) who used five to nine supplements, 11 discussed this with their doctor, five did not, and one did not respond. Supplements included herbal products, vitamins, minerals, and other dietary supplements, including prescribed supplements.

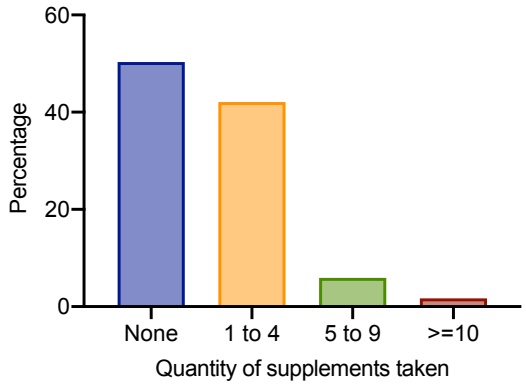

Figure 13 Frequency of biologically based supplements

4.2.3 NUTRITION ADVICE

A total of 61% of oncology patients received advice regarding their nutrition. The majority of patients received this advice from their oncology doctor at 46.9%, followed by nursing staff at 28.8%, dietitians within the hospital and community settings were third at 27.1%, followed closely behind family and friends with 26.6%, shown in Table 9.

Table 9 Questionnaire – nutrition experiences with cancer treatment, section B

Nutrition advice	n=290
Yes	177 (61.0)
No	112 (38.6)
Not specified	1 (0.3)
From whom	n= 177
General Practitioner	27 (15.3)
Oncology Doctor at ACH	83 (46.9)
Friends / family	47 (26.6)
Internet	27 (15.3)
Private Practice Nutritionist	8 (4.5)
Dietitian	48 (27.1)
Alternative Health Practitioner/Naturopath	14 (7.9)
Nurses	51 (28.8)
Cancer Society	17 (9.6)
Other	15 (8.5)
Quantity of supplements taken	n=290
None	146 (50.3)
1 to 4	122 (42.1)
5 to 9	17 (5.9)
≥ 10	5 (1.7)
Supplement use	n=144
Herbal products	53
Vitamins	85
Minerals	55
Dietary Supplements	74
Discussed with Doctor	n=290
Yes	87 (30)
No	86 (29.7)
Not specified	117 (40.3)

Data are number of patients (%)

4.2.4 MALNUTRITION RISK

Table 10 includes the questionnaire results for the self-assessed MST and SGA. Using the MST, 38.3% were at risk for malnutrition (MST $\geq$ 2). Of the 54 patients (18.6%) who scored at risk for malnutrition (MST = 2), seven patients (2%) saw a dietitian. For the 57 patients (19.7%) who self-diagnosed at high risk for malnutrition using the MST (MST 3-5), only 18 patients (6%) saw a dietitian. When looking at the SGA score, 14.1% were in the high-risk group (SGA C), and when combined with moderate risk (score B+C), the total increased to 47.2% [Table 10].

Comparison of the SGA scores across the weight loss categories from the MST showed that for patients with five kilograms or less weight loss the SGA score (median: 1, range: 0-17) was significantly lower than for patients with six to ten kilograms weight loss (median: 4.5 range: 0-15, $p<0.0001$) and for patients with more than ten kilograms weight loss (median: 5, range: 0-14, $p=0.0008$). SGA scores for the six to ten kilograms and greater than ten kilograms categories did not differ significantly ($p=0.908$).

Table 10 Questionnaire – nutrition screening and status, section C

Have you lost weight recently?	n=290
Yes	142 (49.0)
No	138 (47.6)
Unsure	10 (3.5)
How much weight loss	n-290
≤ 5kg	207 (71.4)
6 to 10 kg	43 (14.8)
>10 kg	29 (10.0)
Not specified/unsure	11 (3.8)
MST score*	n=290
MST 0 – 1 (no risk)	179 (61.7)
MST 2 (at risk)	54 (18.6)
MST 3 – 5 (high risk)	57 (19.7)
Nutrition impact symptoms	n= 290
No appetite	95 (33)
Nausea	59 (20)
Constipation	33 (11)
Mouth sores	30 (10)
Taste changes	84 (29)
Swallowing difficulties	23 (8)
Pain	23 (8)
Vomiting	18 (6)
Diarrhoea	26 (9)
Dry mouth	44 (15)
Feeling full quickly	59 (20)
Other	26 (9)
Nutrition impact score	n=290
Score 0	145 (50.0)
Score 1 to 3	33 (11.4)
Score 4 to 8	85 (29.3)
Score ≥ 9	27 (9.3)
PG-SGA score	n=290
A (0 to 3)	153 (52.8)
B (4 to 8)	96 (33.1)
C (≥ 9)	41 (14.1)

Data are number of patients (%)
* Weight loss (Q14) and reduced appetite (Q15)

Half of the patients experienced nutrition impact symptoms due to treatment or tumour burden, as shown in Table 10 and Figure 14. Nutrition impact score is the addition of each symptom to achieve a total score; however, the legend in Figure 14 indicates the SGA scores from each symptom (143).

Nearly 10% experienced multiple symptoms that would impact their nutrition status, with a nine or greater nutrition impact score [Table 10]. A third of patients experienced a loss of appetite, with 20% having early satiety or ‘feeling full quickly’, as seen in Figure 14.

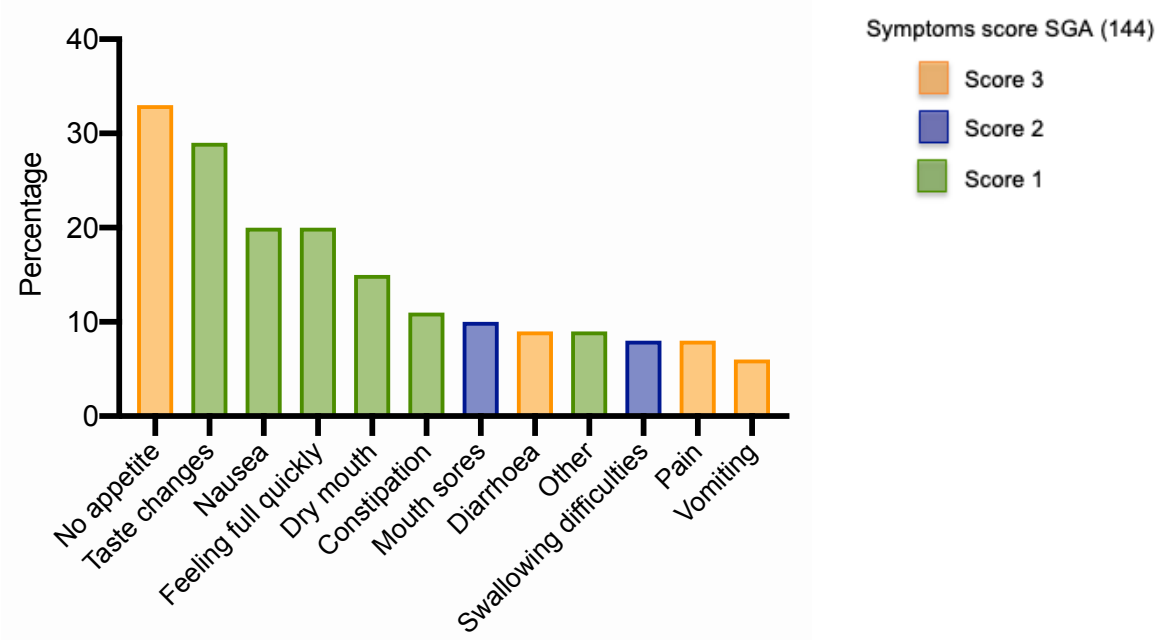

Figure 14 Nutrition impact symptoms experienced by patients

4.2.5 CHANGES TO DIET AND WHY THESE CHANGES WERE MADE

One hundred and eighty-five patients reported changing their diet either as a response to a cancer diagnosis or treatment. The questionnaire responses to dietary change were individually reviewed, and categorised according to the themes identified in the conceptual map in Appendix F. During the triage process, three nutrition focussed themes became apparent; the themes included changes due to treatment side effects, changes to improve health outcomes, and changes due to treatment protocols and procedures.

Changes due to treatment side effects

The majority of respondents reported changes due to the treatment or cancer burden (n=107, 58%). A selection of the typical responses is below, verbatim.

What changes have you made?

> *Much less meat of all sorts, when to sweet [sic] foods under chemo. Slightly more fruit esp apples, passion for cucumber and hummus. Cannot stand green vegetables, so drinking V8 juice.*

Why have you made these changes?

> *Trying to find something, anything, that I did fancy. This remains the same Eaten throughout - baked potatoes with butter and 1-2 cups parsley, chives, puha, mint*

(Female, NZ European, aged 65 – 69 years, breast cancer)

What changes have you made?

I cannot eat a good meal because when I eat my chest gets sore and my breathing is hard.

Why have you made these changes?

Just drinking protein shakes because easier to digest

(Female, Māori, aged 40 – 44 years, breast cancer)

What changes have you made?

Avoid oils, spicy food.

Why have you made these changes?

Vomiting

(Female, Indian, aged 25 – 29 years, Ewing's sarcoma)

What changes have you made?

Not wanting food at all. Smell puts me off food.

Why have you made these changes?

Drs orders

(Male, NZ European, aged 60 – 64 years, prostate cancer)

Changes to improve health outcomes

Nearly a third who changed their diet appeared to make changes to improve their overall health outcomes (n=59, 32%). While many responses seemed to be positive changes, and the motivation to change was clear. Some patients made extreme changes to their diets based on minimal to no evidence in the peer-reviewed literature, such as ketogenic diets, avoiding wheat, dairy or sugar, and focusing on fresh juices. A selection of the typical responses is below, verbatim.

What changes have you made?

Did a 6-month juice treatment but stopped recently

Why have you made these changes?

Advised by nutritionist

(Female, NZ European, aged >80+years, peritoneal cancer)

What changes have you made?

Huge, wheatless, dairy-free, meat-free, no processed min fruit (sugar high) Mainly organic vege, fish, nuts, and seeds. No sugar 600ml carrot, beetroot/other colourful vege; fresh juice daily Lots of garlic, cruciferous vege, onion, no nightshades

Why have you made these changes?

Because it is SCREAMINGLY IMPORTANT and yet UTTERLY ignored by all oncologist, who bafflingly treat diet and nutrition as unimportant side-line NZ is miles behind integrated oncology and the attitudes are depressing antiquated and deadly

(Female, NZ European, 40 – 44 years, colon cancer)

What changes have you made?

I am trying to eat much more healthily. I think there should be routine nutrition advice as part of follow up care

Why have you made these changes?

It's up to me to participate in my recovery and help my body fight off the cancer as well as the chemo drugs

(Male NZ European, 65 – 69 years, bowel and prostate)

What changes have you made?

More fresh vegetables. less meat, less processed foods

Why have you made these changes?

Helping my body to fight with cancer

(Female, Chinese, 60 – 64 years, lung cancer)

Changes due to procedures/treatment protocols

A smaller group of patients referred to surgical procedures or health practitioners' recommendations regarding their dietary changes (n=17, 9%). A selection of the typical responses is below, verbatim.

What changes have you made?

I no longer have a stent so have been able to return to a normal diet, from a low fibre diet

Why have you made these changes?

stent has been surgically removed following a right hemi colectomy

(Female NZ European, 50 – 54 years, bowel cancer metastasis to liver)

What changes have you made?

Avoid fibrous food post stent as per Dr Try to eat whatever I can/what will stay down

Eating is very difficult

Why have you made these changes?

-

(Female, NZ European, 70 – 74years, stomach cancer)

What changes have you made?

As recommended on radiation information less dairy (milk) no tea, coffee, fiz, beer

Why have you made these changes?

-

(Male, NZ European, 70 – 74 years, prostate cancer)

What changes have you made?

Slight decrease in amount of food as asked for radiation therapy. No weetbix, beans, etc

Why have you made these changes?

As asked by radiation staff

(Male, NZ European, 75 – 79 years, prostate cancer)

CHAPTER 5. DISCUSSION

Weight loss leading to malnutrition in cancer patients has been recognised for many decades (16, 17); it is clear from the literature that oncology patients are at high risk for malnutrition. The prevalence can vary within the oncology setting depending on the patient's age, tumour type, and disease stage. Those with advanced disease and over 65 years are at highest risk (1). Patients with HNC, UGI and lung cancer are also at significant risk of malnutrition due to the complicated relationship with tumour and treatment burden, combined with the presence of systemic inflammation, anorexia and tissue breakdown (6).

Patients with cancer are often motivated to improve their health and lifestyle after a life-altering diagnosis. There are many drivers for these dietary and lifestyle changes; with social media and the internet providing popular information sources (154, 155). The questionnaire explored the rationale for these changes, if treatment or cancer burden impacts nutritional status, and explores the nutrition needs and expectations of oncology patients at ACH.

5.1 AUDIT

This thesis's first aim was to identify the degree of weight loss experienced before and during treatment in three groups at the highest risk of malnutrition – HNC, UGI and lung cancers – at ACH with 100 patients in each group. The intention was to investigate if these groups at ACH had similar weight loss to the peer-reviewed literature.

5.1.1 STRENGTHS AND LIMITATIONS OF THE AUDIT

This study's strengths include a large cohort of patients with 100 patients in each HNC, UGI and lung cancer group. This research separated the three different tumour types; this enabled the weight change observed in each group to reflect each cancer's risks. Patients with UGI and lung cancer were selected randomly, and the audit data was collected by one researcher with over ten years' experience working as a specialist oncology dietitian.

Limitations with the audit are the different methods of data collection between the three groups. The UGI and lung cancer data were from a random sample of patients and included various disease stages, treatment options and length of treatment times. These groups could have included those with metastatic disease or second-line treatment, with the potential to influence the degree of weight loss. Whereas data from HNC patients were collected consecutively throughout treatment; those with a metastatic disease could have been included, all were having first-line curative-intent treatment.

The final treatment weight for audit purposes was 31 January 2020. If treatment was on-going for the UGI and lung cancer patients past this date, the recorded weight might not reflect the final treatment weight. The actual weight change for the patient could have either been under- or over-estimated.

Use of feeding tubes in any of the groups was not recorded. A small number of patients, particularly those with HNC and UGI cancer, could have a feeding tube to meet their requirements, either prophylactically or reactively. Reactive feeding via a tube is often due to substantial weight loss that has impacted the planned treatment. In contrast, prophylactic feeding enables stable weight, with intensive nutritional intervention and monitoring (111-114).

Despite having 100 patients within each group, this audit was not sufficiently powered to analyse ethnicity data. Patients who identify as Māori are disproportionally represented in adverse patient outcomes for those with cancer, it is unfortunate that this study cannot reduce these health inequalities.

5.1.2 DEMOGRAPHIC DIFFERENCES

The proportion of males with HNC was significantly higher than females with a ratio of 3.8:1; compared with 1.4:1 for UGI and 1.2:1 for lung cancer patients. There was a statistically significant difference in the average age between the three groups; those with HNC were significantly younger than both groups, but only by two months compared to UGI group and 3.6 years younger than the lung cancer group; the gender and degree of age difference are unlikely to result in clinical difference with treatments or outcome measures. These results are similar to global figures with rising HNC rates attributed to HPV; predominantly affecting younger males (37-39), of European descent in the majority (37). HNC patients having treatment at ACH in this audit were more likely to be of European descent (77%) than the Auckland regional distribution at 53.5%, but indicative of the global HPV and HNC patient profile (15).

The ethnic distribution of lung cancer patients showed a lower proportion of patients from European descent 44% in the audit compared with 53.5% in the Auckland region, but a higher proportion of Māori at 20% compared with 11.5% in the Auckland region (15). A possibility for this discrepancy could be an overrepresentation of tobacco use amongst Māori (32). Sadly both the incidence and mortality rates for lung cancer are higher in our Māori population (12).

The UGI cancer group included 50% from European descent, followed by 19% from Asian descent and 15% identified as Māori; similar to the Auckland regional ethnic distribution with 53.5% European and 11.5% Māori, but substantially less than 28.2% of Asian descent (15). UGI cancers are associated with obesity and tobacco use (32, 34), both of which are lower in the Asian population but higher in European and Māori populations (32).

Baseline characteristics showed HNC patients were significantly taller (P <0.0001) than those with UGI and lung cancer; HNC and UGI patients were also heavier using well weight when compared with the lung cancer patients (P=0.018). HNC patients were heavier at the start of treatment (P=0.002) and the final weight (P=0.0001) compared with UGI and lung cancer patients; however, BMI showed no difference, as seen in Table 7. A higher proportion of European males in the HNC group and a higher proportion of Asians in the lung cancer group may explain the height and weight variation; this could be attributed to physiological differences in body composition between ethnicities. While statistically significant, the clinical significance with treatment or outcomes between patients is unlikely.

5.1.3 HEAD AND NECK CANCER – WEIGHT CHANGE

HNC patients in this audit group experienced 2.2% (1.8kg) weight loss before treatment; this continued with a further 4.1% (3.5kg) weight loss during treatment at ACH. The overall weight loss for HNC patients at ACH was 6.3% (5.4kg). All patients with HNC have an intervention with a dietitian before treatment if indicated, from a nutrition screening tool, and weekly during their treatment. The treatment side effects discussed in the literature review explain the constraints patients experience with achieving adequate nutrition during their oncological treatment.

This audit has shown HNC patients undergoing treatment experience substantial weight loss; however, is the weight loss observed comparable to the peer-reviewed literature? Mulasi et al. (115) showed a 5% weight loss for HNC patients during treatment; even when receiving routine nutritional intervention; 88% of patients required a feeding tube at the end of treatment to meet their nutritional requirements. Arribas et al. (109) found a weight loss of 7% during treatment to the head and neck area; with eight patients requiring a feeding tube, and all patients receiving dietitian input. Both studies had small sample sizes (n=19 and n=20, respectively); however, they did include nutritional intervention. These studies reported similar weight loss to data presented in this audit and included routine nutritional intervention.

A limitation of this audit was the lack of comparison with the use of feeding tubes; however, in the author's experience feeding tubes are used in less than 20% of patients undergoing CRT or RT with HNC. It appears from the audit results, patients with HNC at ACH experience similar levels of weight loss during treatment to the peer-reviewed literature.

While still substantial at 6%, overall weight loss was minimised with routine nutritional intervention in patients receiving their RT or CRT for HNC at ACH. According to literature, 60% of patients with HNC are malnourished using the SGA tool after treatment, with minimal improvement three months after treatment completion (109, 115). These high malnutrition rates suggest a need for on-going nutritional intervention for patients with HNC during their treatment, as recommended in oncology nutrition-based guidelines (2, 3, 5, 150-152). Patients remain at risk for a further three months post-treatment based on the prevalence of malnutrition in these studies; this strongly indicates the need for further intervention in the post-treatment recovery phase (151, 152). In future, SGA would be a more accurate tool to monitor changing nutritional status than weight change; enabling malnutrition trends over treatment and recovery to be monitored.

5.1.4 UPPER GASTROINTESTINAL CANCER – WEIGHT CHANGE

Weight loss in UGI patients before treatment was 8.1% (6.8kg), this continued during treatment with a further 8.7% (6.9kg); both significantly higher than those with HNC and lung cancer. The overall weight loss in UGI cancer patients was 16.8% (13.7kg); significantly higher than the lung and HNC groups. The UGI area is involved with digestion and absorption; unintentional weight loss is often exacerbated by the inability to consume sufficient nutrition, combined with the risk of maldigestion and malabsorption (117). In the 100 patients having treatment, one-third (n=34) received nutritional intervention at ACH.

Those with UGI had the most statistically significant degree of weight loss at all time points compared to those with HNC and lung cancer. Malnutrition can be diagnosed as unintended weight loss of greater than 5% in one month or 10% in six months (43-46). Many UGI cancer patients could be diagnosed as malnourished with a significant degree of weight loss in this audit. When comparing the weight loss in UGI patients from this audit with the literature, Persson et al. (122) found that weight loss was between 8% to 10% over a six- to twelve-month period. Wu et al. (121) had similar findings with between 10% to 23% weight loss. The higher degree of weight loss was observed in those with severe malnutrition (SGA C). Silva et al. (74) and Klute et al. (123) found over a third of participants lost 5% weight in six months. Klute et al. (123) reported a further 25% of participants experienced over 10% weight loss in six months. These studies show a high amount of weight loss over a six to twelve-month timeframe, consistent with weight loss in this audit of UGI cancer patients.

When considering the degree of weight loss with the prevalence of malnutrition using the SGA tool, results suggest nearly 60% of patients with UGI cancer experience moderate to severe malnutrition as seen in Table 4; prevalence can vary depending on tumour type, disease stage and treatment options (117). Weight loss amongst the UGI cancer patients at ACH was statistically significant; when combined with SGA results from the peer-reviewed literature, this patient group is at substantially high-risk for malnutrition, before, during and after cancer treatment. Malnutrition can result in worse outcomes regarding morbidity and mortality (2-6), with poor survival outcomes for this tumour group (99).

Given the audit results, combined with the high prevalence of malnutrition, as per SGA results in the peer-reviewed literature and the recommendations from nutrition-based guidelines for oncology (2, 3); this group could be expected to benefit from early and regular nutritional intervention during treatment. The options for increasing input for these patients could include using the MST at diagnosis and repeated at clinic reviews, with a referral for timely nutritional intervention.

5.1.5 LUNG CANCER – WEIGHT CHANGE

Lung cancer patients experienced 4.0% (3.2kg) weight loss before treatment, with a further 3.7% (2.9kg) during treatment. The overall weight loss for lung cancer patients was 7.6% (6.0kg); with only 16% of patients receiving nutritional intervention from a dietitian at ACH. Often patients with lung cancer experience multiple treatment symptoms that can limit nutrition intake, at a time when there is increased nutritional requirements due to metabolic disturbance and treatment-induced catabolism (131, 132).

In contrast, Sánchez-Lara et al. (138) found that weight loss before treatment for newly diagnosed lung cancer patients was at 8.4%, which is substantially higher than this audit population at 4.0%. Patients did have advanced stage (stage III and IV) lung cancer, which may explain the higher weight loss than those in this audit. The nutritional intervention was not discussed in the study.

When considering weight loss during oncological treatment for lung cancer patients, Lin et al. (135) reported a weight loss of 3.7% (2.4kg); which is similar to the results on weight loss from this audit group at 3.7% (2.9kg) during treatment. Li et al. (134) found that weight loss was 6% for severely malnourished patients and 2.6% for those with moderate malnutrition. The study population was newly diagnosed lung cancer patients at an advanced cancer stage (n=96, 64.6%), with the remainder diagnosed with a benign lung condition (n=52, 35.1%). The nutritional intervention was provided for those deemed in critical need, based on the SGA results; the intervention details were not discussed.

Weight loss was experienced by nearly half or more of lung cancer patients with advanced-stage disease in many studies; the actual weight loss was not quantified to allow for comparison (74, 136, 139). Silva et al. (74) had a small study population (n=32) and included hospitalised and palliative care patients. Whereas Cehreli et al. (136) had a small sample size (n=25), and high numbers were lost to follow up due to mortality (n=18). Nutritional intervention and a high-protein, omega-3 enriched liquid nutritional supplement was provided. The study population for Xará et al. (139) was grouped into early-stage lung cancer (I, II, IIIA) where half gained weight (n=8) and advanced-stage disease (IIIB and IV) where half lost weight (n=22); showing the impact of advancing cancer and the potential for high treatment burden with increased risk of malnutrition.

The overall results of weight loss in lung cancer patients from this audit at 7.6%, in conjunction with the prevalence of malnutrition at 55% according to SGA results in Table 5, indicate nutritional intervention could be of benefit. Only a few lung cancer patients (16%) received dietitian input at ACH. There is a risk of malnutrition in lung cancer patients having treatment at ACH, potentially impacting morbidity and mortality (2-6). ESTRO and ESMO highlight the need for nutritional intervention before and during treatment for all lung cancer patients (8); ESPEN guidelines for ‘Nutrition for Cancer Patients’ (5) and ‘Oncology Evidence-Based Nutrition Practice Guideline for Adults’ from the Academy of Nutrition and Dietetics further endorse these recommendations (2). On this basis, patients with lung cancer at ACH should be screened regularly for risk of malnutrition, with timely referrals for further nutritional intervention, if required.

5.2 QUESTIONNAIRE

This thesis’s second aim was to investigate the changes to patients’ normal dietary behaviours, the rationale for these changes, and how patients source their nutrition information using a questionnaire. Furthermore, the questionnaire was designed to investigate whether these changes, either due to the treatment and cancer or perceived healthy lifestyle changes, impacted the patients’ nutritional status.

5.2.1 STRENGTHS AND LIMITATIONS OF THE QUESTIONNAIRE

A strength of the questionnaire included using the MST and nutrition impact symptoms to enable some degree of comparison with the peer-reviewed literature. The questionnaire was available as a paper and electronic copy; this enabled people to complete the questionnaire while having treatment or waiting for an appointment, or within their own home. The study was widely promoted in Cancer and Blood Services at ACH, with staff engaging with the questionnaire's promotion and distribution. One researcher collected the questionnaires and entered the paper questionnaires into the electronic database, limiting intra-researcher bias as a strength of the questionnaire. The questionnaire was peer-reviewed by a panel of researchers and clinicians. It was also pre-tested to improve readability and comprehension. The questionnaire was anonymous to improve response rate; however, this provided a limitation with ensuring patients completed only one questionnaire. The PIS clearly stated to complete only one questionnaire, but there was no method to measure compliance as it was an anonymous questionnaire.

The response rate to the questionnaire was low, at 18%. This poor response rate could be attributed to participant burden; oncology patients are often introduced to studies; risking an over-burdened and researched group. As the questionnaire was only written in English, it provided a barrier to non-English speaking patients, contributing to the low response rate. While there was an option for non-English participants to have family or friends provide answers, it created another barrier to complete the questionnaire.

The questionnaire was not validated; it used the MST, a validated screening tool within the questionnaire. Another limitation was the lack of the complete SGA form, enabling comparison with the literature. The nutrition-impact symptoms as written in the SGA tool were used; however, despite peer-review and pre-testing, there were errors with 'poor appetite' included twice and the nutrition-impact symptoms 'smells bother me' and 'fatigue' omitted.

If patients were experiencing difficulties eating, unintentional weight loss or had radically changed their diet to improve their treatment outcomes, there might have been a propensity to complete a nutrition-based questionnaire, contributing to selection bias.

5.2.2 PATIENT CHARACTERISTICS

Of the 290 responses, the majority were males (n=163, 56%) at 1.3 times higher than females (n=122, 42%), 72.1% were of European descent, which is above the Auckland region statistics at 53.5% (15), 12.4% identified as Māori which is similar to the ethnicity profile of the Auckland region at 11.5% (15). Asian and Pacific people's responses were lower than the Auckland region's typical ethnic profile (15). Only 7.9% of the respondents identified as Asian despite comprising 28.2% of the Auckland region (15); for Pacific People 6.2%, responded to the questionnaire but accounted for 15.5% of the Auckland region (15). The questionnaire was written in English only; it did offer an option for family, friends or hospital staff to translate the questionnaires; however, hospital staff have limited time to help patients complete a questionnaire. The lower response rate from these ethnic groups is reflected by a lack of translated questionnaires that reflect the patients having treatment in Auckland.

The Regional Cancer and Blood Services provide the specialist services for the four DHBs in Northland and Auckland; respondents of the questionnaires were evenly spread to align with the population profile of the respective DHBs; for example, a third (33.8%), were from ADHB, which make up 548,430, 28.4% of the Northern Region DHBs in 2019 projections (1,933,540) (180). Nearly a further third of the questionnaire responses were from Waitematā District Health Board (WDHB) (31.7%), which make up 32.8% (633,530), followed by 24.1% from Counties Manukau District Health Board (CMDHB) (569,400, 29.5%) and a small group (9.7%) from the Northland District Health Board (NDHB) area, which makes up 182,180, 9.4% of the Northern Region DHBs (180). Only two responses from the questionnaire (0.7%) did not specify their DHB. Questionnaire responses appear to reflect the distribution within the Northern Region DHBs, with Auckland Cancer and Blood providing the specialist service for this region (14).

There was a wide variety of cancer types amongst the responses, the majority of people having treatment due to gastrointestinal (21.5%, n=64), breast (21.1%, n=63), or genitourinary (13.4%, n=39) cancers, which account for a large proportion of cancers within NZ (22). Most patients had surgery and chemotherapy at 25.5%, followed by chemotherapy at 18.3%, and then combined CRT at 13.1%. The majority of patients received more than one treatment modality, impacting nutrition status and risk of malnutrition. The number of treatment modalities could also reflect advanced-stage cancer or metastases; however, the questionnaire did not collect the appropriate information to analyse these factors.

5.2.3 WEIGHT LOSS AND MALNUTRITION SCREENING TOOL

In this questionnaire, the majority (n=207, 71.4%) lost five kilograms or less, 14.8% (n=43) indicated six to ten kilograms weight loss, a further 10% (n=29) reported a recent weight loss over ten kilograms. When weight loss, as indicated, was combined with poor appetite, it scored the malnutrition risk, as in the MST. In this respect, it seems applicable to consider the MST results from the questionnaire; MST – a fast, simple, validated and reliable tool for assessing malnutrition risk (2, 55). This questionnaire showed that 19.7% were at high risk of malnutrition, and a further 18.6% were also at risk of malnutrition. According to the study's MST score, 61.7% (n=179) of patients had no malnutrition risk. Marshall et al. (95) had similar findings with 64% with no risk of malnutrition in 2012, and 67% in 2014; in a large multicentre study in Australia, with a similar patient group attending RT or chemotherapy day stay units.

Rates of weight loss and the MST score indicated a high proportion of the respondents could be suffering from malnutrition. It is reasonable to assume that over a third of the respondents were at moderate to high risk of malnutrition, based on an MST score of two or higher.

5.2.4 NUTRITION IMPACT SYMPTOMS

Patients often modify their diet in response to a cancer diagnosis; these changes could be due to the treatment side effects or the tumour burden; these changes are considered nutrition impact symptoms. With a higher frequency of nutrition impact symptoms, there can be a higher risk of malnutrition (90). The questionnaire did include nutrition impact symptoms from the SGA tool; 50% (n=145) of patients experienced no symptoms during their treatment, with an equal number (50%, n=145) who experienced at least one symptom. Of those that experienced symptoms, 29.3% (n=85) had four to eight symptoms, and 9.3% (n=27) had nine or more nutrition impact symptoms; indicating these patients could be at severe risk for malnutrition. The presence of three or more nutrition impact symptoms indicates a higher risk of compromised nutrition (75).

When considering the leading symptoms, this study found no appetite (33%, n=95), taste changes (dysgeusia) (n=84, 29%), nausea and feeling full quickly (early satiety) (n=59, 20%) had the highest frequency of occurrence. Isenring et al. (90) reported comparable results in Australian cancer patients; 24.1% reported no appetite, 23.6% nausea, 31.4% dysgeusia, and 18.3% experienced early satiety. 'No appetite' is experienced by half of the cancer patients (70, 73, 74, 77), with one study in advanced stage lung cancer reporting 90% of their patients were affected (135). Nausea was present in 20% of oncology patients at ACH, which was less than other studies at 30 to 40% (70, 90, 135). Nearly 30% of patients at ACH also experienced dysgeusia, which is higher than other studies at around 15 to 20% (70, 74, 135).

An explanation in the variation with the level of symptoms between ACH patients and literature could be attributed to the study settings, such as hospitalised versus ambulatory patients. In general, hospitalised oncology patients or those with advancing disease experience higher proportions of nutrition impact symptoms (74, 135). There is a pattern depending on cancer and treatment types; for example, vomiting is higher in patients receiving chemotherapy (70, 74) than RT alone (77). Patients are also likely to have higher numbers of symptoms in the days after chemotherapy, particularly nausea, vomiting, taste changes, diarrhoea, and constipation due to chemotherapy itself, or the antiemetic regimen (135).

Over half the patients (n=107, 58%) who responded to the questionnaire changed their diet due to the treatment's side effect. For example, a woman aged between 40 to 44 years with breast cancer had changed her diet *"Just drinking protein shakes because easier to digest"* and her rationale for the change was as follows "*I cannot eat a good meal because when I eat my chest gets sore and my breathing is hard".* She had not received any nutrition advice but had many nutrition impact symptoms. Another example, a patient who had lost over 10kg, with no nutritional advice; changed her diet as the result of no appetite and mouth sores, "*Trying to find something, anything, that I did fancy. This remains the same Eaten throughout - baked potatoes with butter and 1-2 cups parsley, chives, puha, mint".*

The questionnaire results showed over a third of patients experienced three or more symptoms, with 17% receiving dietitian input. These results highlight the importance of early intervention with symptom management; if nutrition impact symptoms are minimised, malnutrition and its consequences could be reduced. Oncology patients require screening for malnutrition to ensure treatment or tumour side effects do not result in malnutrition, and timely nutritional intervention is received (75).

5.2.5 PREVALENCE OF MALNUTRITION

Despite the limitation of a complete SGA tool in the data collection, 53% of patients could be considered well-nourished, with 47% malnourished (SGA score B+C). Of those who were malnourished, 33% (n=96) were moderately malnourished (SGA score B), and 14% (n=41) were classified as severely malnourished (SGA score C). These figures likely underrepresented the level of malnutrition due to incomplete data according to the validated SGA form.

Results were similar in the published literature, with around half of patients well-nourished in mixed tumour groups, with various oncology settings (75, 90). A large multicentre study (n=4783) by de Pinho et al. (75) found the prevalence of malnutrition at 45%; of those patients, 33.5% were moderately malnourished and 11.8% severely malnourished. Isenring et al. (90) also found a similar prevalence of malnourished patients at 49%; however, 47% were moderately malnourished, and 2% were severely malnourished. This study included inpatients and chemotherapy outpatients with a large sample (n=300) from Australia.

Prevalence of malnutrition appears variable in the literature; however, overall consensus indicates that rates are between 30 to 40% (18). Patients at greater risk and the highest prevalence of malnutrition and severe malnutrition are those with an advanced or unknown cancer stage, HNC, gastrointestinal or lung cancers, and those over 65 years (78, 89, 96).

5.2.6 NUTRITION ADVICE

Nutrition advice is an essential aspect of cancer care and part of holistic cancer treatment. Results from the questionnaire showed, of the 61% of patients who receive nutrition advice, the majority received their nutrition advice from the oncology doctor at 46.9%, followed by nursing staff at 28.8%; dietitians at ACH were third at 27.1%, followed closely behind with advice from family and friends at 26.6%. When the role of nutrition advice falls with doctors, the time to give detailed nutritional advice in the context of a medical review is limited. Medical review appointments are 20 minutes for a follow-up; with a multi-faceted review on the patient's tumour response, physical and metabolic tolerance to the treatment and tumour burden, and symptom control; the time for nutritional intervention is limited.

HCPs provide information and instructions pertinent to the patient and their treatment, which result in a vast amount of information, both written and verbal. Advice is often forgotten, misinterpreted, and sometimes incorrect if beyond the individual's scope providing the advice (171, 172). Kwok et al. (170) found that women with breast cancer were surprised with weight gain, despite the risk explained during their treatment. Sutton et al. (172) reported that men with prostate cancer felt that certain nutrition information provided was

questionable and lacked supporting evidence. Aspects of these themes can be seen in the questionnaire responses for dietary changes and the rationale for the changes, a small proportion of respondents (n=17, 9%) changed their diet as recommended by a HCP. When asked about dietary changes made one comment was *"As recommended on radiation information less dairy (milk) no tea, coffee, fiz, beer",* with another *"Slight decrease in amount of food as asked for radiation therapy. No weetbix, beans, etc*". Patients are not encouraged to avoid dairy as reported by one patient or decrease the amount of food; all patients are encouraged to maintain weight. These statements highlight the need for clear communication and evidenced-based practice between staff and patients.

Many patients (39%) report not receiving any nutrition advice from the questionnaire's responses. While nutrition advice may not be indicated in most cases, occasionally the importance can be overlooked. Alberta et al. (173) found that patients verbalise distress when unable to eat as usual, particularly with rapid and unintentional weight loss; often patients and their families required nutritional advice but found this lacking.

When a patient is committed to improving their health, they often look to the internet for guidance and information. While the internet can provide valuable information, there is equally questionable advice on social media; often, this advice lacks peer-reviewed evidence (154, 155). Social media and the internet has information with dubious practices (156) and is occasionally intended to deceive patients (157). In the context of this questionnaire, nearly a third who changed their diets did so to improve health outcomes (n=59, 32%). These included positive changes, such as *"I am trying to eat much more healthily. I think there should be routine nutrition advice as part of follow up care"*. The basis for these changes as improving health outcomes *"It's up to me to participate in my recovery and help my body fight off the cancer as well as the chemo drugs"* from a NZ European male, aged 65 – 69 years, with bowel and prostate cancer. A second entry from a female of Chinese descent, aged 60 to 64 years with lung cancer *"More fresh vegetables less meat, less processed foods* with the hope of *"helping my body to fight with cancer".*

In contrast, other changes appeared to have limited evidence and could result in harm; from a NZ European female, aged 40 – 44 years, with colon cancer *"Huge, wheatless, dairy-free, meat-free, no processed min fruit (sugar high) Mainly organic vege, fish, nuts, and seeds. No sugar 600ml carrot, beetroot/other colourful vege; fresh juice daily Lots of garlic, cruciferous vege, onion, no nightshades".* With the rationale for these changes *"I am trying to eat much more healthily. I think there should be routine nutrition advice as part of follow up care".* However, it appears some patients when directed to evidenced-based information will change, with an example of a female, aged over 80 years, of NZ European descent with

peritoneal cancer "*Did a 6-month juice treatment but stopped recently*" with the rationale for change as *"advised by nutritionist".*

Nutrition advice should be evidenced-based, for those who score at high-risk of malnutrition when screened; a dietitian should provide the nutritional intervention. For patients looking to make healthy lifestyle changes after cancer treatment nutrition advice should ideally be provided by a dietitian; however, with limited staffing resources, reputable written information and a website based on peer-reviewed evidence could provide the foundation for this information. Timing of the intervention and education is essential, Sutton et al. (172) highlighted that patients preferred the information earlier into their treatment; a website would allow patients, their friends and whānau to access the information when they are ready.

5.2.7 BIOLOGICALLY BASED SUPPLEMENT USE

Often patients seek ways to help their treatment and recovery with the use of complementary therapies. When most supplements are taken at a low dose, they are harmless; however, when taken in large doses exceeding recommended levels, combined with cancer treatments and prescription medications, the risk of harm could increase (103, 158).

Half of the patients (49.7%) in this questionnaire used biologically based nutritional supplements; most respondents consumed between one to four supplements (n=122, 42.1%). Supplement use in oncology patients has been widely studied, with various reports suggesting the use could be between 17 to 87% (164-167); a recently published systematic review by Keene et al. (168) indicated around half of the oncology patients use complementary medicines. The wide variation in reported supplement use between studies could be attributed to the definition of supplements within each study.

There is limited research in supplement use and cancer patients in NZ; Chrystal et al. (162) studied cancer patients from Taranaki and Palmerston North and found similar results to this questionnaire; half of the patients with cancer used some form of complementary medicine. This study was completed in 2003, and a rural location when access to complementary medicines and internet shopping was in its infancy. The authors report that only 41% informed their oncologist of complementary medicine use. In comparison, 30% (n=87) of respondents to this questionnaire discussed supplement use with their doctor. Interestingly, for the five patients (1.7%) who consumed ten or more supplements per day; none disclosed this information to their consultant. While five patients from a sample of 290 questionnaires is a low number, the potential for harm could be significant.

Some patients lack disclosure about their supplement use, could be due to the lack of consultation time for medical reviews, lack of awareness of supplement use and the potential harm these could cause. It may highlight a knowledge gap in complementary and alternative practices and products by oncologists. A study of GPs and specialists in the Otago region found only 27% had sufficient knowledge in the products used; over half (58%) wanted more knowledge about therapies and nearly two-thirds (62%) on a holistic view of Māori health (163). Rongoā Māori (traditional medicines) should receive consideration, if applicable to the patient when combined with conventional treatments. Dew et al. (161) identified a critical philosophical difference in health care due to whānau influences and cultural dissonance. If there were consideration and improved knowledge of Rongoā Māori amongst all HCPs, it might support Māori patients to trust and engage with health services and provide open dialogue, with the potential to reduce health inequalities based on ethnicity.

In summary, around half of patients engage in complementary medicine use at ACH, with a small group taking products in excess with the potential for harm. From the literature, higher use was found in younger, female cancer patients, with higher education, and higher income level, and with previous complementary medicine use (168).

CHAPTER 6. CONCLUSION

This study provided an insight into nutrition and malnutrition for patients with cancer having treatment at ACH. Weight loss is a significant problem, particularly for UGI cancer patients with an overall weight loss of 17%, which was 2-3 fold higher than seen in patients with HNC and lung cancer. Weight loss was likely minimised in the HNC group with weekly nutritional intervention from a dietitian for all patients; for UGI cancer patients, 34 received dietitian intervention and only 16 patients with lung cancer received input during treatment at ACH.

The questionnaire confirmed the risk of malnutrition was present in the broader group of oncology patients with 19% at risk of malnutrition, and a further 20% were at high risk of malnutrition, using the MST, which is in accord with the peer-reviewed literature. In the context of the SGA tool and prevalence of malnutrition, 53% of patients could be considered well-nourished, with 47% malnourished (SGA B+C). These figures underrepresent the level of malnutrition due to incomplete implementation of the SGA tool into the questionnaire. Nearly 60% of patients at ACH experienced nutrition impact symptoms, with 40% having numerous side effects likely to impact food intake and contribute to weight loss.

Nutrition and awareness of malnutrition is everyone's responsibility. Patients with cancer at ACH receive their nutrition advice primarily from their oncology doctors (47%) followed by nursing staff at 29%, then dietitians within the hospital and community settings (27%) along with family and friends (27%). Nearly a third of patients had changed their diet to improve their health outcomes, not all based on peer-reviewed evidence. Supplements were commonplace, 50% of patients used some form of supplements; 30% had discussed supplement use with their oncology doctor. A website dedicated to nutrition for cancer patients could allow patients to manage treatment side effects and provide evidence-based advice to improve long-term health outcomes.

A future direction for the Regional Cancer and Blood Services lies with nutrition screening for all patients. Initially, all patients who identify as high-risk when screened should have access to timely nutritional intervention. Screening should be implemented with an online tool for visibility of nutrition risk for all oncology staff and enable data collection for audit purposes. Routine nutritional intervention should be available for all patients with HNC and UGI cancer. Future research could investigate the overall level of malnutrition in the Regional Cancer and Blood Services at ACH. Research should also assess the success of nutritional interventions with PG-SGA as a validated tool.

APPENDICES

APPENDIX A: ETHICS APPROVAL

EXEMPTION OUT OF SCOPE

Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011
0800 4 ETHICS
hdecs@moh.govt.nz

7 June 2019

Mrs Nicola Brown
Nutrition Service, Auckland City Hospital
nicolabro@adhb.govt.nz

Dear Mrs Brown,

Study title:	Nutrition Experience for Cancer patients at Auckland City Hospital

Thank you for emailing HDEC a completed scope of review form on 31 May 2019. The Secretariat has assessed the information provided in your form and supporting documents against the Standard Operating Procedures.

Your study will not require submission to HDEC as, on the basis of the information you have submitted, it does not appear to be within the scope of HDEC review. This scope is described in section three of the Standard Operating Procedures for Health and Disability Ethics Committees.

Your study comprises two parts: the first is out of scope as it meets the HDEC definition of an audit or related activity, and the second is out of scope as a minimal-risk observational study.

An observational study requires HDEC review only if the study involves more than minimal risk (that is, potential participants could reasonably be expected to regard the probability and magnitude of possible harms resulting from their participation in the study to be greater than those encountered in those aspects of their everyday life that relate to the study).

For the avoidance of doubt, an observational study always involves more than minimal risk if it involves one or more of the following:

- one or more participants who will not have given informed consent to participate, or
- one or more participants who are vulnerable (that is, who have restricted capability to make independent decisions about their participation in the study), or
- standard treatment being withheld from one or more participants, or
- the storage, preservation or use of human tissue without consent, or
- the disclosure of health information without authorisation.

If you consider that our advice on your project being out of scope is in incorrect please contact us as soon as possible giving reasons for this.

This letter does not constitute ethical approval or endorsement for the activity described in your application, but may be used as evidence that HDEC review is not required for it.

Please note, your locality may have additional ethical review policies, please check with your locality. If your study involves a DHB, you must contact the DHB's research office before you begin. If your study involves a university or polytechnic, you must contact its institutional ethics committee before you begin.

Please don't hesitate to contact us for further information.

ADHB ETHICAL APPROVAL

Auckland DHB
Research Office
Level 14, Support Bldg
Auckland City Hospital
PB 92024, Grafton, Auckland
Phone: 64 9 307 4949 Extn. 23854
Fax: 64 9 307 8913
Email: mwoodnorth@adhb.govt.nz
Website:
www.adhb.govt.nz/ResearchOffice

9th September 2019

Institutional Approval

Lindsay Plank
Department of Surgery
University of Auckland

Dear Lindsay,

Re: Research project A+ 8566 (AHREC000132) Nutrition experiences for cancer patients at Auckland City Hospital

The Auckland DHB Research Review Committee (ADHB-RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. ADHB approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following page. If you have any questions please do not hesitate to contact the Research Office.

Yours sincerely

On behalf of the ADHB Research Review Committee Dr Mary-Anne Woodnorth
Manager, Research Office
ADHB

c.c. Nicola Brown, Joe Monkhouse, Richard Sullivan

..../continued next page

MĀORI RESPONSIVENESS

He Kamaka Waiora
Waitematā and Auckland DHB
Level 2, 15 Shea Terrace,
Auckland 0740,
New Zealand
Private Bag: 93-503

05/09/2019

Associate Professor Lindsay Plank
Auckland City Hospital
Auckland

Re: Nutrition experiences for cancer patients at Auckland City Hospital.

Thank you for providing the following documents the:

- RRC application
- Study protocol
- PIS/CF
- HDEC application

The study is a regional investigation of nutrition experiences for cancer patients at Auckland City Hospital**.** There will be 300 participants recruited from within Aotearoa. It is estimated that the number of Māori participants may be approximately 30.

Māori responsiveness:
The researchers state that the research will not reduce health inequity as cancer treatment does not differ between ethnicities. This demonstrates that the research team requires the development of basic knowledge related to causes of health inequity and in particular of treatment inequities. It is recommended that the researchers engage in education activities to support the team to understand how health inequity develops from health service provision.

The study may include ethnicity sub-analysis if there are sufficient participant numbers.

The study includes a small survey tool that is unlikely to pose any cultural risks: however, the researchers are asked to be mindful of issues related to nutrition that are linked to factors such as socio-economic status (i.e., food insecurity) and cultural preference.

On behalf of the Waitematā and Auckland District Health Boards Māori Research Committee, the study has been approved.

APPENDIX B: QUESTIONNAIRE

DEPARTMENT OF SURGERY
The University of Auckland
Private Bag 92019
Auckland 1142
New Zealand

AUCKLAND DISTRICT HEALTH BOARD Te Toka Tumai | THE UNIVERSITY OF AUCKLAND Te Whare Wānanga o Tāmaki Makaurau NEW ZEALAND | MEDICAL AND HEALTH SCIENCES

Questionnaire

If a family or staff member has completed this questionnaire on your behalf, please indicate you consent

- ☐ Yes
- ☐ Not applicable

Patient attitudes and expectations towards nutrition

Section A: Your personal history

We are asking the following questions so we can better understand your background
Please answer to the best of your ability

1. Male ☐ Female ☐ Other, *please specify* ☐ _____

2. Ethnicity:
   - ☐ New Zealand European
   - ☐ Māori
   - ☐ Samoan
   - ☐ Cook Island Māori
   - ☐ Tongan
   - ☐ Niuean
   - ☐ Chinese
   - ☐ Indian
   - ☐ Other European
   - ☐ Other, *please specify* _____

3. Age:

☐ 17 or younger	☐ 35 - 39	☐ 60 - 64
☐ 18 - 19	☐ 40 - 44	☐ 65 - 69
☐ 20 - 24	☐ 45 - 49	☐ 70 – 74
☐ 25 - 29	☐ 50 - 54	☐ 75 – 79
☐ 30 - 34	☐ 55 - 59	☐ 80 or older

4. What is the district health board (DHB) where you live?
   - ☐ Northland
   - ☐ Waitematā
   - ☐ Auckland Central
   - ☐ Counties Manukau
   - ☐ Other, *please specify*: _____
   - ☐ Unsure

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The University of Auckland
Private Bag 92019
Auckland 1142
New Zealand

5. What is your primary cancer diagnosis?
(Please fill in below)

6. How long ago was your first cancer diagnosis?
   - ☐ Less than 3 months
   - ☐ 3 to 6 months
   - ☐ 6 to 12 months
   - ☐ 12 to 18 months (1 to 1½ years)
   - ☐ More than 18 months (1½ years)

7. Please indicate all forms of treatment you have received for your cancer
*(Please tick **all** that apply)*
   - ☐ Surgery
   - ☐ Radiation
   - ☐ Chemotherapy
   - ☐ Targeted cancer drug
   - ☐ Other, *please specify*: _____
   - ☐ Unsure

Section B: Expectations towards food and nutrition

8. Have you had any information or advice about diet after your diagnosis?
   ☐ Yes ☐ No

   If yes, where did you get this advice?
   - ☐ GP
   - ☐ Oncology doctor at Auckland City Hospital
   - ☐ Friends / family
   - ☐ Internet
   - ☐ Private practice nutritionist
   - ☐ Dietitian at hospital / community
   - ☐ Alternative health practitioner / naturopath
   - ☐ Other, *please specify*:

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9. Do you take any herbal products?
   ☐ Yes, *please list below* ☐ No

10. Do you take any vitamins?
   ☐ Yes, *please list below* ☐ No

11. Do you take any minerals?
   ☐ Yes, *please list below* ☐ No

12. Do you take any other dietary supplements?
   ☐ Yes, *please list below* ☐ No

13. If yes to questions 9 to 12, ***have you discussed these with your Oncology doctor?***
   ☐ Yes ☐ No

Please list herbal products, vitamins, minerals and dietary supplements you use here

Section C: Treatment symptoms affecting your food

14. Have you lost weight without trying in the past 6 months?
   ☐ Yes ☐ No ☐ Unsure

If yes, ***how much***?
- ☐ 5 kg or less
- ☐ 6 to 10 kg
- ☐ 10 kg or more

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15. Have the following problems kept you from eating enough during the past **two** weeks?

- ☐ No appetite
- ☐ No appetite, just did not feel like eating
- ☐ Nausea
- ☐ Constipation
- ☐ Mouth sores
- ☐ Things taste funny or have no taste
- ☐ Swallowing problems
- ☐ Pain
- ☐ Vomiting
- ☐ Diarrhoea
- ☐ Dry mouth
- ☐ Feeling full quickly
- ☐ Other (depression, money, or dental problems), *please list below*

16. Has your diet changed during treatment compared to before your diagnosis?

☐ Yes ☐ No

If yes, ***what*** *changes have you made?*

If yes, ***why*** *have you made these changes?*

Thank you for completing this survey, your view is important

Contact investigator:	Nicola Brown	nicolabro@adhb.govt.nz	021 499 862
Lead Investigator:	Associate Professor Lindsay Plank	l.plank@auckland.ac.nz	021 215 0419

If you require Māori cultural support, talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) on 09 486 8324 ext 42324.

Approval by the Auckland Health Ethics Committee (AHREC) on 30 August 2019. Reference number: 000132

Approval by the Auckland District Health Board Research Review Committee (ADHB-RRC) on 9 September 2019. Reference number: 8566

Approval by the Waitamatā and Auckland District Health Boards Māori Research Comment on 5 September 2019. Reference number: 8566

APPENDIX C: PATIENT INFORMATION SHEET

DEPARTMENT OF SURGERY
The University of Auckland
Private Bag 92019
Auckland 1142
New Zealand

Patient information sheet

Patient attitudes and expectation towards nutrition

Principal Investigator: Associate Professor Lindsay Plank
Department of Surgery, University of Auckland, Private Bag 92019, AUCKLAND 1142

Coordinating Investigator: Nicola Brown

What is the purpose of the study?

This questionnaire is to find out if having cancer has changed your food and eating. We would like to know if information about nutrition would be of interest to you. This questionnaire will help us know what services you would like and develop information sheets to help in the future.

What do I have to do to be part of this study?

We would like you to complete **ONE** questionnaire for us, it is completely anonymous. The questionnaire can be completed with the following UR link – bit.ly/NutritionHaveUrSay

or 'snap' the QR code with your camera or QR app →

or as a paper copy and returned to the Oncology Department, in the sealed box at reception.

Filling out this form is your choice and you are free not to fill it out. You can stop the questionnaire at any time, but once finished, we will not be able to remove your information as it is not linked to you.

It is ok if you are not able to answer the questions. Please provide as much information as you can and feel free to discuss this with nurses, treatment staff or contact one of the research team whose contacts are listed below.

By submitting this questionnaire, you are agreeing to participate in the study.

Who do I contact for further information or questions?

You are welcome to have a friend, family or whānau to help you understand the questions. Please feel free to discuss any further questions with the research team, nurses or treatment staff before deciding to take part, or at any time during the questionnaire.

If you have any questions or concerns about this questionnaire, please contact Nicola Brown at nicolabro@adhb.govt.nz or 09 307 4949 ext. 23355 or 021 499 862.

If you require Māori cultural support, talk to your whānau in the first instance. Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) on 09 486 8324 ext. 42324.

Thank you again for your valuable contribution to our study.
Your input will help shape practice.

APPENDIX D: ADVERTISING MATERIAL

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

Auckland Academic Health Alliance

AUCKLAND DISTRICT HEALTH BOARD
Te Toka Tumai

We would like to hear from you...

Please complete a questionnaire on

'Nutrition Experience for Cancer Patients at Auckland City Hospital'

This questionnaire is to find out if having cancer has changed your food and eating. We would like to know if information about nutrition is of interest to you. If you are over 17 years of age and undergoing cancer treatment at Auckland City Hospital, we would love you to complete ONE questionnaire. The questionnaire will be available over one month until 30 xxx 2019 and is completely anonymous.

This can be done with a paper copy **or** follow the survey link **or** QR code below. If completing the paper copy, please return to the sealed box at reception.

Please provide as much information as you can and ask staff or research team on the information sheet, if you would like some help.

For further details there is an information sheet at reception.

https://auckland.au1.qualtrics.com/jfe/form/SV_238rkYP7kglfDbT

Approved by the Auckland Health Research Ethics Committee on [date] for three years. Reference number: 000132
Approved by the Auckland District Health Board Research Review Committee on [date] for xx years. Reference number: 8566

APPENDIX E: COLLECTION BOX STICKER

Completed Questionnaire

'Nutrition Experience for Cancer Patients at Auckland City Hospital'

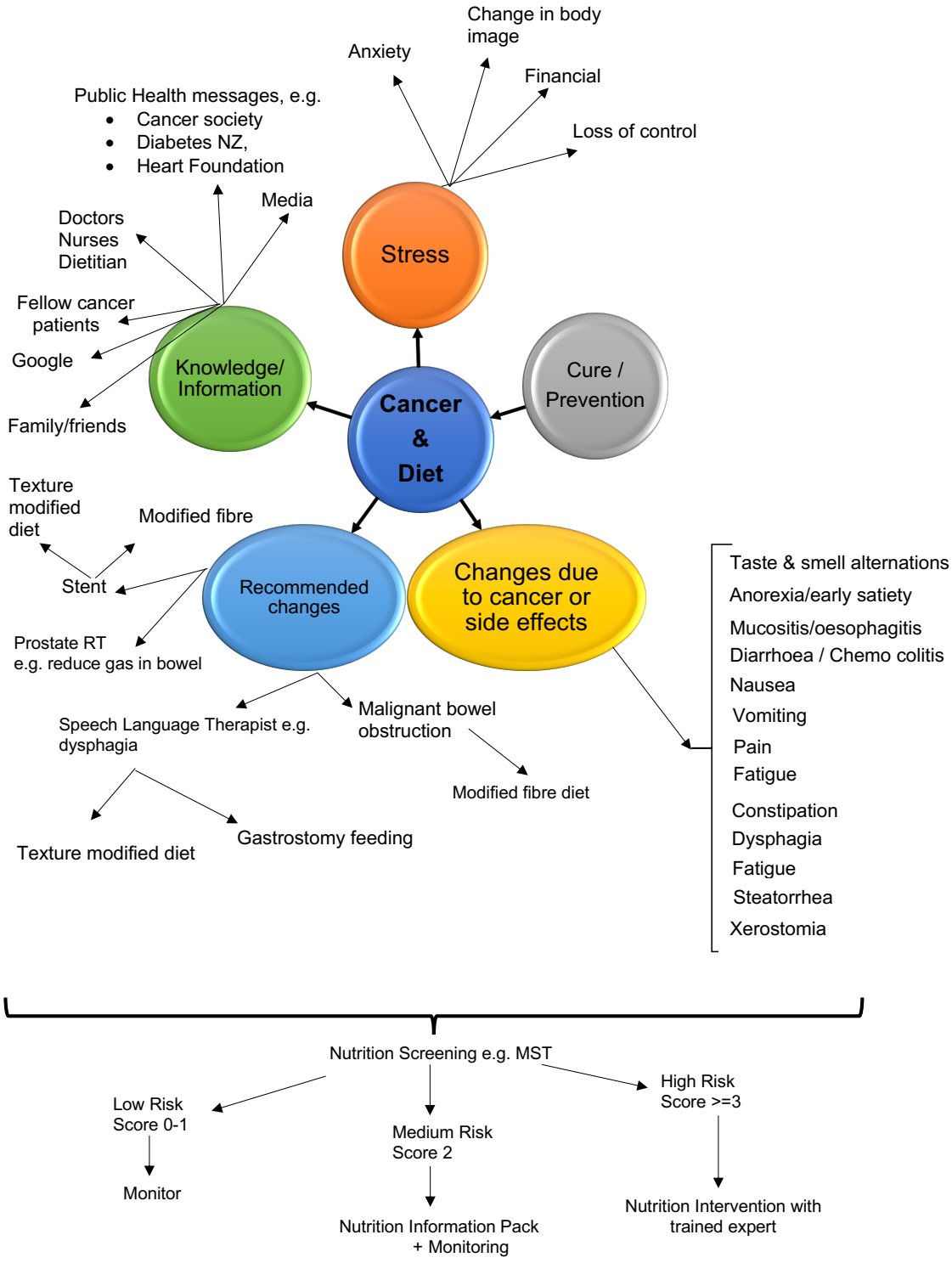
Thank you again for your valuable contribution
Your input will help shape practice

OR Just use a QR code app or 'snap' with your camera

OR Follow the UL link: **bit.ly/NutritionHaveUrSay**

Approval by the Auckland Health Ethics Committee (AHREC) on 30 August 2019. Reference number: 000132
Approval by the Auckland District Health Board Research Review Committee (ADHB-RRC) on 9 September 2019. Reference number: 8566
Approval by the Waitamatā and Auckland District Health Boards Māori Research Comment on 5 September 2019. Reference number: 8566

APPENDIX F: CONCEPTUAL MAP



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